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EXECUTIVE SUMMARY

Background

The eHID project (electronic Health Indicator Data) was developed from a continuing program of EC funded projects, all concerned with optimizing the use of data collected as a routine in primary care. It was specifically developed in response to the need for national information on health indicators. Many conditions including several major diseases are mainly managed in primary care and even when specialist intervention is required it is generally provided on a temporary basis for a specific purpose; for example coronary arterial surgery for ischaemic heart disease. The continued care of the patient is usually undertaken on a 'shared care' basis. For this reason the medical record held in general practices and other primary care facilities is a particularly comprehensive source of health care information. From a cost perspective it is particularly attractive to use routinely collected data as opposed to specific surveys (which are very labour intensive). Furthermore routine data provide an ideal opportunity to monitor change and results from them are available more quickly.

The introduction of computers into general practice has provided new opportunities for systematic capture of data. Computer use by general practitioners and within primary care in several European countries already permits use for epidemiological investigation of selected chronic diseases. For other and particularly for minor conditions recording discipline is variable and not sufficiently consistent to permit international epidemiological comparisons.. Nevertheless, in most countries there are dedicated networks of general practices providing more detailed data for descriptive epidemiology appropriate for national monitoring programs. This project was concerned with the operation of these networks; the recording discipline within the practices; the data extraction and analytic procedures; and the capacity of the networks to deliver data on health indicator diseases.

Project Objectives and Methods

<u>To investigate the operational features of networks providing epidemiological information based on the extraction of routinely collected health related data in order to make recommendations on best recording practices.</u>

The investigation included:

- a program of visits to all sites involving interviews with the network management teams and with GPs contributing data;
- interrogation of the network databases in relation to the defined indicator disease in 2004 and in 2005
- discussions between project partners of the results of site visits and of the interpretation of the data on health indicator diseases

Recommendations were derived from the results of the investigation and considered by the project partners.

Participants

Altogether nine networks in eight member states were involved

1. Belgium (Flanders) - (Intego) The network covers the Flanders area of Belgium and included 55 General Practitioners (GPs) in 47 practices. Represented by V Van Casteren Scientific Institute of Public Health, Belgium
2. Spain (Catalonia) - (Xarxa d'Investigadors Informatitzats en Atenció Primàri-XIIAP) - a regional network which covers the Catalonia Autonomous Community and includes 14 practices with 71 GPs and 52 nurses. Represented by Valeria Pacheco from IDIAP Jordi Gol Institute, Spain
3. Denmark - (Den Almenmedicinske Kvalitets Enhed-DAK-E) – an embryonic network at the outset but later incorporated within the project. Represented by John Sahl Anderson, University of Copenhagen
4. England-Q Research - a national network of 488 practices using a single computer software system, mainly in England, but with small contributions from Wales and Scotland. Represented by Mike Pringle, University of Nottingham
5. England - The Royal College of General Practitioners Weekly Returns Service which included 73 practices and 345 GPs in England and Wales. Represented by Douglas Fleming, RCGP Birmingham
6. France - (Observatoire de la Médecine Générale-OMG) is a national network of 96 GPs. Represented by Gilles Hebbrecht, Societé Française de Médecine Générale de France
7. Italy - (Health Search) - a national network of 750 GPs. Represented by Roberto Nardi, Scuola Europea de Medicina Generale, Italy
8. Malta -(Accessing state in 2004) Transhis network collecting data from 10 GPs. Represented by Jean Karl Soler Transhis Network, Malta
9. Netherlands - (Landelijk Informatie Netwerk Huisartsenzorg-LINH) a national network of 112 GPs from 80 practices. Represented by Robert Verheij, Nivel Institute Utrecht

José Marinho Falcão of Lisbon, Portugal was appointed as the Project Monitor.

Primary Health Indicators

The four primary health indicators were:

- incidence of diabetes
- prevalence of diabetes
- prevalence of ischaemic heart disease
- prevalence of mental illness

These primary health indicators were chosen because they presented a wide range of problems in relation to the way in which diagnostic information was recorded. In all these examples the GP record was considered a particularly important reference source because of the large contribution to care made by general practitioners.

