

The historical development of the Dutch Sentinel General Practice Network from a paper-based into a digital primary care monitoring system

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Abstract

Aim The Dutch Sentinel General Practice Network (SGPN) was founded in 1970 for disease surveillance in primary care, based on paper questionnaires. Advances in information technology offered new prospects of data collection from electronic health records (EHRs). This study investigates the resulting challenges for the SGPN and its transition towards electronic data collection.

Methods A qualitative approach included triangulation of SGPN annual reports, network publications, its computerisation project protocol of 2004, public health policy documents, and expert interviews.

Results In the 1990s, the design of the SGPN, coordinated by the research institute NIVEL, no longer corresponded to new Dutch government information demands regarding developments in primary care utilisation and quality. The emergence of the EHR-based Netherlands Information Network of

General Practice (LINH) could have rendered the SGPN obsolete. However, NIVEL researchers recognised that routine EHR data on health problems could not fully provide required information obtained by questionnaires and samples for laboratory analysis. They developed a plan (1) taking EHR-based routine data collection as a basis, and (2) simultaneously retaining the more detailed supplementary data collection that was the core of the SGPN. The transition towards electronic data collection from 2005 onwards was followed by the integration of both networks into the NIVEL Primary Care Database in 2014.

Conclusion The Dutch model is an example of a process responding to the challenges and opportunities associated with the emergence of electronic data collection, leading towards the integration of routine and supplementary data collection for both sentinel surveillance and health services research.

Keywords General practice · Surveillance · Public health · Sentinel network · Electronic health record · Netherlands

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Introduction

A sentinel general practice (GP) network—or sentinel network of general practitioners (GPs)—“can be defined as a system that keeps a watchful eye on a sample of the population by supplying regular and standardized reports on the incidence and the main epidemiological characteristics of specific diseases and of procedures in primary health care” (Van Casteren 1993, p. 253). Sentinel networks are well known for providing early warning of communicable diseases such as influenza and monitoring them over time (Fleming et al. 2003; Fleming 1998).

Sentinel GP networks have developed in several industrialized countries since the 1960s. Today, sentinel GP networks

surveying influenza exist in the majority of European Union (EU) member states (Valenciano et al. 2008; European Centre for Disease Prevention and Control (ECDC): Influenza surveillance. Sentinel surveillance). Some of the early GP networks in Europe simultaneously investigated several diseases or conditions in general practice (Deckers et al. 2006), notably the Weekly Returns Service (WRS) for England and Wales, operational since 1967 (Fleming 1999; Thomas et al. 2001), and the Dutch Sentinel General Practice Network, founded in 1970 (Bartelds et al. 1989). Other countries followed such as Belgium in 1979 (Van Casteren 2009), Switzerland in 1986 (Sentinella (n.d.) Themenübersicht Allgemeinpraktiker), Portugal in 1989 (National Health Institute Doutor Ricardo Jorge (INSA) (n.d.) Rede Médicos Sentinela) as well as regional Spanish sentinel GP networks from 1989 onwards (Vega Alonso et al. 2006, p. 497). Most of these networks included influenza surveillance at foundation or shortly thereafter.

Originally, the early network foundations such as the English, Dutch and Belgian sentinel networks relied on paper-based data collection by GPs. Since the 1980s, emergent information and communication technology (ICT) has provided new opportunities for data collection in primary care. In 1984, the French National Institute of Health and Medical Research (INSERM) established a computerised sentinel GP network, targeted at specific frequent infectious diseases in primary care and requesting GPs to connect to a central server for data entry (Flahault and Valleron 1997). In 1991, the WRS coordinator anticipated exciting prospects in the coming decade, because the “computerised record with its comprehensive coverage of both morbidity and prescribing” brought “a new dimension to epidemiological survey” (Fleming 1991, p. 183). During the 1990s, the WRS developed into a fully computerised collection system for data on routine diagnoses and episode types in general practice, based on data extraction from electronic health records (EHRs; Fleming 1999; The Royal College 2002).

Underlining the importance of the specific health care context, Griffiths and colleagues stated the following: “Each network develops in a particular time and place, with all the past experiences of the health service and its health care professionals influencing its development. It will also be influenced by research policy and resources, and the activity of other research institutions” (Griffiths et al. 2000, p. 914). The transition of the Dutch Sentinel GP Network towards computerised data collection displayed a distinctive feature: it was connected with the simultaneous integration into an existing EHR-based network. In this regard, this case study investigates the characteristics of the Dutch situation leading to the specific transition of the Dutch Sentinel GP Network towards computerisation. It aims to (1) track important decisions made during its foundation history which set the course for its further development, (2) analyse the consequences of Dutch health care policy in the 1990s for the development of

the sentinel network, (3) show the subsequent strategies for transition towards electronic data collection, (4) describe the specific features of the resulting network structure, and finally, (5) discuss the specific characteristics of the Dutch experience in comparison with those in other selected European countries—countries, in which national/major regional GP networks not exclusively devoted to influenza surveillance were also founded (Belgium, France, Portugal, Spain, Switzerland, and the United Kingdom).

Methods

The development of the Dutch Sentinel GP Network was traced in six steps. First, the network foundation history was explored with regard to the determination of the network mission, organisation, and structure, taking into account the positions of the Undersecretary of Health and the first directors of the Netherlands Institute of General Practice (NHI) by consulting the first annual reports of the network, articles in “Medisch Contact” and the “Nederlands Tijdschrift voor Geneeskunde”, together with the autobiographical history of the first NHI director (Van Es 2006).

Second, the functioning of the network and its research design prior to the 1990s were explored by consulting the annual reports as well as publications by the first two project leaders. Also, an expert interview (expert 1) was conducted with the second project leader (in office 1976–1985) by the first author.

Third, the consequences of Dutch health policy changes in the late 1980s and the 1990s for GP network surveillance were explored. Documents of the periods 1986–1987 through 2004–2005, published by the Second Chamber of Parliament (House of Representatives), were consulted regarding appraisals and the future of the sentinel network and/or the second national GP network LINH (Netherlands Information Network of General Practice). These documents are available online under “www.statengeneraaldigitaal.nl” and “www.officielebekendmakingen.nl”. For the document search, the keywords “peilstation”, “peilstations”, “morbiditeitsregistratie”, “Landelijk Informatie Netwerk”, and “LINH” were employed. Information on LINH was also gathered from the LINH project report and subsequent annual reports.

