



# **HEALTH MONITORING IN SENTINEL PRACTICE NETWORKS**

**Final report**

DM Fleming, FG Schellevis, WJ Paget  
March 2001

Project title: **Health monitoring in sentinel practice networks**

Project number: **1998/IND/1021**

Contract number: **SOC 98 201401 05F03 (98CVVF3-507-0)**

Programme: **Community Action on health monitoring within the framework for action in the field of public health (1997-2001)  
European Commission Directorate General SanCo**

Institute: **Netherlands Institute for Health Services Research (Nivel)  
PO Box 1568  
3500 BN UTRECHT  
The Netherlands  
Tel: + 31 30 2729 700 / 724  
Fax: + 31 30 2729 729**

Project coordinator: **Douglas M. Fleming**

Project leader: **François G. Schellevis**

Researcher: **W. John Paget (from April 1, 2000)**

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## EXECUTIVE SUMMARY

This is the final report of the project "Health monitoring in sentinel practice networks" carried out between December 15, 1998 and December 15, 2000 as part of the Health Monitoring Programme of the European Commission (Directorate-General SanCo).

### Objective

The objective of the project was *"to contribute to the establishment of a Community health monitoring system with information from primary care by studying the feasibility of providing information about health indicators from primary care based sentinel practice networks"*.

### Activities

The project activities included the following: (1) an inventory of operational sentinel practice networks in Europe; (2) the establishment of an Expert and Documentation Centre at the Netherlands Institute for Health Services Research (Nivel) in Utrecht (NL) on sentinel practice networks; (3) coordinated collection of epidemiological information about two health indicators in sentinel practice networks in different countries; (4) formulating recommendations on data collection, analysis and presentation of information from sentinel practice networks.

### Results

The results of the project can be summarized as follows:

- \* 33 operational registration networks have been identified. Networks on a national or major regional scale exist in the following Member States: Austria, Belgium, Denmark, France, Germany, Greece, Ireland, Italy, The Netherlands, Portugal, Spain, Sweden, and the United Kingdom (England & Wales) and in three non member countries (Switzerland, Croatia and Slovenia). Some of these networks are mainly involved in influenza surveillance. Only the networks in Belgium, France, The Netherlands, Portugal, Spain, and England & Wales (and Switzerland, Croatia and Slovenia) also collect data about other diseases. These networks are funded by Ministries of Health or other government departments: many have been operational for more than 10 years, some of them even 30 years.
- \* The foundations for an Expert and Documentation Centre have been established, including a database with information about operational networks in Europe, relevant scientific publications, annual reports, and operational and management information relating to the networks.
- \* Epidemiological information has been collected and presented about two exemplary health indicators (varicella as an example of a communicable disease and diabetes mellitus as an example of a chronic disease). Apart from incidence rates of varicella, we were able to show that the cases reported to sentinel practices represent on the average 85-90% of the cases in the population. Diabetes mellitus age and sex specific prevalence rates showed a remarkable similarity between countries. In addition we have been able to collect information on the actual management and health care utilisation of patients with diabetes mellitus.
- \* From experiences with the inventory of networks, the documentation, and the collection of information about health indicators recommendations have been formulated on the following issues:
  - practice and population sampling
  - data collection, data processing and data presentation (including guidelines on age standardisation)
  - validation of information.

### Conclusions

- (a) Primary care based sentinel practice networks are a valuable source of information about selected health indicators, especially diseases for which a medical professional diagnosis is important and for which other data sources (such as health surveys, hospital admission data, disease registries or mortality statistics) are less appropriate.
- (b) Primary care based sentinel practice networks are able to provide epidemiological information on health indicators.
- (c) Information about health indicators from primary care based sentinel networks need interpretation and annotation before use on a wider scale.

- (d) The establishment of nationally representative primary care based sentinel practice networks should be supported in Member States. Where sentinel practice networks exist, these should be extended with regard to the number of monitored diseases.
- (e) The Expert and Documentation Centre should be encouraged to provide support and to ensure comparability between networks and Member States.
- (f) These conclusions lead to specific recommendations which are summarized in the last chapter of this report.

## 1. INTRODUCTION

### 1.1 General introduction

This document is the final report of the project "Health monitoring in sentinel practice networks" (HMSPN project) carried out between December 15, 1998 and December 15, 2000. The project was funded by the European Commission as part of the "Programme of Community action on health monitoring within the framework for action in the field of public health (1997 to 2001)" [1] (further referred to as "Health Monitoring programme"). The Health Monitoring Programme is coordinated by the Directorate-General Health & Consumer Protection (SanCo).

### 1.2 Relation with the Health Monitoring Programme

The objective of the Health Monitoring programme of the European Commission is: "to contribute to the establishment of a Community health monitoring system which makes it possible to:

- (a) measure health status, trends and determinants throughout the Community;
- (b) facilitate the planning, monitoring and evaluation of Community programmes and actions; and
- (c) provide Member States with appropriate health information to make comparisons and to support their national health policies by encouraging cooperation between Member States and, if necessary, by supporting their action through promoting coordination of their policies and programmes in this field and encouraging cooperation with non-member countries and the competent international organizations" [1].

On the basis of the Decision of the European Parliament and of the Council adopting the Health Monitoring Programme, a draft working programme 1998-1999 was established in which priorities were formulated for the first period of the programme [2], under three pillars:

- Pillar A: the establishment of Community health indicators;
- Pillar B: the development of a Community-wide network for sharing health data;
- Pillar C: analysis and reporting.

The actions to be implemented under the Health Monitoring programme include the establishment of comparable European Community Health Indicators (ECHI) "by means of a critical review of existing health data and indicators by developing methodologies for obtaining comparable health data and indicators, and by developing appropriate methods for the collection of progressively comparable health data needed to establish these indicators" [1, Annex I]. The HMSPN project fits mainly in this action.

### 1.3 Relation with the project European Community Health Indicators (ECHI)

A central project within the Health Monitoring programme, "Design for a set of European Community Health Indicators" (further referred to as "ECHI project") played a crucial role by proposing European Community Health Indicators, to be included in a Community wide information system [3]. The HMSPN project is related to this ECHI project with its aim *"to contribute to the establishment of a Community health monitoring system with information from primary care by studying the feasibility of providing information about health indicators from primary care based sentinel practice networks"*. The HMSPN project aims at the provision of information about the incidence and prevalence of indicator diseases for which primary care is the most appropriate information source.

### 1.4 The value of information from primary care

Two main general issues reinforce the need for monitoring health: the concern for equity of care between different populations [4,5] and the dramatic acceleration of medical advances. Currently, information about the health of populations is usually derived from national statistics such as mortality statistics, hospital admission data or registries for specific diseases (e.g. cancer registries). The value of these information sources is indisputable. However, it is generally recognized that these figures represent only a part of the information about populations' health. Diseases in the population which do not lead to death or to hospital admission are not included but many have a much larger impact on health than diseases for which people are admitted to hospital or which are a frequent cause

of death. To complete the picture it is necessary to have information about the distribution of diseases in the community, either from health interview surveys or from health care providers with direct access for the population. Information from health interview surveys include self-reported morbidity, whereas information from health care providers is professionally defined and therefore comparable to other information sources such as cause of death and hospital admission diagnoses.

Another source of information is provided by incidental ad hoc epidemiological research. This information source has only limited value because the primary focus is on the research objective and the information obtained is limited to the case definition and the time period for the study.

As has been established repeatedly in the United Kingdom and The Netherlands, 90% or more of all health problems presented to primary care are exclusively managed in primary care and do not go further into the health care system [6,7]. This emphasises the need for monitoring health in primary care settings to complete the picture of health status in the population. Monitoring of health in primary care, and the data derived from it, should however not be seen in isolation from other sources of information about health.

For some conditions, the boundary between normality and illness is impossible to draw. For these it is far more significant to focus the measurement of illness at a level in which treatment is sought. This is particularly the case for the health care provider who has to ensure that resources are available to respond to demand. The point is illustrated by reference to two groups of diseases – respiratory and mental illnesses. The majority of acute respiratory infections are minor and self limiting. The demand they impose on health care is of greater importance to health care providers than is the totality of infection. Indeed health care providers commonly operate to discourage the use of health care facilities in persons with minor respiratory disease. Selective studies of seroconversion can provide particular information where relevant, as for example, to rationalise a national vaccination strategy. The distinction between depression consequent on personal circumstances and pathological depression is well nigh impossible to draw. Health care providers require information on mental illness requiring treatment and not persons adjusting to their circumstances. Most of those consulting, but few among those who choose not to consult, have illness requiring treatment. Changes over time in the total level of health care provision could be indicative of change in the community with respect to either of these two groups. Sentinel surveillance recognises change; it may not explain change. Indeed, one of the functions of sentinel surveillance is to identify trends prompting the use of other instruments to explain them.

This project included a small exercise in which we sought the opinions of leading general practitioners (GPs) on conditions they considered particularly appropriate to surveillance in sentinel practice networks.