Estimations of the health indicators were performed separately on data for 2004 and 2005. Experience from 2004 was used to agree common protocol definitions for the 2005 extract, Age specific rates were derived in each network based on identified population denominators in countries with a policy of fixed person registration with a general practitioner or practice or on population denominators estimated from the person consulting population. Statistical comparisons were made using data for persons aged 15 years and over after standardisation to the EU 15 country standard population for 2004 in the reported adult age groups). The detailed results are available in the main body of the report but we provide here a tabular summary of the combined male and female population age standardised rates and the 95% confidence intervals for the four main health indicators.

	MALES & FEMALES	Belgium	Catalonia	*Denmark*	England-QRes	England-WRS	France	Italy	Malta	Nether-lands
Diabetes Incidence	Standard-ised rate	4.0	8.2		4.0	2.8	3.9	5.9	10.1	7.0
	95%CIs	3.6-4.4	7.9-8.6		3.9-4.1	2.7-3.0	3.4-4.4	5.7-6.1	6.7-13.5	6.5-7.5
Diabetes prevalence	Standard-ised rate	36.5	55.6	*37.9*	22.3	27.7	41.3	64.6	62.5	44.7
	95%CIs	36.4-36.6	54.7-56.3	*34.5-41.3*	22.0-22.5	27.4-28.1	39.7-42.8	63.9-65.2	53.5-71.5	43.5-45.9
IHD prevalence	Standard-ised rate	33.6	16.1	*17.0*		18.4	23.1	51.5	27.9	25.8
	95%CIs	32.4-34.8	15.7-16.5	*14.8-19.1*		18.1-18.8	22.0-24.3	51.0-52.1	21.7-34.2	24.9-26.8
All mental illness prevalence	Standard-ised rate	18.1	109.5	*54.4*		70.5	199.5		106.0	53.1
	95%CIs	17.2-19.0	108.4-110.6	*50.0-58.7*		69.8-71.2	196.2-202.9		97.1-115.0	51.9-54.4

Table 0.1: Summary of findings for the four primary health indicators in all participating networks in 2005 – rates per 1000 population standardised to the adult European EU15 population [Denmark is in italics because the results were extrapolated from 4 months of data]

The differences between network estimates are discussed in the report. They relate to:-

- True differences between populations which is the likely explanation for the differences observed in the prevalence of diabetes and ischaemic heart disease which are comparable with other sources of data.

- National differences in the role of general practitioners in the provision of certain types of healthcare: e.g. paediatrics, mental illness Cultural differences in the assignation of diagnostic labels add to the difficulties for interpreting data on mental illness.

We have demonstrated that data from healthcare utilisation can be used for providing estimates of incidence and prevalence consistently over time. National estimates of prevalence and incidence can be made readily where diagnostic definitions are clear and well observed. When interpreting apparent international differences for diseases which are less clearly defined, it is necessary to consider the unique features of national health care systems.

Dissemination of findings and presentation of recommendations

In the early phases details of this project were presented at meetings of the European General Practice Research Network (EGPRN) in Malta, Estonia and Denmark and at other meetings where the project leaders had the opportunity. The results of the project, both as they concerned recording methods and the epidemiological findings, were disseminated as they became apparent, according to the opportunities available but in particular at the World Organisation of National Colleges and Academic Bodies (WONCA) Europe division in Florence in 2006, European Union Public Health Association (EUPHA) Montreux in 2006, meetings of the Health Services Working Party in Luxembourg and other national meetings in partners' countries.

Finally the recommendations for recording in Electronic Medical Records (EMRs) were disseminated as specific lectures in workshops at medical meetings:-

SAPC, London July 2007,
RCGP, Edinburgh September 2007,
WONCA Paris October 2007,
EUPHA Helsinki October 2007.