Fourth, activities of the Sentinel GP Network in the 1990s and strategies to position it in adaptation to the new circumstances were identified via annual network reports from this period, publications of cooperation partners such as the National Institute for Public Health and the Environment (RIVM), an expert interview by the first author with the NIVEL GP project leader (expert 2), and the project proposal of 2004 which requested financial support from government for the transition.

Fifth, the transition towards computerisation is documented through annual network reports, information on the NIVEL homepage, and a NIVEL publication on the transition. For steps 4 and 5, an expert interview, supplemented by answers to written questions, was carried out by the first author with the third Sentinel GP project leader (in office 1985–2005; expert 3). Authorisation for all interview summaries in English was sought and obtained.

Sixth, in order to place the Dutch experience into a broader context, information provided by homepages, annual reports and research literature of other national/major regional research GP networks in Europe was explored, supplemented by a PubMed title/abstract search to identify other networks of this type (search words: “general practice” [Title/Abstract] together with the name of the respective country [Title/Abstract] and “database” [Title/Abstract]).

The setting

The Netherlands is one of those European countries, where general practice has a strong position in the health system, similar to England and Denmark (Wiegers et al. 2011, p. 7). In these countries, the GP acts as a gatekeeper who controls access to specialised medical care (Pedersen et al. 2012; Loudon 2008; Schellevis et al. 2005). In the Netherlands, “virtually all non-institutionalized Dutch citizens are registered with a GP so the total practice population represents the general population”, and “doctor-defined health problems as presented to GPs in the Netherlands provide a valid profile of morbidity in the population” (Schellevis et al. 2005, p. 265). Thus, primary care research in the Netherlands is in a fortunate situation compared with other countries, where no mandatory patient list and referral system exist.

Results

The development of the Dutch Sentinel GP Network can be divided into three periods. The first period dates from its foundation until the end of the 1980s. The second period covers the 1990s and early 2000s, during which the future of the Sentinel GP Network was uncertain. During the third period, from 2005 onwards, an alignment of the Sentinel GP Network with LINH took place before both networks were integrated into the NIVEL Primary Care Database in 2014. The timeline is shown in Table 1.

Decisions of the foundation period which determined the future course of the network

In 1965, professionalisation efforts of committed GPs and their professional organisation, the Dutch College of General

Practitioners (NHG), led to the foundation of the Netherlands Institute of General Practice (NHI) in 1965 for GP research and training (Van Es 2006, pp. 43–58). Support came from the Ministry of Health,¹ which charged the NHI with the mission to provide information for government policy (Ministry of Health 1966, p. 164).

Another important actor of the foundation period was the Chief Medical Office of Health, which had been running sentinel practices since 1962 (Programme Committee Sentinel Practices 1971, p. 9). The resulting structure foresaw the NHI as the coordinating research institute and its director as chairperson of the Planning (later Counselling) Committee, with two Ministry of Health representatives and representatives from the foundation which had contributed to the formation of the NHI in the Planning Committee, as well as an officer from the Chief Medical Office of Health as the first project leader (Programme Committee Sentinel Practices 1971, p. 10).

Another strand of professionalisation of general practice was the foundation of chairs of general practice at Dutch universities in the late 1960s and 1970s, starting with Utrecht University in 1966 (Van Es 2006, pp. 70–71, pp. 82–83). By 1977, each university had its own chair of general practice (Crebolder and Stalman 2003). When the first director of the NHI became a professor at Utrecht University in 1966, he was charged with developing the Department of General Practice and the NHI simultaneously, so that his staff and tasks became interwoven across the two institutions (Van Es 2006, p. 127). When the NHI obtained separate management and new directors in 1971, the Sentinel GP Network did not become a university-based network but remained part of the NHI (Van Es 2006, p. 92). According to the new NHI directors, the sentinel practice project was relevant for health policy, as well as other NHI activities, namely the creation and maintenance of a GP database—used for manpower planning (Groenewegen and Van der Zee 1979; Tweede Kamer 1984–1985, pp. 38–39)—and maintenance of a record of research in primary health care (Bol 1976, pp. 237–238). Furthermore, the universities were in charge of training future GPs and had taken over regional functions, while the NHI activities had a more nation-wide focus. Moreover, the university departments of general practice were part of the medical faculties, such that these university institutes were only very

¹ The name of the Ministry of Health changed over the course of time because the policy areas of public health, social affairs, culture, and sport were grouped in different ways in different periods. See: Rijksoverheid, Ministerie van Volksgezondheid, Welzijn en Sport (n.d.) Geschiedenis: Ministerie van Sociale Zaken en Volksgezondheid (Ministry of Social Affairs and Public Health) 1951–1971, Ministerie van Volksgezondheid en Milieuhygiëne (Ministry of Public Health and Environmental Hygiene) 1971–1982, Ministerie van Welzijn, Volksgezondheid en Cultuur (Ministry of Well-being, Public Health, and Culture) 1982–1994, Ministerie van Volksgezondheid, Welzijn en Sport (Ministry of Public Health, Well-being, and Sport) since 1994.

Table 1 Timeline: development of the Sentinel GP Network

Year	Context	Sentinel GP Network	Netherlands Information Network of General Practice (LINH)
1965	Foundation of the NHI		
1966	The NHI director becomes professor of general practice at Utrecht University (Van Es 2006, pp. 70–71)		
1970		Foundation of the Sentinel GP Network, NHI director chairperson of the programme committee (Programme Committee Sentinel Practices 1971, p. 10)	
1971	Management of the NHI separated from staff of Utrecht University, new NHI directors (Van Es 2006, p. 128)		
1972		New NHI director chairperson of the programme committee (Programme Committee Sentinel Practices 1973, p. 7)	
1985	Establishment of NIVEL as successor of NHI		
1987/1988	First National Survey of Morbidity and Interventions in General Practice		
1991			Foundation of LINH (NIVEL/WOK)
1994		Uncertain future of the network made public during annual meeting with GPs (Bartelds 1995, p. 4)	
1996			LINH ends project status, declared fully operational and collecting referrals and prescriptions with associated morbidity
2000-2002	Second National Survey of Morbidity and Interventions in General Practice		LINH is the basis of data collection for national survey of morbidity and interventions in general practice (Schellevis et al. 2004)
2002		Ministry of Health demands Sentinel GP Network alignment towards LINH (Bartelds 2003, p. 16)	LINH transition towards logging all morbidity recorded in general practice (Verheij et al. 2002)
2004		NIVEL proposal to Ministry of Health to integrate Sentinel GP Network and LINH	
2005		Integration of Sentinel GP Network and LINH starts	
2006		Integration of routine EHR data from the Sentinel GP Network into LINH starts (Verheij et al. 2010, p. 14)	
2009		Routine data collection of diagnoses computerized (Schellevis 2011, p. 5)	
2014		Establishment of NIVEL Primary Care Database integrating the Sentinel GP Network, the Netherlands Information Network of General Practice, and several other primary care databases	
2015		All questionnaire data of sentinel general practices collected electronically	