The primary care setting is well suited to deliver three types of information:

- information on threats to public health from communicable infectious diseases;
- information on the incidence and prevalence of chronic diseases;
- information on common health problems which have major economic consequences (e.g. work absence).

This information will come from data collected routinely at consultations within primary care and will have to be obtained at minimal costs partly for obvious reasons of economy, but equally because normal routines for health care delivery cannot be disrupted: disruption will lead to bias which is unacceptable in a monitoring context. Data collection which is integrated in routine daily care provision is very inexpensive when compared to other data collection methods such as health surveys, especially when continuous (or intermittently repeated) data collection is required. This economic advantage is even more important in view of the decreasing willingness of people to participate in surveys. According to information from The Netherlands, the response rates in recent household surveys have decreased to 60% and the non-response increases by 1% per year [8].

## **1.5 Existing infrastructure: sentinel practice networks**

In a number of Member States and non-member countries primary care based sentinel networks are operational on a continuous basis. These networks collect information about disease indicators in the population at a regional or national level and include only primary care based physicians with direct access for the population. This infrastructure is particularly well suited for the provision of information on the distribution of diseases in the community with the advantage of professionally defined morbidity. The term “sentinel” in this context has several meanings [9]. Within the framework of this project “sentinel” refers to keeping watch as a guard applied in relation to the spread or increase of disease

and to the concept of a monitoring force simply describing on behalf of a larger community the important elements of ill health. Timeliness is of the essence when considering the sentinel function.

## **1.6 Description of the HMSPN project**

The HMSPN project fits into the Health Monitoring programme with its aim to study the feasibility of the delivery of health information from primary care (see paragraph 1.2 and 1.3). This document reports on the methods and results of this project and provides recommendations for the future. Originally a proposal for a 5-year project had been submitted with more ambitious and further reaching goals. At the request of the European Commission, however, the original plans were reduced substantially to fit into a 2-year project.

The working plan for the HMSPN project included the following activities:

- a) to make an up-to-date inventory of primary care based sentinel practice networks in European countries;
- b) to study the feasibility of a coordinated collection of data on two health indicators in sentinel practice networks;
- c) to formulate recommendations about
  - harmonizing data collection
  - presentation of information
  - the appropriateness of primary care based sentinel networks to collect information about Community health indicators.

## **1.7 Contents of this report**

The final report is organised around different themes. Chapter 2 reports on the previous and current cooperation between sentinel practice networks, on the results of the inventory of functioning networks and on the establishment of an Expert and Documentation Centre. In chapter 3 the results are described of coordinated data collection in networks from different Member States on two health indicators. Chapter 4 provides an overview of important issues, based on the experience of cooperation between networks in different countries. In chapter 5 recommendations are formulated.

## **1.8 Project organisation**

The HMSPN project was carried out at Nivel, the Netherlands Institute for Health Services Research by the following persons:

- Douglas M. Fleming (Director of the Birmingham Research Unit of the Royal College of General Practitioners in the United Kingdom; for this project stationed at Nivel), project coordinator;
- François G. Schellevis (Nivel), project leader;
- John Paget (Nivel), researcher (from April 1, 2000).

For the project a steering group was established, consisting of experts and representatives from sentinel practice networks in European countries. The steering group had 3 meetings during the 2 years of the project: in February 1999, in October 1999 and in September 2000. Reports of these meetings can be found in appendix 1 of this report. The steering group included the following persons:

- Aad Bartelds (The Netherlands)
- Viviane van Casteren (Belgium)
- Jean-Marie Cohen (France)
- Isabel Marinho Falcao (Portugal)
- Antoine Flahault (France)
- Ahilya Noone (Scotland)
- Martin Schlaud (Germany)
- Tomas Vega Alonso (Spain).

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## 2. SENTINEL NETWORKS: PAST AND PRESENT

### 2.1 Introduction

The HMSPN project represents a new phase in a tradition of cooperation between sentinel practice networks in Europe. Since 1987 a number of cooperative projects have been carried out including the "Interface study", the "Eurosentinel project", the "European Referral Study" and the "Denominator project". The HMSPN project is built upon the experience gained from these projects; the results of which are summarized in paragraph 2.2. At present, many sentinel practice networks cooperate within the European Influenza Surveillance Scheme (see paragraph 2.3). The results of the inventory of primary care based sentinel practice networks in European countries carried out as part of the HMSPN project are summarized in paragraph 2.4. Finally, the foundation for an Expert and Documentation Centre on sentinel networks has been established at the Nivel Institute. In paragraph 2.5 the initial activities of this Centre are reported.

### 2.2 Previous cooperation of sentinel networks in Europe

#### 2.2.1 Eurosentinel project

The Eurosentinel project, carried out within the framework of the Medical and Public Health Research Programme of the European Community between 1988 and 1991 and coordinated by the Belgian Institute of Hygiene and Epidemiology was aimed at encouraging and assisting in the development of sentinel networks of general practitioners (GPs) in as many Member States as possible. A sentinel network of GPs was defined as: "a network that keeps a watchful eye on a sample of the population by supplying regular and standardized reports on specific diseases, procedures in primary health care, etc." [1]. The second objective was to start the recording of conditions in which there was a specific international interest, with the collaboration of existing networks. A collaborative recording on measles, mumps, influenza-like-illness and requests for HIV-tests was started with the participation of national or regional sentinel networks in Belgium, France, The Netherlands, England & Wales, Portugal and Spain. Two European projects were concerned with HIV. From September 1992 until September 1993 the project "Collection of data about HIV-antibody tests. Surveillance of prescriptions of HIV-tests in general practice by sentinel networks in Europe" was carried out [2]. The aim was to provide indicators on the demand pattern for HIV-antibody testing, possibly reflecting changes in the perception of the risk for HIV-infection by the general population or by GPs in different countries. The recording was continued in a further EC project from June 1994 to June 1995, "Data collection on patterns of demands for HIV-testing and other HIV/AIDS-related consultations in general practice" [3]. The conclusion of this project was that although the number of prescribed HIV-tests per GP per year was a valuable indicator, one needs to study the distinct patterns in more detail both geographically and over time. It was possible to identify several factors influencing requests for HIV-tests.

#### 2.2.2 The Interface study

This study, carried out between 1986-1987, was aimed at describing the interface between primary and secondary medical care in European countries, the differences in relation to health care systems and the role of primary care doctors in these systems. The study resulted in a comprehensive description of primary and secondary care in 16 European countries, the function and tasks of GPs in these countries and problems encountered in the cooperation with medical specialists [4]. A major recommendation led to the European Referral Study.

#### 2.2.3 European Referral Study

This study, carried out within the framework of the Concerted Action on Health Services Research at the Birmingham Research Unit of the Royal College of General Practitioners in the United Kingdom, had three aims [5]:

- to define and compare national referral patterns;
- to compare practice and doctor characteristics of doctors with high and low referral rates within countries and between countries;
- to examine delay patterns for specialist consultation and surgical treatment.

The conclusions of this project, for which 44,134 referrals in 15 countries were analysed, were:

- there are substantial differences in referral patterns between countries which are related to differences in physician density and access to secondary care;

- referral rates are more influenced by the health care system (position of the GP in the health care system, accessibility of secondary care) and expectations of the patients about medical expertise than by practice and doctor characteristics;
- the mean delay between the referral and the first appointment was 18 days (range 2-36) and between specialist consultation and surgical treatment 20 days (range 10-30).

The project showed that cooperation and comparisons between countries leads to valuable information, but also that experts must be involved in interpreting results of international comparisons.

#### *2.2.4 European Denominator Project*

From 1994 until 1996 this project was coordinated by the Department of Epidemiology, Social Medicine and Health System Research of the Hannover Medical School in Germany [6]. The project was funded within the framework of the BIOMED programme of the European Community. The aim was to make recommendations to solve the “denominator problem”, representing the incomparability of information from primary care settings in different countries due to the lack of comparable data about the population to which the information refers. As a result of the project four potential ways of harmonizing denominator data for international comparisons were presented as recommendations [6].

### **2.3 Current cooperation of sentinel networks in Europe**

#### *European Influenza Surveillance Scheme*

The European Influenza Surveillance Scheme (EISS) has existed as such since 1996 [7,8] and is still active. EISS has received funding from Home & Consumer Protection Directorate-General of the European Commission since November 1999. The objectives include:

- facilitating the rapid exchange of information on influenza activity in Europe;
- combining clinical and virological data in the same population;
- identifying causal viruses in the population and recognising virological changes;
- providing standardised information of high quality.

The main activity of EISS is the publication during the influenza season of a weekly electronic bulletin on the Internet (<http://www.eiss.org>). The Bulletin provides a weekly overview of influenza activity in Europe in the form of a map, a table and a commentary written by experts from the EISS group.