Main Conclusions and Summary Recommendations

Use of EMR for Epidemiology

1. Routinely updated Electronic Medical Records (EMRs) can provide reliable epidemiological data on a contemporary basis for major and chronic diseases.
2. Data on chronic and clearly diagnosed conditions are directly comparable between countries.
3. Data derived from EMR can be used to monitor health trends at a national level.
4. For minor and less precisely diagnosed conditions, national data need to be interpreted in relation to the health system and service provision in each country. A central organisation to co-ordinate this activity was desirable.

Role of Sentinel Practice Networks

5. Information networks of sentinel practices, with special resources, skills and commitment, are needed primarily to benchmark the data collected in routine EMR; and to pioneer new developments in the use of EMR to quantify disease and for managing public health services.

Software design for EMR

6. Comprehensive software facilitating uniform systematic and consistent data entry is needed at a national level (ideally at EC level).

7. From the perspective of epidemiology, the primary data entry was the medical or assessment diagnosis and the software needs to allocate all consultation, intervention and prescribing data to that diagnosis. In some cases it was not possible to advance the diagnosis beyond a symptom definition.

8. The systematic entry of episode type was highly desirable and should be incorporated in the software design

9. Classification systems both of diagnoses and process of care must operate seamlessly at a national level between health service providers in primary and secondary care in each member state.

Data protection and Privacy Issues

10. The interest of patient safety requires records to be accurate and complete. The EMR has become the substantive and sole record. The doctor should not selectively omit relevant data.

11. Computerised information systems offer no threat to personal confidentiality where the principle of true anonymisation is preserved. Personal identification of patients was not needed for descriptive epidemiology for health service management; reliable and complete data organised in unique patient specific datasets were.

12. For research and healthcare analysis, only pre-coded data are needed. Free text data should not be transferred except in specified circumstances where ethical approval had been specifically obtained.

13. Selective opt out by patients from national recording systems could be accommodated with difficulty though was to be discouraged.

Chapter 1: INTRODUCTION

We here outline the background to the project, its relationship to previous European projects involving sentinel practice networks and define the aims of the project.

There is a widely circulated aphorism relating to computers and their use –

"garbage in brings garbage out"

In the context of electronic medical records (EMRs) there is very little garbage in but statistically there is much garbage out. Most information on the computer is factual or expressions of considered opinion but because it is not entered consistently and sometimes selectively with omissions, the net result is garbage out. By this project we hope to show that disciplined and reliable data entry linked to appropriate filing of data within the software system brings the delivery of valuable information and not garbage.

Background

There have been a series of European Commission sponsored projects involving sentinel practice networks and the provision of health care information for health management purposes. The studies on the interface between primary and secondary care (Crombie, van der Zee et al. 1990) and European Study referrals (Fleming 1992) investigated the process of patient referral in respective national health care networks. These studies were conducted by the European General Practice Research Network (EGPRN) (formerly known as European General Practice Research Workshop). The European referral study was conducted in 15 countries all of which are now members of the EU. The Eurosentinel project (Van Casteren and Leurquin 1991; van Casteren and Leurquin 1992) involved collaboration among 15 networks of sentinel practices in 9 countries and was primarily concerned with the surveillance of common infectious diseases, particularly influenza related disorders. This project was the forerunner of what is now known as the European Influenza Surveillance Scheme (EISS 2008), which continues to be partially funded by the commission. After the Eurosentinel project was completed, collaboration continued under the title 'The Healthcare Telematics project (Snacken, Bensadon et al. 1995) and eventually became the EISS collaboration.

Particularly relevant to the project reported here there have been two previous projects undertaken by the NIVEL Institute in Utrecht.

Health monitoring in sentinel practice networks

The Health Monitoring in Sentinel Practice Networks project (Schellevis 2001) was particularly concerned to establish and describe how health monitoring was currently being undertaken within primary care and how extensive such information systems were in place across Europe. As illustrative examples, incidence information as identified in persons consulting the General Practitioner (GP) for varicella (example infectious disease) was compared with self reported information both within and between the national networks (Fleming, Schellevis et al. 2001); and the capacity of participating networks to deliver prevalence data on diabetes was tested (Fleming, Schellevis et al. 2004). This project involved the practice networks in specific studies to achieve the project objectives. The project also paved the way towards establishing the NIVEL Institute as a focal point for collecting and disseminating information from primary care in Europe.