NHI Nederlands Huisartsen Instituut (Netherlands Institute of General Practice), *NIVEL* Nederlands Instituut voor Onderzoek van de Eerstelijnsgezondheidszorg (Netherlands Institute for Primary Care Research), from 1995 onwards Nederlands Instituut voor Onderzoek van de Gezondheidszorg (Netherlands Institute for Health Services Research); *WOK* Werkgroep Onderzoek Kwaliteit (Quality Research Working Group), *LINH* Landelijk Informatie Netwerk Huisartsenzorg (Netherlands Information Network of General Practice), *EHR* Electronic Health Record. Sources: Sentinel GP Network annual reports, LINH project and annual reports, 2004 NIVEL proposal to Federal Government, NIVEL publications, NIVEL homepage Van Es 2006

indirectly accessible to policy suggestions coming from the Ministry of Health (Bol 1976, pp. 237–238). The sentinel network thus remained attached to the NHI and, from 1985 onwards, to its successor NIVEL.

Mission and characteristics of the Sentinel GP Network

According to the Undersecretary (staatssecretaris) of Health, the original mission of the Sentinel GP Network was to explore the morbidity pattern in the Dutch population as far as it could be diagnosed in GP care, to signal diseases as well as shifts in disease patterns. The collected data could provide the backdrop for an analysis of disease phenomena and their causes, which, in turn, might lead to clues for a more speedy and effective health policy (Overeenkomst 1969).

The network was initiated with the ambition to be as representative of the general population as possible—with a nationally representative regional distribution and data collection in urban as well as rural areas—in order to obtain a representative picture of conditions seen in general practice. This principle has been retained to the present day (Programme Committee Sentinel Practices 1971, p. 12; Donker 2015, p. 16). To this end, it was necessary to report information on the practice populations (Programme Committee Sentinel Practices 1971, p. 10), with an update every 2–3 years (Programme Committee Sentinel Practices 1974, p. 10; Donker 2015, pp. 16–19).

Questionnaires were completed by GPs on a weekly basis, sent to the NHI and, in the early days of the network, processed at the Chief Medical Office of Health (Programme Committee Sentinel Practices 1971, p. 13, p. 15). In order to advance the varying research topics, a “topic holder” approach was developed for a subset. The topic holder is the expert responsible for analysis of the collected data on a given research subject. The sentinel network must be informed about use, presentation and publication of the data (co-authorship) (Deckers and Schellevis 2004, Appendix B, pp. 118–119). The topic holder may be an NHI/NIVEL researcher but this is not mandatory. Aside from his/her expertise, the topic holder might also provide funding for analysis of the research topic. Thus far, the Sentinel GP Network has attracted topic holders from a broad variety of backgrounds, such as government and regional institutions, universities and private foundations.

The first project leader, simultaneously in charge of infectious diseases at the Chief Medical Office of Public Health from 1963 until 1988 (Geneeskundig inspecteur 1989), contributed a strong interest in infectious disease surveillance (Bartelds 1995, p. 5). From the beginning, influenza-like illness (ILI) was included, the only topic to be observed continuously up to the present day; however, the network did not

limit itself to infectious diseases. Aside from ILI, the Sentinel GP Network weekly returns in 1989 included the observation of topics as diverse as cervical smears (continuously observed 1976–1998), sterilisation of men (1972–1999), sterilisation of women (1974–1999), prescription of the morning-after pill (1972–1991), burns (1988–1989), suicide (attempts) (1979 to present), acute atypical headache (1988–1992), pregnancy despite contraception (1987–1991), outpatient mammography (1988–2000), consultations regarding concern about HIV/AIDS (1988 to present, from 2008 onwards as part of sexually transmitted infections), and referrals to a speech therapist (1989–1990²) (Bartelds 1991, p. 18, p. 140; Donker 2015, pp. 167–169).

In 1988, a project for the processing of sentinel network data by a working group of the Ministry of Health was successfully completed (Bensing 1988, p. VII). The Sentinel GP Network Counselling Committee recommended further pursuing the path towards computerisation but without impairing the functioning of the network (Bensing 1988, p. VII). In 1991, the NIVEL directors expressed the need to obtain computerised data from primary care and emphasized that few tools existed for the collection of longitudinal annual data. Indeed, the Sentinel GP Network did collect annual data, but “only relating to a limited number of auxiliary questions” (Bensing et al. 1991, p. 51, our translation). Computerised GP data collection had become part of a new government research agenda, but with a focus on procedures in general practice (as described in the following paragraph), while the Sentinel GP Network, with its epidemiological research design, could not satisfy this new priority.

A new government research agenda since the 1980s and its consequences

Since the publication of the Policy Programme Health Care Structure in 1974, strengthening primary care in the Netherlands had been on the political agenda due to the expansion of more expensive secondary care (Boot and Knepen 2005, pp. 53–54). Several documents from the early 1980s show government plans to extend primary care research. The Primary Health Care Outline 1979–1980 considered the extension of the NHI research programme to include activities such as methodology development, documentation, evaluation, needs assessment, recording systems, and experiments in primary care (Ministry of Health 1980, p. 42). In the Policy Programme Primary Care of 1983, the Ministry of Health dedicated a separate chapter to “research: situation and bottlenecks”. It diagnosed a lack of research on the

² Here, we have followed the time frame provided in the biannual report for 1989/1990 (Bartelds 1991) and Dekker et al. 1992. Later reports state 1988–1989.

practice of primary health care, offer and demand, the care delivery process, and multidisciplinary cooperation between primary care facilities (Ministry of Health 1983, pp. 41–42). Subsequently, the Ministry of Health commissioned the first Dutch National Survey of Morbidity and Interventions in General Practice, which was carried out in 1987–1988 under the responsibility of NIVEL (Bensing et al. 1991, pp. 51–52). This study still relied on pen and paper data collection, but the plans of the Ministry of Health went in a different direction: the Ministry was engaged in supporting automation of GP practices as well as measures to improve the quality of care in general practice. In order to evaluate the latter, the Ministry of Health planned a GP information network—not only would regular production data (such as the number of procedures, referrals, prescriptions, and diagnostic requests) become available, it would also be related to the quality of care. Improving the quality of care could include the use of standards, impact assessment of standards and training, and the relationship between the complaint of the patient and the activities of the GP (Ministry of Health 1991, p. 146).