**Figure 2.1** Map of Europe showing the countries participating in the European Influenza Surveillance Scheme

Within the framework of the HMSPN project an inventory of currently operational sentinel practice networks in Europe has been carried out. Networks were contacted by using previous inventories [1,9], contacting national GP associations and other informal contacts. We defined a sentinel practice network as being: “A network of practices or community based primary care physicians who monitor one or more specific illness problems on a regular and continuing basis”. In total, 33 networks could be identified.

Networks on a national or major regional scale exist in the following Member States: Austria, Belgium, Denmark, France, Germany, Greece, Ireland, Italy, The Netherlands, Portugal, Spain, Sweden, and the United Kingdom (England & Wales) and in three non member countries (Switzerland, Croatia and Slovenia). Some of these networks are mainly involved in influenza surveillance. Only the networks in Belgium, France, The Netherlands, Portugal, Spain, and England & Wales (and Switzerland, Croatia and Slovenia) also collect data about other diseases. With regard to the continuity of the networks it is important to notice that the national networks in Belgium, The Netherlands, Portugal, Spain, the United Kingdom, Switzerland, Croatia and Slovenia are funded by their respective Ministries of Health, whereas the French network is funded via governmental research funds. Some of these networks have existed for more than 10 years, or even 30 years.

In conducting this inventory we distinguished between networks available to undertake specific research projects and those actually undertaking surveillance [9]. There are many other practice-based research networks capable of undertaking research projects [10], but these are not constrained by the

issues of representativeness, critical for the surveillance function. It depends on the basis for which the network was constructed. Some networks are simply a local outreach of an academic department of general practice, others are concerned with particular diseases and recruitment is selective, others with audit and educational functions, others to provide prescribing data or monitor adverse events.

**Figure 2.2** Map of Europe showing countries with sentinel networks involved in collecting data about more health indicators than influenza alone

**2.5 Expert and Documentation Centre**

### *2.5.1 Introduction*

One of the aims of this project was “to establish a centre of reference to which existing and new networks can look for advice and support in developing networks for monitoring morbidity in primary care” (citation from the project description). During the 24 months of the project a number of activities have been carried out to prepare the establishment of an Expert and Documentation Centre at Nivel, the Netherlands Institute for Health Services Research. The choice of Nivel for this centre was approved by the steering group of the project for several reasons:

- the existing infrastructure: a renowned and stable institute with a national and international reputation;
- language ability: the most frequently used European languages (English, French, German, and ,of course, Dutch) are spoken at Nivel;
- the geographical location of Utrecht in Europe makes Nivel easily accessible;
- 30-years experience of registration in sentinel practices.

It has been emphasised that the choice of Nivel for the Expert and Documentation Centre does not imply that all expertise will be available at Nivel, but that the Centre has knowledge about whom to contact or where to find further information or documentation.

Activities undertaken within the framework of the project include:

- a) establishing a database containing information about primary care based registration networks in Europe (paragraph 2.5.2);
- b) the establishment of an archive of publications and documents relevant for the Expert and Documentation Centre (paragraph 2.5.3);
- c) starting a consultation service for existing and new networks (paragraph 2.5.4).

Finally, in paragraph 2.5.5 the possible further development of the Centre is described.

### *2.5.2 Information about registration networks in Europe*

As a result of the inventory of registration networks in Europe (see paragraph 2.4) Nivel has information on 33 active registration networks including:

- name of network
- correspondence address, telephone, telefax, e-mail address,
- main objectives of the network
- network characteristics: size, distribution, lifetime of the network, main source of funding
- (brief) comments on how the network operates
- persons or institutions who usually use the network data
- accessibility and costs of the data.

### *2.5.3 Archive of publications and documents*

Publications relevant for sentinel surveillance in primary care have been identified by a systematic literature search, from the reference lists of the selected publications and from lists of publications from the networks participating in the project. 114 publications have been identified and included in the library database of Nivel.

Apart from these scientific publications the networks participating in the HMSPN project have submitted documents regarding the functioning of their own network (e.g. handbooks, description of procedures for data collection, data handling, data analysis and presentation of information, annual reports, publication lists) for inclusion in the Documentation Centre.

### *2.5.4 Consultation service*

Within the framework of the HMSPN project advice has been given on two occasions. Firstly, in February 2000 the project coordinator (DM Fleming) paid a visit to Slovenia on the request of the manager of the national Slovenian primary registration network for a site visit and advice on a number of practical points regarding data collection methods and reporting information from the network. This visit has led to a scientific paper on information from primary care which has been submitted for publication.

Secondly, a three-person delegation from the Göteborg University Department of General Practice in Sweden lead by Prof. Cecilia Björklund, visited Nivel in November 2000. After a pilot phase, this research group is preparing a continuous registration network of general practices. During a one-day meeting with DM Fleming and FG Schellevis a considerable number of problems were discussed regarding aims, methodology, infrastructure, financial support and management of such a network. It became clear that the Göteborg Department of General Practice aimed at the establishment of a network of practices for research purposes, in particular for carrying out clinical trials in general practices, rather than the establishment of a network of sentinel practices.

### 2.5.5 Further development

Depending on the continuity of funding, the Expert and Documentation Centre will be developed further from the current pilot status to a fully functioning Centre. This development includes:

- procedures for updating information (e.g. on networks and network activities);
- dissemination of the information available, including presentation of the Centre on Internet;
- improving the accessibility of publications and documents at Nivel;
- education and training of a Nivel researcher to coordinate the activities of the Centre and acting as contact person and representative;
- developing training modules for managing registration networks and research with data from registration networks
- developing a glossary of essential terms and definitions used in sentinel surveillance.

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### **3. DATA ON HEALTH INDICATORS**

#### **3.1 Introduction**

One of the activities of the HMSPN project was to study the feasibility of a coordinated collection of data on two health indicators in sentinel practice networks. For this chickenpox (varicella) was chosen as an example of a communicable disease and diabetes mellitus of a chronic disease. The aim of this part of the project was to demonstrate that the participating networks have the capacity to deliver information on the basis of data collected within their networks and that it is possible to integrate this information into epidemiological figures at the European level.

#### **3.2 Chickenpox**

##### *3.2.1 Introduction*

Chickenpox (varicella) is a disease which in most countries is largely managed in primary care. Estimates of the burden of illness due to chickenpox are important to assess the need for, and (if substantiated) the population to be targeted for vaccination. Incidence information is also needed to provide warnings, in case vulnerable groups are placed at increased risk. Vulnerable groups include the foetus [1], very young infants before the immune system has developed [2], the immune compromised [3] and the frail elderly in whom there is increasing evidence of a failing immune system – which has been demonstrated particularly in relation to influenza [4].

Recent publications from the sentinel networks of both England and Wales and Slovenia have shown reducing age of first incidence [5,6]. A reducing age of incidence bears particularly on the risk to the foetus.

In sentinel practice networks incidence is measured as it presents to doctors or, in some cases, other primary health care workers. The value and comparability of information from such networks depends, among other factors on the degree to which the condition is managed outside primary care (e.g. self management or management by medical specialists). This study was primarily concerned with this point: the incidence of chickenpox which is not presented to health care, or - expressed in another way - with the gap between true incidence (incidence in the community) and incidence reported in primary care. The research question to be answered was: what is the difference between the incidence of chickenpox reported in the practices participating in the networks and the total incidence in the community?

##### *3.2.2 Methods*

The study consisted of two parts. The first part included the collection of data in the participating sentinel practice networks about incident cases of varicella according to the routines of the networks. The second part included an enquiry by questionnaires to identify cases of chickenpox not presented to primary care occurring in the same household additional to cases routinely reported. Five sentinel practice networks in four EU countries participated:

- England & Wales
- The Netherlands
- Portugal
- Spain (networks of Castilla y León and País Vasco [Basque country]).

##### *3.2.3 Results*

The five networks delivered information on 4089 cases of chickenpox. In table 3.1 incidence rates based on routine reporting are presented by age group for each network. The incidence rates are of the same magnitude in England & Wales, the Netherlands and Portugal, varying from 13 to 25 per 10,000. The rates in Spain are much higher and differ substantially between the two networks.

**Table 3.1** Incidence of chickenpox January-June 2000 per 10,000 persons: presented cases in five sentinel practice networks by age group and in total

	0 - 4	5 - 14	15+	Total (all ages)
England & Wales	270	44	5	25
The Netherlands	166	22	1	13
Portugal	183	77	4	21
Spain (País Vasco)	898	151	10	145
Spain (Castilla y León)	344	114	4	57

Participating practitioners in the sentinel networks provided further data on approximately 80% of the reported cases from which we identified a further 300 cases for whom no consultation had been made. The relative proportions of additional cases varied by network and country (in 2 to 32% of the useable questionnaires one or more additional cases were identified) but not within country by age group. The incidence rates after adjustment for identified additional cases who had not consulted a doctor is given in table 3.2.