In the early 1990s, EHRs made it possible for the first time to collect data on a much larger scale than had been possible with paper forms. By the mid-1990s, an inventory counted 14 general practice registration networks in the Netherlands, of which 9 were computerised and 2 were in transition from paper forms to computer registration (Hart et al. 1999, pp. 173–174). EHR-based data collection in combination with quality of care improvement was a field in which NIVEL was by no means the only competitor. The Quality Research Working Group (WOK) from the Universities of Nijmegen and Maastricht which became an eminent research institution in the following decades and is known today as the Scientific Institute for Quality of Healthcare, IQ Healthcare for short (Van der Avoort et al. 2008; Hoogleraar Richard Grol neemt afscheid 2011), was also eager to embrace the topic.

The government commissioned NIVEL together with WOK to set up such an EHR-based GP network, the Netherlands Information Network of General Practice (LINH; De Bakker et al. 1997, p. 11). NIVEL was responsible for the overall functioning of the network, generating annual reports and maintaining the database, whereas WOK dealt with the data collection process and contacts with participating practices (Abrahamse et al. 1996, p. 24). The mission of LINH was to generate representative and continuous quantitative and qualitative information on the care provided by Dutch GPs (De Bakker et al. 2001, p. 9). LINH was set up in 1991 and obtained formal operational status in 1996 (De Bakker et al. 1997, p. 11, p. 43). GPs were instructed to combine each referral and prescription with the entry of a working diagnosis, in the form of an ICPC code (International Classification of Primary Care, an internationally recognised classification for registration in general practice (WHO (n.d.) International Classification of Primary Care); De Bakker et al.

1997, p. 12). Data were continually collected on (1) GP-patient contacts, (2) drug prescriptions with associated diagnosis, and (3) referrals with associated diagnosis. In addition, data were collected on specific topics in the field of quality of care (De Bakker et al. 2001, p. 9). LINH data quickly entered government policy documents. By 1994, LINH data on referrals to specialists, collected since March 1993 (De Bakker et al. 1997, p. 14), were already being used in the government planning document Financial Overview Care 1995 (Ministry of Health 1994, p. 271). In 1999, the Minister of Health took LINH as a model for the development of sentinel practices in physiotherapy and exercise therapy (Ministry of Health 1999, p. 64). Data collection from the LINH network also played an important role in the Second National Survey of Morbidity and Interventions in General Practice 2000–2002 (Schellevis et al. 2004, p. 11, p. 123). Since 2002, LINH has also collected GP-patient contacts with an ICPC diagnosis. LINH thus changed “from a registration of procedures with associated morbidity into a registration of morbidity with associated procedures” (Tielens 2002, Voorwoord, our translation) in general practice.

Uncertain future of the Sentinel GP Network in the 1990s

While LINH routine data collection was extended, the future existence of the Sentinel GP Network became uncertain. The NIVEL director addressed the situation of the Sentinel GP Network publicly at the annual Sentinel GP Network meeting of 1994 (Bartelds 1995, p. 4). In the late 1990s, Ministry of Health officials had the impression that they were financing two networks which performed essentially the same tasks: they believed that either only one network was needed, or that the two networks could be merged (interview with expert 2).

During this period of insecurity, the Sentinel GP Network continued and extended its engagement in the following areas of expertise:

1. The network provided additional material from the patient (urine samples, throat and nasal swabs, stool, etc.). The samples were sent to laboratories for further investigation into the cause of the infection. These additional diagnostic activities and the related questionnaires often went beyond the routine activities of a GP. From 1996 to 1999, the incidence of gastroenteritis in patients consulting sentinel network GPs and the role of several pathogens were studied (De Wit et al. 2001). This research was commissioned, among others, by the Health Care Inspectorate (part of the State Public Health Inspectorate; De Wit et al. 1999, p. 1).
2. The network continued international cooperation among sentinel networks on influenza surveillance, which had commenced with participation in the Eurosentinel project 1988–1991 (Bartelds 1991, p. 2; Bartelds 1997, p. 2).

European cooperation continued to develop and resulted in the European Influenza Surveillance Scheme (EISS) in 1996, which was coordinated by NIVEL. EISS became part of the European early warning and response system for communicable diseases, which was “officially launched on 1 January 2000” (European Influenza Surveillance Scheme 2001, pp. 9–10).

From the winter of 1992/1993 onwards, GPs sent random swabs from patients with influenza-like illness (ILI) symptoms to the RIVM, which diagnosed the ILI pathogen (Ministry of Health et al. 2004, p. 28). For monitoring of Chlamydia pneumoniae in the Netherlands, which was carried out during the winter seasons by the RIVM in the mid-1990s, the Sentinel GP Network was the only source (Heijnen and De Boer 1998, p. 251). According to the national plan on influenza in 2004, about 75 % of sentinel GPs sent in 400–500 swabs during a typical influenza season (Ministry of Health 2004, p. 28). In the context of the nationwide Infectious Diseases Surveillance Information System, which was established in the course of the 1990s, the RIVM considered the sentinel practices as necessary to complement the microbiological laboratories, in particular for diseases which in the majority of cases did not lead to a consultation and diseases for which no laboratory diagnosis was necessary such as influenza and foodborne infections (Bartelds 1997, p. 5; Sprenger and Schrijnemakers 1998, p. 1925). The sentinel network favoured continued collaboration with the RIVM in the future as well (Bartelds 1999).