**Table 3.2** Incidence of chickenpox January-June 2000 per 10,000 persons after adjustment for additionally identified cases not presented to a doctor in five sentinel practice networks by age group and in total (between brackets: % increase after adjustment)

	0 - 4	5 - 14	15+	Total (all ages)
England & Wales	311 (15%)	50 (14%)	5 (0%)	28 (12%)
The Netherlands	220 (33%)	30 (36%)	1 (0%)	17 (31%)
Portugal	222 (21%)	92 (19%)	5 (25%)	25 (19%)
Spain (País Vasco)	930 (3%)	156 (3%)	10 (0%)	150 (3%)
Spain (Castilla y León)	356 (4%)	120 (5%)	4 (0%)	59 (4%)

### 3.3 Diabetes mellitus

#### 3.3.1 Introduction

Diabetes mellitus has been chosen as an example of a chronic disease. Global patterns of diabetes mellitus prevalence and the association with physical inactivity and obesity suggest that diabetes mellitus is an important health indicator [7-9].

Data on the incidence and prevalence of diabetes mellitus have been collected within the routines of each network. Volunteer practices participated in the collection of additional data on the management and health care utilisation of diabetics. In most countries these data were collected during the year, in other countries, where practices have a list of diabetics, this information was collected at the end of the year 2000. This was for example the case in The Netherlands; therefore, these data were not available in time to be included in this report. The data on the management of diabetes and health care utilisation will be analysed in more detail and submitted for publication afterwards.

#### 3.3.2 Results

The prevalence of diabetes ranged between 16 per 1000 in Slovenia to 33 per 1000 in Belgium with remaining networks ranging between 20 and 26 per 1000 (table 3.3).



**Table 3.3** Period prevalence of diabetes mellitus in the year 2000 per 1000 persons in seven sentinel practice networks for males, females and both sexes

	M	F	M+F
England & Wales	21.0	18.0	19.9
Belgium	30.9	34.0	33.4
Portugal	22.0	18.0	20.0
Spain (Comunitat Valenciana)	17.1	21.9	19.5
Spain (País Vasco)	24.4	46.3	26.0
Spain (Catilla y León)	20.4	28.6	24.4
Slovenia	16.0	16.1	16.1
France	23.0	17.1	19.9

More detailed information in age and gender groupings are provided in tables 3.4 (for males) and 3.5 (females) and disclose particular points of interest:

- in the youngest age groups prevalence was highest in England & Wales, where GPs are responsible for total prescribing, even in circumstances where management is largely undertaken by specialists;
- patterns of higher prevalence in males were found in all networks and these were generally consistent in each network in the three youngest age groups;
- in the networks from Northern European countries prevalence was higher in males 65-74 years than in females but this structure was reversed in Spain, Portugal and Slovenia;
- prevalence in the age group 75+ years was similar or slightly greater than in the age groups 65-74 years in England & Wales, Belgium in both males and females. In the remaining networks, however, these age trends were inconsistent. The arrangements made for managing patients in residential institutions for the elderly may have a bearing on these results.

**Table 3.4** Period prevalence of males with diabetes mellitus in the year 2000 per 1000 persons in seven sentinel practice networks by age group

	0 - 24	25 - 44	45 - 64	65 - 74	75+
England & Wales	2.0	8.1	34.4	77.0	83.6
Belgium	1.1	6.3	54.6	112.5	122.3
Portugal	0.1	5.0	41.0	80.0	57.0
Spain (Castilla y León)	0.8	4.5	30.9	70.6	67.3
Spain (País Vasco)	1.0	3.3	47.7	110.1	106.6
Spain (Comunitat Valenciana)	0.8	2.7	26.7	59.1	55.6
France	0.7	4.6	48.6	99.1	76.1
Slovenia	0.7	7.5	33.3	55.0*	

\* rate for 65+

**Table 3.5** Period prevalence of females with diabetes mellitus in the year 2000 per 1000 persons in seven sentinel practice networks by age group

	0 - 24	25 - 44	45 - 64	65 - 74	75+
England & Wales	1.9	6.4	21.6	56.3	60.4
Belgium	1.5	6.6	42.8	95.9	137.2
Portugal	0.1	4.0	42.0	71.0	45.0
Spain (Castilla y León)	0.8	2.7	35.5	94.5	82.6
Spain (País Vasco)	0.8	2.5	34.4	109.9	99.2
Spain (Comunitat Valenciana)	1.4	2.3	25.0	80.3	58.4
France	0.3	3.7	30.6	66.5	63.5
Slovenia	0.5	4.0	21.0	56.6*	

\* rate for 65+

The audit on the management of prevalent cases included 16623 diabetics (table 3.6; exact figures on an additional number of approximately 2000 diabetics from the Dutch sentinel practice network were not yet available). In England & Wales there were more males than females, whereas in the remaining countries there were more females. The proportion in the age groups 25-44 years was also higher in England & Wales and the high proportion receiving insulin probably reflects the role of GPs as sole prescribers for all patients with diabetes. Fewer patients were managed by diet alone in Belgium than in the remaining networks.

**Table 3.6** Distribution by gender, age and management of audited diabetics

	England & Wales N=1387	Belgium N=4231	Croatia N=2962	Spain - C Valencia N=2119	Spain - Castilla N=2778	Spain - P Vasco N=3146
Males (%)	55.2	45.9	41.4	44.5	43.1	48.9
Age (%):						
0-24 yr	25.0	1.1	0.6	1.3	1.3	1.3
25-44 yr	10.8	4.9	3.8	5.4	3.3	3.3
45-64 yr	34.0	32.3	35.9	31.7	22.9	30.5
65-74 yr	27.6	30.7	37.5	37.6	38.5	36.5
75+ yr	25.0	31.0	22.2	24.0	34.1	28.4
Treatment (%): diet	24.0	15.3	21.8	17.6	22.5	32.5
Oral antidiabetics	51.2	61.9	53.3	51.3	54.0	54.4
Oral + insulin	1.3	8.1	9.8	6.0	2.9	2.4
Insulin only	23.5	14.7	15.7	25.1	20.6	10.8

### 3.4 Lessons of integrating information from different networks

#### 3.4.1 Chickenpox

The difference in incidences of chickenpox over the six month period can for the most part be explained by the differences in establishing the populations under surveillance. We focus here especially on the

deviating results from Spain. In contrast to the other networks, the two Spanish sentinel networks include both GPs and community based paediatricians. The GP population is derived from the list of individual health record cards held by the GP at the beginning of the year. In some parts of Spain there is independent access to community based paediatricians and children aged less than 15 years may be assigned to them as an alternative to GP but not as an addition. The denominator in these paediatrician practices is available in age groups 0-1, 2-4, 5-9 and 10-14 years. In the Basque country, 55% of the doctors reporting were paediatricians and they reported 95% of the cases; in the Castilla y León network the equivalent proportions were 37% and 85% respectively.

Moreover, chickenpox is a notifiable disease in Spain (and not in any of the other participating countries) and the incidence reported by the national notification procedure for the period January to June 2000 was 35 per 10,000 in the Basque region and 33 per 10,000 in Castilla y León. It is clear that this country-specific information is necessary to interpret the differences in incidence rates presented to and reported by sentinel practice networks.

We conclude that sentinel practice networks can be used to examine the distinction between incidence in the community and incidence in the consulting population. Practice population denominators are needed from the separate recording elements in sentinel practice networks. In particular, where paediatricians provide primary care, the data must be assembled in a way that allows an estimate by age group of the population under surveillance which may, in the case of children, need to be banded in a maximum of five yearly intervals.

### 3.4.2 *Diabetes mellitus*

Sentinel networks are a realistic way of gathering data provided the surveillance populations are known to be representative. Two points emerge from this study emphasising the importance of representativeness. In England & Wales, the higher prevalence of diabetes in children, compared with other networks is almost certainly due to the GPs' responsibility for total prescribing. There is no possibility for loss of those cases that may be almost completely managed by specialists. In some networks, prevalence in the 75+ years age group was less than in the age group 65-74 years. Many persons in the 75+ age group live in residential institutions; health care for these patients is sometimes provided outside usual GP care. Selective loss of cases (diabetes increases pressure on the frail elderly to enter residential institutions) may well lead to non-representativeness of diabetic patients in the community. The prevalence of diabetes in the oldest age groups is also influenced by the type of treatment chosen to treat ischemic heart disease and hypertension and the increasing survival of persons experiencing major cardiovascular incidents.

The distribution of cases by age, gender and management may also be a product of non-representativeness among the diabetic population [numerator] as much as of the underlying population [denominator]. However, the comparatively high prevalence of diabetes in Belgium, especially in the most elderly, was associated with the lowest proportion managed by diet alone. This finding along with other features of the diabetes audit of prevalent and incident cases will be reported separately.

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## 4. CURRENT ISSUES

### 4.1 Introduction

In this chapter we consider issues in relation to the operation of sentinel networks and potential developments. The long term goal of providing comparable information from sentinel networks will require all issues considered here to be addressed.

### 4.2 Practice and population sampling

#### 4.2.1 Sampling of practices

It is incumbent on networks to ensure that the participating practices are representative. There are two issues, the representativeness of populations and of practices.

In most countries the culture of primary medical care involves patients of one family all attending the same practice. For this reason it is not difficult to recruit patients with the socio-demographic mix of the area in which the GPs work. However, it remains important that practices are well distributed geographically, with special attention given to areas with substantial populations of particular subgroups such as ethnic minorities. Representativeness of populations will reflect morbidity in the community. The representativeness of the doctors is not considered here since interventions are not the primary focus for sentinel practice networks. Nevertheless it is useful if networks can show evidence of representativeness of the practices, their practitioners, as well as the populations under surveillance.

#### 4.2.2 The population denominator

The science of epidemiology demands an established denominator or at least an estimate with acceptable reliability. The availability of exact denominator data or estimations about populations served by general practices is largely dependent on whether the health care system includes a fixed practice list for GPs, which is not universal in Europe [1].

The most comprehensive information system identified exists in *Slovenia* [2]. In this country of approximately 2 million people, every consultation with a doctor has been logged against the individual person over several years. However, persons such as itinerants are not necessarily recognised as registered citizens. Of course, such 100% coverage is expensive and costs a lot of effort.

The system in use in the sentinel network in *England and Wales* falls a little short of the Slovenian ideal, being based on a sample, but the population definition is precise and reported weekly. In the national health service of England and Wales all patients wishing to take advantage of health service facilities are required to register with a GP. It is extremely difficult to avoid inclusion in a GP's list and less than one percent of the population are not registered. The process of registration/de-registration when patients change their GP (usually on change of address) leads to small inaccuracies, but since delays in new registration on changing address equal the delays on de-registration from a previous doctor, the potentials for error cancel each other in practices with stable total populations.

A comparable system of registration with a GP exists in *The Netherlands*. For two thirds of the population, registration with a GP is obligated by their public health insurance, for the remaining one third registration with a GP is usual. Virtually the entire non-institutionalised Dutch population is registered with a GP. In the sentinel network in The Netherlands the population is counted biennially from patient files held in the practice [3]. Such a count is subject to the errors described in relation to registration and de-registration but otherwise is accurate. The sentinel network is also a weekly information system and procedures are in place to adjust the denominator for practices failing to report in a particular week. The Dutch sentinel practitioners are representative of the national distribution of GPs by age and sex.

The situation in *Spain* where sentinel networks include paediatricians as well as GPs highlights the difficulty of combining data. When there is a need to obtain data for specific diseases (also) from paediatricians it is necessary that GPs and paediatricians provide both numerator and denominator data separately for the population they cover. With this information the contribution of each doctor to the numerator and the denominator of the entire network can be calculated.

In *Portugal* patients are registered with specific practices and the age and gender composition of the practice is known. Practices participating in the sentinel network provide a summary of registrations by age and gender which is updated annually. The denominator for calculating weekly incidence represents the registered population in those practices participating in that week.

In some sentinel networks, e.g. in *France*, the number of consultations is used as a denominator. This denominator was also used in the European referral study [4]. The total number of consultations, broken down by age and gender, is relatively easy to ascertain though continuous monitoring of consultations in this detail would involve practices in a substantial workload. For some purposes (e.g. the monitoring of influenza) a consultation based statistic has been demonstrated as acceptable if the objective of monitoring is simply to identify a change or trend [5]. Consultation data (if well sampled throughout the year) can be used to demonstrate that the underlying population is constant and that is a useful approach when the purpose of surveillance is solely to identify trends. However, where the purpose of health care monitoring is to produce quantifiable information, consultations are not an acceptable denominator. Apart from the obvious variability in the way individuals consult even with regard to different types of problem, there is doctor based variability in the interaction with patients such that the same problem may generate several consultations in one practice but only one in another. Also, there are natural variations in consultation patterns at different times of the year and major differences in the consultation frequency by gender and age group. The lynch pin of routine disease monitoring in a population, however, is patient registration [6,7]. The system of patient registration results in all health information being assembled in one record held by the GP. The policy of patient registration is spreading in other European countries thus opening further opportunities for comprehensive disease monitoring.

### 4.3 Data collection

#### 4.3.1 *The medical record: the basis of monitoring*

Comparability of data sets necessitates agreement on the basis of data capture and the elements of recording discipline. Whilst it might be easy to accept the principle that a record is required for every contact, it is more difficult to agree the basis of that record. Traditionally, the medical record includes the patient's history exactly as presented with the subtle details of time sequence, symptom description and symptom linkages all described in the patient's words. These remain important and whether entered in written form on a paper record or keyed into a computer database, are not capable of systematic analysis without summary and interpretation. Using the acronym SOAP (Subjective complaints, Objective findings, Assessment, Plan of action) as devised as part of the problem oriented record [8]:

- the Subjective description of the problem is the set of patient presenting symptoms;
- the Objective findings include the findings on examination and the results of investigations. For this part of the record, it is equally important to record not only the results of examinations undertaken but also the fact that a particular examination had a negative result and/or was not performed. This part of the record can partly be systematised and theoretically it is possible to compute this information in a way that can be analysed (e.g. results of blood pressure readings, laboratory test results). However, the potential for useful information is minimal and the discipline necessary, is scarcely justifiable;
- the Assessment is that of the clinician managing the case and this is the basis for any intervention or action. The assessment has several components, reflecting the pathological nature of the problem, the response of the patient (anxiety, psychological overlay, etc), and the social context (employment, marital status etc.). These can all be recorded and described in a systematised way.

From the perspective of health monitoring the most significant item is the assessment made of the pathological nature of the problem (the diagnosis) and in an operational setting this has to be described within a framework of probability rather than proof. Health monitoring needs a common basis for recording which should be the doctors assessment diagnosis [6].

- the Plan of action completes the acronym SOAP, and includes interventions such as advice, education, prescriptions of medication, referrals etc..

In summary therefore, if health monitoring is to exploit the potential available in routine data capture for health management purposes, we believe and favour the adoption of the assessment diagnosis of the doctor as the most useful item of information. That of course does not preclude computerised recording of all the other items of information mentioned in this section, but it does put an onus on recorders to enter their assessment of the relevant problems at each consultation.

#### 4.3.2 *Data capture*

In operational research, data capture has to be efficient and reliable. In an information system based on patients who consult doctors the chief component of efficiency is time efficiency. The longer the task of reporting the data item, the more routine the working arrangements are disturbed and the less likely

the discipline of recording can be maintained. At the one extreme there are networks in which every contact between doctor and patient is logged and it is essential to collect only sufficient data about each case to facilitate the surveillance exercise. If surveillance itself disturbs routine health care delivery it will lead to non-cooperation of doctors and a biased group of recording practices. At the other extreme, detailed enquiries about persons with a particular disease may be conducted and the workload controlled by the number of reports anticipated over the surveillance period. It is important to strike the right balance to ensure the amount of work is sufficiently controlled that the recording requirement can be met within routine operational activity and is distributed with sufficient regularity that the discipline of recording can be maintained. In situations where the recording requirement is infrequent, it is easy to forget the need to record when confronted by an appropriate case.

A minimum data set appropriate to health care monitoring includes the age, gender, diagnosis or problem and episode type. Age banding is discussed later (paragraph 4.5.2) but the link between the individual patient record and the numerical age banded data presented by a network must allow for checking in individual records.

Methods of data capture are in a state of transition. Historically, data capture using paper summarised record sheets have been the starting point for most sentinel networks. In the first national morbidity study in England and Wales conducted in 1956 [9] relevant information about each patient contact was stored on an individual patient summary card. In the fourth morbidity study [10] conducted in 1992 the relevant information was captured on practice computers using menu driven software programmes collecting data as routinely used medical terms and storing it in the form of Read codes. These were one-year surveys. A weekly information system can be based on these data capture methods but the extraction routine needs to be appropriate to the monitoring task on hand. Alternatively, the data may be collected on simple log diaries or even score grids, diagnosis by diagnosis. A computer template may serve as an alternative to paper for these simple versions.

#### *4.3.3 Computers in practice*

Replacement of the paper record in medicine by a computerised record is inevitable. EU countries are in differing stages of the replacement process. In the Netherlands for example it has been estimated that 70% of GPs no longer maintain a paper record. There are already major problems in storing paper based records which often include considerable correspondence with specialists and report forms from medical investigations. Anxieties over the security of computer based records have been largely overcome.

There has been much optimism about the potential of computers in practice. This potential can only be realised if the discipline of data entry can be standardised. Within the national sentinel practice networks there are small but significant differences in the way data are entered.