3. At the turn of the century, NIVEL acted as the coordinator of two European GP network research projects, the “Health monitoring in sentinel practice networks” project (1998–2000; Fleming et al. 2003), and the “Health information from primary care” project (2001–2004; Deckers and Schellevis 2004). During the first project, the foundations for an Expert and Documentation Centre, “to which existing and new networks can look for advice and support in developing networks for monitoring morbidity in primary care”, were established at NIVEL (Fleming et al. 2001, p. 12–13). The WRS director, who served as advisor to the Dutch Sentinel GP Network from 1997 onwards (Bartelds 1998, p. 3), was involved as project coordinator for the first project (Fleming et al. 2001, p. 2) and as a WRS representative for the second project (Deckers and Schellevis 2004, p. 10).
4. Furthermore, the Sentinel GP Network investigated the possible use of EHR data for the weekly returns, particularly with regard to which extent ICPC coding led to the same morbidity registration results. The network concluded that routine registration and ICPC classification were not suitable to obtain the type of information which was typically generated by the sentinel practices. Notably, providing supplementary information went beyond routine

GP registration activities. Data on some topics such as making a cervical smear or requesting a mammography could also be derived from EHRs, as was done in LINH. In order to avoid double registration, improved cooperation with LINH was envisaged (Bartelds 1998, pp. 5–6).

The NIVEL GP project leader recalled that NIVEL positioned the Sentinel GP Network vis-à-vis the government as a network for special assignments to demonstrate the added value of the Sentinel GP Network: routine information, such as prevalence and incidence rates, could be derived from EHR data. This task had thus been taken over by LINH. However, the Sentinel GP Network remained necessary (1) for special questions beyond routine EHR registration, when nose, throat and/or urine samples were of interest and to be sent to the laboratory for further diagnosis of the pathogen; (2) in order to investigate the etiology of specific conditions such as sports injuries. A large number of diagnostic codes for fractures and injuries already existed, but from these it was not known whether they were related to sports. This constituted additional information which was not available from routine electronic health records; and (3) to investigate diseases or events, which were sensitive issues from a political or medical point of view, or both, such as suicide and euthanasia. The Ministry of Health accepted this argumentation (interview with expert 2). It even commissioned research on the management of unwanted pregnancies in general practice and the role of the GP from 2003 onwards (Tweede Kamer 2002, p. 3, Bartelds 2004, pp. 125–129). Data for that research were collected until 2011 (Donker 2014, p. 176); however, the Ministry of Health also made clear to the NIVEL directorate that an adjustment towards LINH had to be made (Bartelds 2003, p. 16).

An integrated network: more than the sum of its parts—adjustment strategy towards LINH

In 2004, NIVEL researchers in charge of the Sentinel GP Network and LINH submitted a proposal to the Ministry of Health to integrate the Sentinel GP Network into LINH. This proposal underlined the different profiles of the sentinel network and LINH (Verheij R, Bartelds A, De Bakker D, Schellevis F. Van Weekstaat tot HIS: Gezondheidsinformatie uit één geïntegreerd huisartsennetwerk [From paper based weekly reporting to EHR: Health information from an integrated GP network], 29.09.2004 [project protocol], pp. 2–3). In the sentinel network, morbidity would be registered by ICPC codes in the same manner as in LINH in the future (protocol, p. 8). In this way, the Sentinel GP Network would extend the LINH network data collection, allowing better precision and regional differentiation.

The core innovation proposed was the development of a module integrated into the EHR, so that data could be extracted weekly, not only half yearly as in LINH (protocol, pp. 8–9).

By using ICPC codes for health problems, NIVEL aimed to diminish the double workload experienced by GPs who had to record data in their EHR systems as well as on paper forms as participants of the Sentinel GP Network. Information was now to be requested using replacement online forms. Furthermore, ICPC codes entered routinely could be linked to a so-called “trigger” function integrated in the EHR system—when GPs entered ICPC codes which were related to a specific research question to be explored in depth, a pop-up screen with instructions such as requests to send a swab to the laboratory (protocol, p. 10), and/or questions related to the topics to be answered by the GP in order to identify a case was to appear. An example provided in the protocol (p. 10) was research on injuries by dog bites, with the pop-up triggered by the entry of ICPC code A80 (trauma/injury, not otherwise specified). Thus, the GP could mark whether or not a dog bite was the cause of the injury and enter further information when this was the case. The protocol marked the transition of the sentinel practices towards EHR-based registration before week 40 of 2005, the start of the 2005/2006 influenza season (protocol, p. 11).

Computerisation of the Sentinel GP Network and integration into the NIVEL Primary Care Database

With the subsidy, the Sentinel GP Network proceeded towards a mixed data collection system between 2005 and 2009. The introduction of coding standards in the sentinel network meant that sentinel GPs were requested to record a symptom/health problem or diagnostic ICPC code for every patient contact in the EHR. These efforts paralleled those of the Dutch College of General Practitioners (Nederlands Huisartsen Genootschap) to advance comprehensive EHR recording among GPs in general.

The workgroup preparing the first set of guidelines on adequate EHR file creation, published in 2004, adopted the position that an ICPC code had to be provided for complaints, diseases, or disorders (Nederlands Huisartsen Genootschap 2004, p. 16). The project protocol had envisaged that a few of the sentinel practices might quit when requested to record morbidity completely in the EHR and would have to be replaced (protocol, p. 8). No pressure was put on practices to change software providers in case they did not work with the EHR software included in the project, and arrangements were made for practices wishing to continue using paper registration only. Despite these measures, implementation of the sentinel module in the practices went along with a major shift in GP participation. More than half of the 56 GPs from the 2004 sentinel network had left it by January 1, 2009 (Bartelds 2006, pp. 179–180; Donker 2011, pp. 163–164),³ whereas the

turnover of GPs had been less than 5 % per year at the beginning of the decade (Deckers and Schellevis 2004, Appendix B, p. 113).

For several weeks, GPs were requested to record both on paper and electronically, and the respective numbers were checked by the project leader. The project team discovered that the implementation of computerised registration required a tailored approach for each practice, and that the quality of paper registration deteriorated rapidly during parallel digital recording (Schellevis et al. 2009, pp. 19–20). By 2009, routine data collection in the Sentinel GP Network had been implemented with regard to four EHR software programmes and for other GPs via upload to a website (Schellevis et al. 2009, p. 19). Routine EHR data in 38 of 46 sentinel practices was collected digitally to the satisfaction of the participating GP (Schellevis et al. 2009, pp. 19–20). The collection of supplementary non-routine data on in-depth questions remained mainly paper based (Donker 2011, p. 5). In 2013, 10 of 13 weekly return research topics still required GPs to send paper questionnaires to NIVEL. These questionnaires were used in order to obtain information not routinely recorded in the EHR (e.g., sexual and risk behaviour of patients with concerns about a sexually transmitted infection) or for which no suitable ICPC main code existed at all (e.g., symptoms caused by the oak processionary caterpillar) (NIVEL, Continue Morbiditeits Registratie, Peilstations Nederland: Toelichting op: Rubrieken 2013).

In 2010 and 2012, NIVEL applied a data quality feedback tool to 92 voluntary LINH practices (Van der Bij et al. 2016), before, in 2014, both the Sentinel GP Network and LINH were integrated into the NIVEL Primary Care Database. NIVEL took over LINH coordination completely from IQ Healthcare and increased the number of contributing practices substantially. In 2014, the NIVEL Primary Care Database collected data from 433 general practices with over 1.7 million enrolled patients (Prins et al. 2015, p. 6), encompassing more than 10 % of the Dutch population. The sentinel network was integrated as a particular set of practices willing to collect additional information beyond the data recorded in the EHR systems, but the number of practices can be extended if there is a need and budget. Since 1 January 2015, also all supplementary, previously paper-based, data in sentinel practices has been collected electronically via online questionnaires. Only specimens such as nose and throat swabs and urine are still sent by regular mail. The characteristics of the sentinel GP practices are shown in Table 2. External cooperation and proposals for new research topics are welcome.

Furthermore, the NIVEL Primary Care Database has extended the monitoring of health and the utilisation of health services in a representative sample of the Dutch population to GP out-of-hours services and other primary health care professionals (primary care psychologists, physiotherapists, exercise therapists, dieticians, speech therapists, and pharmacists) (NIVEL (n.d.) NIVEL Zorgregistraties eerste lijn). Its data

³ The fluctuation can be observed by comparing the names of participating GPs in the annual reports for 2004 and 2009.

Table 2 Characteristics of the Dutch sentinel GP practices within NIVEL Primary Care Database

Aspect	Characteristics
Reporting period	Weekly
Routine data collection	EHR data extraction (contacts, morbidity by ICPC codes, referrals, prescriptions)
Supplementary data collection (questionnaires)	Up to 15 specific research topics, observation period ≥ 1 year, annual decision on prolongation and new topics
Number of practices	40 (2014) (Donker 2016, p. 16)
Number of GPs	58 (2014) (Donker 2016, p. 16)
Population of the Netherlands covered	0.7–1.2 % (2014, differences according to province group) (Donker 2016, p. 19)
Representativeness	As representative as possible for the Dutch population (including gender, age, regional distribution—north, south, east, west— and population density; Donker 2016, pp. 15–21)
Documentation and publications	Annual reports in Dutch and English (publications available online from www.nivel.nl); scientific publications of research results are mentioned in the annual reports
Umbrella organization	NIVEL Primary Care Database (since 2014)

Sources: NIVEL (n.d.) NIVEL Zorgregistraties eerste lijn; Donker 2016 [annual report for 2014]

protection and pseudonymisation principles have already been described elsewhere (Kuchinke et al. 2016).

Development of sentinel GP networks and other GP databases in six other European countries

Development of sentinel GP networks

Regarding the development of sentinel GP networks in other European countries, a heterogeneous picture emerges. The computerised networks in England and France further developed their network. In the WRS, a database with patient-linked and pseudonymised data was introduced as of 2007 (Fleming 2011) and operational for influenza swabbing in 2011 (RCGP: Weekly Returns Service Annual Report 2011, p. 12). In 2015, the network, now under the name “Royal College of General Practitioners Research and Surveillance Centre” (RCGP RSC), commissioned a new data and analytics hub at the University of Surrey (Correa et al. 2016).

In the French Réseau Sentinelles, a web interface became the preferred mode of data collection in 1996, with a client module for the GP computer being developed by 2009 to widen choices for GPs regarding the mode of data reporting (Turbelin et al. 2010). In Portugal, the Médicos Sentinela network initiated computerisation shortly after the turn of the century. In 2002, the RIOS platform was created to facilitate sentinel and other network notification via Internet in addition to paper-based entries (National Health Institute Doutor Ricardo Jorge (INSA) (2008) Plataforma RIOS). By 2003, a pilot

project with Internet-based data collection had begun in the sentinel network (webpage, 2 GPs) (Deckers and Schellevis 2004, p. 128).

In Spain, GP sentinel networks developed regionally, notably the GP Sentinel Networks of Castile and Leon (operational in 1989), the Basque Country (1990), Madrid Community (1991), and Valencia Community (1995; Vega Alonso et al. 2006, p. 497), followed by other Spanish regions. In 1991, the Castile and Leon GP network opened up to paediatricians, and in 2006 to nursing staff, becoming the Health Sentinel Network of Castile and Leon (Junta de Castilla y León, Consejería de Sanidad (n.d.) ¿Qué es?). Based on a Royal Decree issued in 1995, a national epidemiological surveillance network was created in 1996, including integral influenza sentinel surveillance (Vega Alonso et al. 2006, p. 497). In the Health Sentinel Network of Castile and Leon, new influenza tracking software was introduced on GP computers in 2015 (Saludadiario.es (2015) En Castilla). In Belgium and Switzerland, paper forms have been retained at least as an option until recently (see Table 3).