In some networks the computerised record is in effect the normal patient management record and in others, data are captured independently of and supplementary to clinical management. It can be difficult for doctors to appreciate the necessity of entering data into specified fields and in a particular way to ensure retrieval for analysis. Many mistakenly think that computer entry somewhere equates with the ability to analyse these data. There is a much greater future in using data routinely gathered as part of clinical management rather than collecting data independently. There is a trade off between planning on the basis of crude information obtained at little cost and detailed information obtained at higher cost. If the cost of obtaining detailed information falls, the balance is shifted. The use of computers effectively reduces the cost of capturing and analysing data and thus has shifted this balance.

#### *4.3.4 The episode of illness*

Information systems need to provide data which distinguish between the new incidence of illness and follow up consultations. One person may have two episodes of otitis media during one year and see the doctor for a total of five times. The numerator for epidemiological purposes can thus be one, two, or five. The one person informs on prevalence, the two episodes are important for allocating resources and the five consultations for evaluating workload in primary care. Comprehensive information systems must therefore distinguish new episodes from ongoing consultations and first ever episodes from new or recurrent episodes. In some practice information systems, data are collected exclusively from new episodes and not from ongoing consultations. If data are required solely to monitor episodes of illness it is unnecessary to distinguish between first ever and new episodes.

#### *4.3.5 Conditions monitored*

Most sentinel networks started by recording a limited set of diseases particularly infectious disease. Some networks have been established to monitor one particular disease such as influenza, asthma or

diabetes mellitus. There is a danger of gathering data in disease specific networks because the patients and doctors involved tend not to be representative of the population nationally. Asthma and diabetes networks attract doctors with particular interest in these conditions and they in turn attract patients in their area with these problems. This is especially so in countries without patient registration (see paragraph 4.2.2).

At the other extreme, networks may collect data from every consultation. This routine can be readily established in practices using computerised medical records provided the software data entry systems are suitably user friendly. The major benefit lies in the discipline of data capture. There is no opportunity to exclude a consultation.

Between the extremes of disease specific and comprehensive monitoring, networks may report systematically and continuously on a core set of conditions, (though these may be recorded in a planned rotating programme), complemented by detailed enquiries on particular issues. Both the Dutch and Belgian sentinel networks operate in this way. The selection of the core set of conditions is particularly important. It needs to be sufficient to keep the wheels of routine reporting well oiled, but not so excessive as to generate an unacceptable work load. A potential disadvantage however, relates to the risk of excluding cases. This may happen by oversight but equally may happen because of the application of rigid entry criteria. Surveillance is more concerned with the totality of illness and the spread of illness than with quantifying its impact among cases which are classical in a clinical sense.

#### *4.3.6 Criteria for diagnosis*

For most serious physical illnesses, criteria for diagnosis are commonly agreed. However, for many there is a considerable dependence on the history which cannot easily be verified [11]. For many illnesses there is an evolution of symptoms and signs which may be reported by the patient but it does not necessarily follow that the patient consulted at a time when these were clearly evident and thus the doctor is denied access to the most valuable signs. In the routine provision of medical care it is also often the case that the doctor or practice undertaking the surveillance is reporting on cases diagnosed elsewhere by another doctor, and the relevant clinical or laboratory details appropriate to the original diagnosis are no longer available, e.g. in case of diabetes mellitus. From time to time, well entrenched diagnoses are challenged and sometimes overturned. Some diseases may be active for a number of years and then disappear (asthma is a good example); others, for example multiple sclerosis, never disappear completely but may have very long asymptomatic periods; finally, some disease states are permanent, once a patient has had a myocardial infarction he inevitably continues to have ischemic heart disease.

*Evolution from symptoms to diagnosis:-* In making a list of definitions it is sometimes assumed that the doctor has the ability to observe the case continuously throughout the illness. This is not so in primary care when the opportunity to make a judgement usually lasts no longer than the duration of consultation – about 8 minutes. For many illness episodes this is the only consultation that takes place. Diagnoses are often unclear at the first consultation, but when monitoring on the basis of information at consultation a label must be applied. Where it is not possible to assign a conventional medical diagnosis a looser symptomatic term might be used. Where the time frame for reporting needs to be short, (e.g. for influenza or infectious diseases) the preferred diagnostic term is the best available diagnosis based on clinical probability [6]. If it is impossible to assign a diagnosis, a compromise needs to be accepted which relates to the predominant symptom, for example low back pain or headache. Where surveillance is based on an extended time period (e.g. a year) the monitoring system can be designed to accommodate evolving diagnoses if the protocol for data capture includes patient linkage and data extraction from the practice medical record is capable of retaining these links. This can be particularly important where practice derived information about the patient is complemented by data from other sources such as pathology reports or letters from specialists.

*Assessing diagnostic accuracy:-* Routine check lists may be considered where doctors are recording very few problems but in most sentinel networks, monitoring ranges over a variety of problems and it becomes much more difficult to observe the discipline of checking criteria in relation to each consultation. There is often uncertainty about the gold standard for diagnosis. For example, in the case of influenza a raised temperature is commonly specified as a diagnostic criterion but in reality patients may not have their temperature taken or even if they do, it may not be raised at the time of consultation. In the large study of the effectiveness of Zanamivir in the treatment of influenza 60% of the patients recruited to the trial did not have a temperature above 37.8° at the time of initial consultation. However, the majority of these cases were proven by virus isolation to have an influenza infection [12].

## 4.4 Data processing

### 4.4.1 Data extraction

Data collected in an office or practice setting must be assembled for analysis. Where these are collected on a simple log diary or score grid, no extraction from the patient record is needed. The material is simply posted or communicated electronically to the co-ordinator. The content of a computer template may be transferred electronically, or by copying to a disk and posting. Alternatively, the initial data can be captured and stored as part of the individual patient record. Here an extraction routine is required either by copying the primary data (after anonymization) and transferring it to a central unit for analysis or by summarising the data into a tabular format and transferring the summary. Such a summary extraction procedure involves the commissioning of computer software whereby compatibility between differing hardware and software systems is achieved.

### 4.4.2 Data classification and coding

The collection and analysis of consultation related data involves the coding and classification of primary data. However, where computerised systems are used as the basis for the medical record, data storage is an even more important consideration. For routine medical purposes it is necessary to store data at a precise level of detail and only subsequently group it for analysis. Historically, classification systems in medicine have been mainly concerned with issues relating to grouping for analysis. This remains important but the emphasis has switched to efficient data storage and from that classification can be automated.

For health monitoring purposes, the classification system of disease is often completely irrelevant. There needs to be a clear understanding of what information is required. If the use of classification systems makes it easier to capture and analyse the data (especially when many diseases are monitored), the most appropriate classification systems for the purpose should be employed. However, an underlying need for the comparability of data between health care sectors within a country and with primary care in other countries must be recognised.

### 4.4.3 Databases

Data accumulated in sentinel practice networks have a particularly valuable potential for retrospective research. It is prudent to store data in as much detail as can be economically justified. The primary numerical data should be stored rather than the rates derived from them. Ideally, the individual practice data should be retained. Primary data can be grouped for analysis but aggregated data cannot be decomposed.

## 4.5 Data analysis and presentation

### 4.5.1 The numerator and epidemiological measures

Epidemiology is predominantly concerned with disease incidence and prevalence but these are not the only important health care statistics for health monitoring. To illustrate this point, two case records (A and B) are described at the point of presentation to medical care in 1999.

*The disease history of case A starts retrospectively from the position immediately after a coronary artery bypass graft operation in October 1999. A man, now aged 64, first had a myocardial infarction (diagnosis suitably confirmed) 25 years previously in 1974. He was admitted to hospital twice in 1974, about 8 weeks apart and may indeed have had a second infarction but the diagnosis on the second occasion was not confirmed by the conventional diagnostic criteria of the day. For 18 months afterwards he took diuretics and glyceryl trinitri and gave up smoking. Between 1976 and 1988 he experienced no limitation of activity, had no symptoms, took no medication and did not consult in relation to any heart disorder. In 1988 he consulted because of a recurrence of angina pectoris and was treated with glyceryl trinitri as required and later with oral isosorbide and a statin drug. In 1996 he was re-evaluated by a cardiologist (he had not seen a cardiologist between 1975 and 1996) because of deterioration of symptoms and had his cardiac function reassessed. As a result, he was offered coronary artery bypass surgery which he declined. He remained under shared cardiologist and GP care on a variety of drug regimes but in January 1999 he suffered a further myocardial infarction. Altogether, between January and September 1999 he had four hospital admissions with chest pain, but it is not at all clear how many of these followed clearly*



*identifiable new infarcts. He had episodes of serious heart rhythm disturbance and was defibrillated on two separate occasions as a medical emergency. His cardiac function deteriorated rapidly and eventually in October 1999 he underwent bypass surgery as an emergency case. He had a very stormy post-operative period but was eventually discharged from hospital.*

*Case B, also viewed retrospectively from October 1999, concerns a woman aged 49 years who presented for influenza vaccination because of a history of asthma. Review of her records showed that 7 years previously (1992) she presented with a serious attack of asthma clinically diagnosed and substantiated with peak flow readings. There was no previous history of asthma and no suggestion that the condition was occupation related. She was treated with salbutamol and beclomethasone inhalation. The following year (1993) her asthma was even more troublesome, she had two courses of oral steroids and on one occasion was admitted to hospital because of her asthma. In 1994 she had minor trouble from asthma and for the last 5 years had not consulted because of asthma nor received any medication but continued to receive influenza vaccination because of this history.*

*Disease prevalence:-* The strictest definition of prevalence is concerned with the number of people with recognisable disease at any one time. Case A had a myocardial infarction in 1974. In the context of prevalence he has had ischemic heart disease (IHD) ever since regardless of the severity, treatment or medical intervention. For case B the concept of prevalence is much less clear. The patient was certainly part of asthma prevalence in 1992, 1993 and 1994: it would be difficult to argue that she remained an asthmatic subsequently, nevertheless there may be good grounds to vaccinate her against influenza in 1999 because of the history of asthma. Some of the excessively high prevalence statistics quoted for asthma arise because of the use of cumulative prevalence and are based on the principle 'once an asthmatic always an asthmatic'.