Development of other GP networks

The development of other GP networks was heterogeneous as well, with the United Kingdom as a forerunner in Europe. In England, several other GP research databases were founded, run by public health authorities, universities and/or commercial enterprises. Notable among these is the General Practice Research Database (GPRD), formerly the VAMP (Value Added Information Medical Products) Research Databank,

Table 3 General practice sentinel surveillance networks in six European countries with partly or completely computerised data collection or planned transition (for networks founded up to 1990, see also Van Casteren 1991)

Country/Region	General Practice Network	Coordinating institution	Network foundation/operational	Computerised data collection
Belgium	Réseau des médecins vigiles/peilpraktijken	Belgian Scientific Institute of Public Health (WIV-ISP)	1979 (Van Casteren 2009)	Transition towards computerised data collection planned for 2016/2017 in the context of the Healthdata.be initiative, providing data collection infrastructure for Belgian health registries (Scientific Institute of Public Health, Healthdata (n.d.) Sur Healthdata.be); extraction from EHR and/or manual data entry (application on computer of provider) (Scientific Institute of Public Health, Healthdata (n.d.) Collecte des données)
England/Wales (United Kingdom)	Weekly Returns Service, today Royal College of General Practitioners Research and Surveillance Centre (RCGP RSC) (without Wales) (Correa et al. 2016)	Research and Surveillance Centre of the Royal College of General Practitioners	1967 (Fleming and Elliot 2006, p. 821)	Transition towards computerised reporting 1994–1998 (The Royal College 2002). Since 2007 new extraction routine introduced with collection of patient-specific longitudinal data (Fleming 2011), 2011 used for influenza swabbing (Royal College of General Practitioners, Research & Surveillance Centre (n.d.) Weekly Returns Service Annual Report 2011, pp. 9–12)
France	Réseau Sentinelles (French General Practitioners Sentinel Network)	French National Institute of Health and Medical Research (Inserm)/University of Paris VI; Pierre and Marie Curie	1984 (Institut national de la santé et de la recherche médicale (Inserm)/University Paris VI Pierre et Marie Curie (n.d.) Réseau Sentinelles)	Computerised at foundation: videotex data entry application (Garerin et al. 1992, p. 35); web-based entry preferred (1996), data entry via an application on local GP computer offered (2009) (Turbelin and Boëlle 2010)
Portugal	Médicos Sentinela	National Health Institute Doutor Ricardo Jorge (INSA)	1989 (National Health Institute Doutor Ricardo Jorge (INSA) (n.d.) Rede Médicos Sentinela)	2002 creation of online RIOS platform (Redes de Informação e Observação em Saúde) (platform also for other networks) (National Health Institute Doutor Ricardo Jorge (INSA) (2008) Plataforma RIOS); 2003 pilot project via internet (Deekers and Schellevis 2004, Appendix B, p. 128); today utilization of RIOS platform or data collection on a specific paper form, sent weekly by mail to the central coordination office in Lisbon (Ana Paula Rodrigues, personal communication to the first author, 21 February 2016)
Castile and Leon (Spain)	Red de Médicos Centinela (since 1991 also pediatricians), since 2006 Red Centinela Sanitaria de Castilla y León (also including nursing staff) (Junta de Castilla y León, Consejería de Sanidad (n.d.) ¿Qué es?)	Regional Government of Castile and Leon, Ministry of Health, Directorate General of Public Health and Research, Development and Innovation (DGSPIDI) (Junta de Castilla y León, Consejería de Sanidad (2011) Procedimientos, p. 28)	1989 (Véga Alonso et al. 2006, p. 497)	Influenza-tracking software on GP computer (2015) (Saludadiario.es (2015) En Castilla); data transfer from the diabetes cohort via Medora information system from January 2015 onwards (Junta de Castilla y León, Consejería de Sanidad (n.d.) Nueva recogida)
Switzerland	Sentinella (GPs, specialists in internal medicine, and pediatricians)	Swiss Federal Office of Public Health, Division of Epidemiology and Infectious Diseases	1986 (Swiss Federal Office of Public Health (n.d.) The Swiss)	Paper forms or online reporting on web page (Schweizerische Eidgenossenschaft, Bundesamt für Gesundheit (n.d.) Das schweizerische Sentinella-Meldesystem)

established in 1987 (Independent Scientific Advisory Committee for Medicines and Healthcare products Regulatory Agency (MHRA) database research (ISAC) (n.d.) Annual Report 2012, p. 20). Since 2012, it has been known under the name of the Clinical Practice Research Datalink (CPRD) (Independent Scientific Advisory Committee for Medicines and Healthcare products Regulatory Agency MHRA database research ISAC (n.d.) Annual Report 2012, p. 3). Further examples include Qresearch, UK IMS Disease Analyzer and The Health Improvement Network (THIN) (Williams et al. 2012, p. 91); furthermore, research infrastructure was developed further into the United Kingdom Clinical Research Network (UKCRN) with a central role for primary care (Sullivan et al. 2007).

In France, the computerised Observatory of General Medicine (OMG) database was initiated by the French Society of General Practice in 1993 (De Pange 2004, p. 10). However, it did not survive due to a lack of resources and was closed in 2011 (Société Française de Médecine Générale (2012) *L'avenir*). The commercial Open Rome Observatory (Organize and Promote Epidemiological Network, Réseau d'Observation des Maladies et d'Epidémies), a creator of multidisciplinary networks involving caregivers and researchers in epidemiology, public health, risk management, and economic evaluation in health (Organize and Promote Epidemiological Network, Réseau d'Observation des Maladies et d'Epidémies (Open Rome) (n.d.) *Bienvenue*), does not target general practice specifically but has also been engaged in primary care initiatives such as the GROG (Regional Groups Influenza Observation) network since 1984 (Organize and Promote Epidemiological Network, Réseau d'Observation des Maladies et d'Epidémies (Open Rome) (2013) *Réseau des GROG*). The Permanent Epidemiological Observatory Thales, a commercial database which also includes other specialties, was set up in 1990 (Cash (2000) *THALES*). Its coordinator also cooperates with the Italian GP network Health Search (Istituto di Ricerca della Società Italiana di Medicina Generale (SIMG) (n.d.) *Health Search*).

In Belgium, the EHR-based Flemish Intego general practitioner network, coordinated by the Academic Centre for General Practice at Leuven University, was set up in 1990 as the first computerised morbidity registration network in Belgium (Truyers et al. 2015, p. 9). In French-speaking Belgium, the Federation of Integrated Primary Health Care Centres (Fédération des maisons médicales et des collectifs de santé francophones) established the “tableau de bord” (monitoring chart), starting with a pilot project in 2004 (Carbonez 2010, pp. 4–5). The Belgian national Sentinel GP Network has remained paper-based so far (Van Casteren 2009, p. 10), but will organise its transition to computerised data collection in the context of the Federal Healthdata.be initiative in 2016/2017. Healthdata.be has begun to build a research infrastructure for—according to the Belgian Federal Minister of Health, preferably

all—Belgian health databases (Scientific Institute of Public Health (WIV-ISP) (n.d.) *Healthdata.be: une nouvelle plateforme*).

In Spain, the General Practice Pharmacoepidemiologic Research Database (BIFAP) was founded in 2000 (Salvador Rosa et al. 2002), and contains information provided by GPs and paediatricians in the Spanish National Health Service (NIH National Cancer Institute (2013) *Base de datos*). In Catalonia, SIDIAP, the Information System for the Development of Primary Care Research, was founded in 2010 (SIDIAP Information System for the Improvement of Research in Primary Care (n.d.) *Background*). It is based on electronic medical records of about 5 million people from Catalonia, around 80 % of the population in this region (Muñoz-Ortego et al. 2014, p. 1771).

In Switzerland, EHR-based data collection has also begun within Swiss primary care settings. Established in 2009 at the Institute of General Practice of the University of Zurich, the FIRE project (Family Medicine ICPC Research using Electronic Medical Records) (Universität Zürich, Hausarztmedizin - FIRE (n.d.) *Das FIRE-Projekt*) “provides the first and largest standardized collection of structured medical routine data from Swiss primary care” (Streit et al. 2015, p. 2). Regarding Portugal, where many obstacles to primary care research have been identified (Granja et al. 2014, p. 7), no other major GP network has been found.

Discussion

Foundation history and institutional context of Sentinel GP Network development

The Sentinel GP Network owes much to three factors shaping the context of its development: (1) during its foundation period, a national GP research institute already existed, independent of the Dutch universities and before chairs of general practice were created there; (2) professionalisation efforts of committed GPs met government interests in the field of surveillance in primary care; and (3) from the beginning, government had a stake in the mission of this institute and the mission of the Sentinel GP Network, namely providing data for health policy planning. For a federal government eager to obtain such data, the NHI as the coordinating institution of the sentinel GP network was the more obvious choice than a university department. At the NHI, representation of the government in the Planning/Counselling Committee provided the possibility to exert influence directly and to suggest research topics which were relevant in their eyes.

A Dutch peculiarity is the consecutive twofold involvement of two different institutions, first the Chief Medical Office of Health and the NHI in the foundation period, and then NIVEL as successor to the NHI and WOK for setting up

LINH. Both times, NIH/NIVEL was in charge of the overall functioning of the network and ultimately remained the sole responsible institution. In England, where general practice has also had a strong position in the health system the whole time, the Royal College of General Practice remained in charge of the sentinel GP network. In other European countries, coordination was typically assigned to a public health surveillance institution and remained there.

The eagerness of NIVEL to embrace digital data collection in the early 1990s led to its running large parts of LINH infrastructure. This in turn provided the foundation for an adjustment of the Sentinel GP Network towards LINH based on the experience and infrastructure available. The integrated coordination of nationwide routine and supplementary data collection in general practice—and subsequently other primary health care providers—for both sentinel surveillance and health services research by the same primary care research institute is another distinctive feature of Dutch primary care monitoring and research. In several other European countries such as England, Belgium, France, and Switzerland, EHR-based general practice research networks developed at institutions different from those already coordinating sentinel networks.

Integration of routine and supplementary data collection: challenges of the transition

The Dutch example illustrates that the transition of a paper-based into an EHR-based data collection system can take a considerable period of time. In spite of additional resources and more than a decade of experience with LINH at the same institute, computerisation of routine data collection in the sentinel network took much longer than foreseen in the project proposal of 2004, but not much longer than the English WRS that had been computerised a decade before, between 1994 and 1998. The Netherlands have been one of the leading countries in GP EHR utilisation: a 2006 study found that 98 % of Dutch GPs used EHRs (Schoen et al. 2006, p. w558), and a study on GP eHealth utilisation in 2002 and 2007 ranked the Netherlands among the leading EU-15 countries (Ortega Egea et al. 2010, pp. 546–547). Thus, attention needs to be given to the considerable length of time to be allowed for such a transition. Furthermore, the major turnover in GP participation during the transition of the sentinel GP network towards digitalisation demonstrates that even in a country with highly computerised general practice and the professional GP association proposing similar coding standards, the effort necessary to keep the network running during the transition period should not be underestimated. Quality monitoring in the transition period is important, but the Dutch experience shows that it is a challenge to keep GPs motivated to continue the additional work when registering on paper and electronically.

Furthermore, the Dutch were in a fortunate position of being able to carry out the transition with four different EHR software programmes and a website for other GPs. A much greater challenge exists in Belgium, where 15 different recognized GP software programmes co-existed in 2015 (Institut national d'assurance maladie-invalidité (INAMI) (2015) Prime télématique). In the sentinel GP network there, an investigation found nine different EHR software programmes for about 80 % of Belgian sentinel GPs, with only one software programme being used extensively in both Flemish-speaking and French-speaking Belgium (Boffin et al. 2010).

Baakman argued that the strongest stimulus for behavioural change in an organisation is the understanding that failure to adapt could lead to its ruin (Baakman 1991, p. 86). It was far from self-evident that the Dutch Sentinel GP Network would survive alongside this promising second computerised GP network, in spite of a health policy climate generally favourable towards primary care. During the 1990s, the Sentinel GP Network demonstrated its added value for infectious disease surveillance in the Netherlands, and NIVEL emerged with a prominent role in European GP network research. The adaptation strategy included an alignment and progressive integration of the Sentinel GP Network, while also (1) contributing to EHR routine registration, (2) continuing to provide supplementary data for in-depth research as added value of the sentinel practices, and (3) implementing innovations in EHR registration so that routine registration supported improved supplementary data collection.

Today, the continued added value of sentinel GP data collection is shown by recent publications on diverse projects such as unwanted pregnancy (Goenee et al. 2014), predictors of gastroenteritis in day-care children (Enserink et al. 2013), and trends in palliative sedation in the Netherlands (Donker et al. 2013).

Conclusion

The Dutch experience is an example of the challenges and opportunities for the established traditional Sentinel GP Network. The main challenge for the network turned out to be a second EHR-based national general practice data collection network in the 1990s against the background of emerging ICT opportunities and new government demands to obtain data on procedures in general practice for health policy planning.

The subsequent adaptation strategy with a transition towards digital data collection led to an integrated national general practice database developing into a primary care database, while preserving complementary data collection for in-depth research. The Dutch experience offers points of attention for

the transition period from paper to electronic recording, such as the substantial turnover of reporting GPs comprising the knowledge base for the network.

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Compliance with ethical standards

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