*Annual period prevalence:-* The concept of prevalence as seen from a GP with the task of treating patients over many years is that of the annual period prevalence. This is the basis on which sentinel networks might most usefully deliver data on prevalence. It is a measure of persons with disease which is active by manifesting itself in the need for consultation or treatment in a one year period. Thus, Case A would have been part of annual period prevalence in 1974 and 1975 and in every year from 1988 onwards. Case B is part of the annual prevalence in 1992, 1993 and 1994.

*Disease incidence:-* The term incidence is usually ascribed to "first ever" incidence of disease. For Case A the incidence of IHD occurred in 1974 at age 39 and for Case B for asthma in 1992 at age 42.

*Disease episode incidence:-* The concept of an illness episode within a long history of illness experience, helps in the understanding of the seasonality of disease and its resource provision. Case A had 2 new episodes of IHD in 1974 (but only one definitely involved a myocardial infarction): in 1988 something clearly happened to make his condition worse and a new illness episode occurred: similarly a new episode occurred in 1996: in 1999 he experienced at least one further new episode of illness (myocardial infarction) in January and thereafter 3 further episodes which required admission and management appropriate to myocardial infarction even though he was not proven to have new areas of infarction on each occasion. Case B had at least one new episode of asthma in 1992 and at least 3 separate episodes in 1993: it is a moot point as to whether she had any new episodes in 1994. In chronic conditions where people experience recurring episodes of illness it is sometimes difficult to decide if the patient is experiencing continuing symptoms or if something new has occurred which has precipitated the attack. This issue is important from three perspectives:

- (1) attacks of an illness may be precipitated by an independent factor; by assigning new episodes to a particular time, the influence of extraneous factors can be investigated. In Case B it was very significant that all her attacks (episodes) were in summer;
- (2) the illness episode is the driver for the use of health services. Case A was part of prevalence from 1974 onwards, but it was the new episode particularly in 1999 which led to major consumption of healthcare resources. Furthermore it was not simply that this one person had one single new episode in 1999, he had four new episodes;
- (3) it can be easier to define a new episode than make a diagnosis. For example, patients with headache, abdominal pain or low back pain may present with such varying or diffuse symptomatology that even a probable diagnosis cannot be defined, but the episode of illness may have important impact in terms of health care utilisation and associated costs. Thus episode incidence is a valuable addition to the more traditional epidemiological descriptors of disease.

The concept of illness episode has been adapted to the derivation of hospital statistics. In Case A during 1999, it is easier to define four hospital episodes and two defibrillation episodes than possible separate episodes of illness by diagnosis, other than the generic diagnostic category of ischemic heart disease.

4.5.2 Age standardisation

Whilst information can be gathered in considerable detail according to the purpose, it is necessary in the interests of comparability to present the data by gender and age groups comparable with health related statistics derived from other sources. Currently, active sentinel networks mostly present the data separately by gender and in the age groups 0-4, 5-14, 15-44, 45-64 and 65 years and over. From a general consideration of health care statistics we would encourage the use of further break points at the first, twenty fifth and seventy fifth birth dates. For specific diseases this degree of breakdown may be unnecessary, but when networks are involved in collecting data about several conditions, age specific data are important. Uniformity in the use of age break points is essential to enhance comparability between networks.

In some circumstances age standardisation of data is desirable. Firstly, within a country standardisation to the current national population limits bias in the population of the sentinel practice network. Such a procedure is adopted in the Dutch sentinel network allowing for conflicting biases in data collected in recent years. Major changes in health care delivery might affect the population under surveillance in a particular network.

Finally, there is a wish to compare results in different Member States in any one year. The European standard population has been suggested as a reference point primarily for use in time series analysis [13]. Its artificial nature is deliberate, with no adjustment for gender. This population is based on 1% of the population over 85 years and 11% over 65 years. The current UK population as an example includes 1% males and 2% females over 85 years and 14% and 17% respectively over 65 years. By way of illustration we have used the prevalence data on diabetes presented earlier (see table 3.3) to describe the prevalence of diabetes in the national data sets (table 4.1). Whilst the prevalence rates established nationally clearly distinguish higher rates in Belgium, these are less apparent after standardisation to the European population. There are small changes in the ranking, notably for France and Spain (Castilla y León), but more importantly the standardisation exercise results in an impression of artificially low prevalence rates.

**Table 4.1** Period prevalences of diabetes mellitus in the year 2000 per 1000 persons in seven sentinel practice networks based on the practice population of the respective networks and on the European standard population (defined in 1976)

	Network population	European standard population
England & Wales	19.9	17.1
Belgium	33.4	27.7
Portugal	20.0	19.4
Spain (Comunitat Valenciana)	19.5	14.8
Spain (País Vasco)	26.0	23.2
Spain (Castilla y León)	24.4	18.4
Slovenia	16.1	14.4
France	19.9	19.6

We conclude that standardisation to a national European population should not be adopted as routine. It is potentially confusing when comparing the prevalence of diabetes in Member States. Age specific incidence and prevalence data are much preferred. There is nevertheless a strong case for presenting national data standardised to an all age national population, not as a substitute for the age specific rates but as an addition.

## 4.6 Validation

The use and limitation of diagnostic criteria to support existing data requirements has been discussed in paragraph 4.3.6. Whilst validation derived from a network is ultimately dependent upon the quality of diagnosis in individual cases, the validity of the information system in its totality is more important. This depends on matters already discussed such as the sampling frame, the accuracy of the denominator, the reliability of the data capture and the quality of the diagnosis. If surveillance is needed on a weekly basis and is largely based on a single consultation, quality standards at the individual case level must reflect that. In the surveillance of influenza-like illness in the Weekly Returns Service of the Royal College of General Practitioners in England and Wales and in the Sentinel Networks of the Netherlands there is an extremely good match between information obtained from the isolation of influenza viruses from swabs cultured in the sentinel networks [14]. This does not mean that the diagnosis of influenza was accurate in every case but it does validate the quality of the information. In the study reported in chapter 3 we have shown that loss of cases of chickenpox due to non consultation amount to approximately 13%. In the WRS sentinel network, we have demonstrated close correlation between seasonal trends in consultations of new episodes of asthma presenting in general practice and those provided in hospital episode statistics [15]. The problems of diagnosing asthma were recognised but the consistency of the time trends in the two series provides cross validation. Internal consistency of the findings from sentinel networks provides other evidence of quality, e.g. the consistent differences between age groups in the incidence of chickenpox.

Detailed checks of patient records are possible but costly, and can only be undertaken on a limited basis. In the English national morbidity survey, samples of source records were reprocessed and the data content compared [9]. In the routine operation of the network in the Netherlands and in England and Wales considerable attention is focussed on extreme results from practices (either high or low) and these are followed up. This aggregation of data by region also help. Whilst regional differences may be the norm for some conditions there are others for which these are not expected. Consistency of trends by region is therefore another useful quality control measure especially when this is evident in the individual age groups [16].

## 4.7 Integrated surveillance

For a number of infectious diseases, such as influenza and gastro-enteritis, and for antibiotic resistance surveillance is dependent on good links between clinical incidence and laboratory based data. At a European level the importance of integrated clinical and laboratory surveillance has been demonstrated [5,17]. It is not always essential that the linkage is retained within the sentinel practices as long as the population under surveillance includes the population from which laboratory specimens are collected. In an ideal world we would want to collect specimens in a systematic manner so that they were a representative sample of the incident cases. This is rarely practical because of the costs of investigation, the willingness of some patients to provide samples, and the willingness of doctors to obtain samples for investigation which may not necessarily help clinical management. Hitherto, the need for precise diagnosis by causative organism has not been quite so important. However, the increased availability of vaccines, the problem of antibiotic resistance and the introduction of highly specific antiviral remedies are particularly relevant and likely to lead to some changes in the detailed surveillance of acute illness.

Other issues apply in the context of chronic diseases. Here there is particular concern with regard to the epidemiology of these diseases in ethnic minorities and regional populations. Increasing evidence that lifestyle and social deprivation influence the incidences of these diseases suggest there is need for more detailed patient specific information than is usual in sentinel monitoring networks. The basis of diagnosis will be increasingly important, even if it can only be investigated on a sampled basis. As health standards rise and particularly as health expectations increase, the need for more precise information becomes increasingly evident. The problem of antibiotic resistance illustrates this point. There is increasing evidence of resistance of urinary pathogens to ampicillin and trimethoprim where these have been measured in urine specimens examined in pathology laboratories. If this is true of urinary infections in the general population, prescribing policies should reflect it. There is no information on representative urinary tract infections in community dwelling persons. Even if such information were available, patterns of resistance change with time and they vary geographically. If antibiotic resistance is a problem and most doctors agree that it is [18], community based systems of surveillance on a continuing basis are necessary. That surveillance will involve integrating information from clinical and laboratory sources from the same patient. Primary care based sentinel networks are the obvious focus for integrated clinical and laboratory based surveillance as illustrated in the European Influenza Surveillance Scheme, where feasibility has been demonstrated.

The concept of integrated surveillance is more comprehensive than simple laboratory integration. It is equally important to integrate information from a monitored population on prescribing and hospital admission information. For limited purposes these data do not have to be individually patient linked though interrogation of a patient specific database enhances the research opportunity.

#### 4.8 Conclusions and anticipated developments

The WHO initiatives *Health for All by the Year 2000* and *Health 21* [19] are the pressures towards routine health monitoring implicit in the European Union initiative on Health Indicators [20] and these will exert pressure on data capture in primary care. Advances in computing will make data acquisition and analysis more cost efficient. The routine discipline of data capture by doctors in primary care is easily acquired providing the computer systems used for routine patient management can be adapted in user friendly ways. Many of the methods are well established in some European countries and it is only a matter of time before they are universally available. Health monitoring and the interpretation of data is much easier where patient registration exists and this approach to the provision of primary care is spreading.

An enquiry, conducted as part of this project among leading general practice researchers in the European General Practice Research Workshop identified eight conditions for which primary care was considered the most important (and in some cases the only) source of data by 75% or more. The eight conditions were effectively selected from a list of 52 used as the health indicators in the Dutch Health Forecast Study 1997 [21]. From the authors' understanding of data collection in European sentinel networks it is reasonable to anticipate that the following indicators of the European initiative can be achieved by 2005:

Influenza	Gastro-enteritis
Diabetes mellitus	Dementia
Back problems	Depression
Ischemic heart disease	Alcohol and drug dependency

There remain some matters which need to be addressed if this state is to be achieved. The public perception of confidentiality and the ethics of using patient specific data for health service management have changed over the last fifty years, largely because of computing advances. Disease surveillance in the interests of public health needs to be brought into an ethical framework which is separate from that associated with research and that for individual doctor/patient relationships. Equally, community based disease surveillance for the public benefit needs to be seen as important, resourced appropriately and be undertaken with appropriate quality controls in place. Administrative initiatives are necessary if these are to be ensured. Whilst monitoring of specific items may well be undertaken in some networks, our anticipation is that comprehensive monitoring of all contacts in sampled practices is more likely and can be adapted to all purposes for which monitoring is desirable. The advances in computing are so rapid that technically all this can certainly be achieved by the year 2005. The main obstacles relate to the national importance attached to public health and the appropriate ethical framework for meeting these needs.

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## 5. RECOMMENDATIONS

### 5.1 Introduction

Data from sentinel practice networks are provided from operational research. They have to be interpreted within the context of the operation. Since health care systems in differing countries differ in their organisation it is inevitable that data from health care utilisation will have to be considered in the context of the health care system. There is therefore the need for an interpretation interface when considering data from sentinel networks in differing countries. Whilst pre-harmonisation in the sense that survey instruments can be standardised prior to their use is an obvious goal for health survey data, it is not achievable in the same way in data from operational research. Operational research will always have to be interpreted retrospectively in relation to the relevant health care system and there are limited numbers of persons available with the expertise to do this. A model procedure has been adopted in relation to problems of influenza surveillance. Different surveillance networks provided national data on a different basis. There is clearly a lack of comparability in the data but with interpretation there is comparability of information.

The health monitoring programme is striving towards acceptance and measurement of national health indicators in Member States. As has been pointed out, information from primary care will be essential for some of these indicators. If indicators are to be used which call for a contribution from primary care there must necessarily be an infrastructure to obtain and deliver the relevant information.

### 5.2 Recommendations: background

The recommendations presented here are made against the background of

- the accumulated experience of the authors in their work on morbidity surveillance in national health care institutions;
- the findings in the field studies undertaken as part of this project;
- the progress made in the development of community health care indicators as part of the present EC Health Monitoring Programme;
- the contributions of the steering group members of this project and of persons involved in the other projects co-ordinated within the health monitoring programme and made especially when posing questions at co-ordinators meetings;
- the relative infancy of many sentinel networks and the need to encourage them and to enhance the quality of their work;
- the importance of primary care as the main point of access into health care in most countries;
- the pressure on health care delivery systems for containment within primary care of those conditions which can be effectively treated without migration into more costly secondary care facilities;
- the acknowledgement of Member States of the WHO health 21 targets.

### 5.3 The structure and operation of sentinel networks

1. Sentinel networks must aim to achieve **representativeness of the population** under surveillance.
2. **Representativeness of the practices** is also important and networks should not be biased towards practices with particular interests. Such grouping of doctors may make valuable contribution to research but surveillance is more appropriately based on reliably monitoring diseases in which the doctors are not especially interested.
3. Networks should be encouraged towards the **comprehensive monitoring of all morbidity**. Where for practical purposes a network collects data on selected diseases the number of conditions should be sufficient to ensure regular input of data.

### 5.4 The status of sentinel networks

1. Sentinel networks need to be **recognised by the health ministries of Member States**. Their development should be planned strategically and not left to ad hoc initiatives.

2. Networks should be reimbursed for the work they do. **Effective surveillance requires effort and an appropriate infrastructure.**

### 5.5 The presentation of data from sentinel networks

1. Data from sentinel networks should be **presented in separate sex and age bands** with minimum break points at ages 5, 15, 45 and 65 years.
2. Data must be **based on estimated populations**. This recommendation is made fully acknowledging the difficulties of denominator definition in health care systems where there is no patient registration. Nevertheless methods of extrapolating from consultation patterns or physician distribution can be used to make crude estimates of populations which we consider more valuable than presenting data in relation to consultations as a denominator.
3. Where networks exist in parallel (e.g. general practice and community paediatrics) **relevant network data should be presented separately** in the agreed gender and age specific bands.
4. Data from sentinel networks should be **based on agreed time periods** – weekly, annual, etc. compatible with data from other routine sources.
5. Surveillance calls for **continuous monitoring**. There can be few instances in which surveillance can be justified as a one-off event. This is obviously achievable within the setting of a comprehensive surveillance programme, but where data are collected on selected diseases continuity can be achieved by a properly structured rotating programme.

### 5.6 The use of data for the provision of health indicators

1. Sentinel networks **can provide health indicator data** on selected conditions.
2. For some health indicators there is **no practicable alternative source of data outside primary care**.
3. When considering sources of data it is essential **to consider first the health indicator and second the appropriate sources of data in a Member State**.
4. Whilst data appropriate to health indicators can be obtained from sentinel practice networks there is **an interface between data acquisition and data recognition**. This interface has a wide application across the health monitoring programme which is not considered in detail here. However, with respect to primary care data gathered in sentinel practice networks, it is vital that a reliable interface is established.
5. **Further work is called for to establish sentinel practice networks** which are representative of national populations, acknowledged by the health ministries and encouraged to provide appropriate data in an expanding programme centred on specific health indicators.

## ACKNOWLEDGEMENTS

The authors wish to express their gratitude towards all persons who contributed to this project, especially

- the doctors and their practice personnel participating in all networks involved
- the coordinators of the networks and their staff participating in this project and/or contributing to the information used in this report:
  - \* Belgium: sentinel network (dr. Viviane van Casteren)
  - \* Croatia: dr. Milica Katic
  - \* England & Wales: Weekly Returns Service
  - \* France: Open Rome (dr. Jean-Marie Cohen)
  - \* The Netherlands: Continuous Morbidity Registration Sentinel Practices (dr. Aad Bartelds)
  - \* Portugal: sentinel network (dr. Isabel Marinho Falcao)
  - \* Slovenia: dr. Danica Rotar-Pavlic
  - \* Spain: network of Castilla y León (dr. Tomas Vega Alonso), network of País Vasco (Mrs. Maribel Larrañaga Padilla, network of Comunitat Valenciana (dr. Oscar Surriaga Llorens)
- the other members of the steering group.



## **APPENDIX**

**Reports of the meetings of the steering group of the project “Health Monitoring in sentinel practice networks”**

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