Health information from primary care

European practice networks collaborated to harmonise the presentation of information derived from healthcare utilisation. Health Indicator Profiles were developed for selected diseases chosen to illustrate a range of conditions for which nationally comparable information may be useful. These included acute diarrhoea/gastro-enteritis, asthma, low back pain, chickenpox, depression, diabetes mellitus, herpes zoster, stroke (including transient ischaemic attack). A fundamental conclusion of this project was the need to interpret the findings in the context of the structure of primary care in the participating countries (Schellevis 2004).

Other European Projects

Complementary to these projects concerned with diseases managed and information reported from primary care, the European Denominator Project (Schwarz 1997) has explored methods for defining the population at risk for use in their comparisons of rates reported in sentinel networks. In addition, there are a number of EC sponsored projects which focus on drug utilisation which have indirect links to the project reported here.

Important in providing the rationale for the present project, the European project on health indicators (Kramers 2003) was conducted between 1999 and 2003. The establishment of a standard set of health indicators had been seen as desirable in the context of the ‘Health for All’ initiative taken by the WHO (WHO 1985; WHO 1990). The project led by Kramers proposed a number of health indicators to be collected at a European level in order to

make comparisons between countries. Some health indicators such as mortality rates are routinely available from nationally established data sources. Others need to be obtained from health interview surveys or from available health care utilisation data. In a few cases, there is a need to undertake complementary examination and make specific measurements (for example of weight or blood pressure). The conditions which routinely call for regular medical treatment are particularly suited to measurement in primary care. The availability of health care indicators in routine medical records makes this route of ascertainment very cost effective and much less costly than conducting specific surveys. Furthermore, if relevant data can be captured routinely on a regular basis, seasonal and secular trends can be monitored. Diabetes provides a good example of such a condition. In many countries this disease (notably maturity onset diabetes) is managed almost exclusively in primary care and information available from hospital episode statistics is very limited in scope. Most people with diabetes die from other diseases and hence information about diabetes derived from death certification is of very limited value. In contrast much information about both the presence of diabetes and measurements related to its management are contained within general practice records.

The current electronic Health Indicator Data (eHID) project has evolved out of these earlier projects but it is focussed on what is available from routine records rather than records which are generated for specific purposes; and on the minimum necessary requirements for consistent record keeping to produce data for epidemiological purposes. It has evolved against a background of rapid computerisation of general practices throughout Europe. This expansion has been commercially driven and has resulted in many different approaches to record storage and different emphases on the part of the respective software houses. Some of these differences have been driven by the pressures of the end-users (mainly general practitioners) who have in turn imposed their own differences relating to the way they use the system and in particular in the discipline and consistency they exert when recording.

Computer use in primary care

We here describe the development and expansion of computer use in the UK illustrating points which have general applicability in most countries of Western Europe. The use of computers in primary care goes back much longer than most persons appreciate (Abrams 1968). In the early days they were used as little more than advanced ledgers maintaining a basic record of registered patients and in some cases a limited disease indexing system. In England in the early nineteen seventies attention was given to applications for disease surveillance but at this time no thought was given to the idea that they might replace paper based systems. The computer was very much an ‘add on’ in research minded practices and information stored

in the computer record was supplementary to the paper record. Indeed from a medico-legal perspective a reliable paper record was a pre-requisite. Estimates of computerisation in practices published by the Department of Health in England increased from 10% in 1987 to 79% in 1993 (Pringle, Hayden J. et al. 1996).

The existence of a computer is not of course a measure of how and what it is used for. In most countries the attraction to the practice lay in the capacity to undertake routine administrative functions. In some countries chiefly as an efficient billing or insurance reimbursement claim system; in others the mechanics of repeat prescribing were facilitated by computers and this became the driving force for market penetration. Inducements for the practices were provided by software houses who saw the potential of computerised prescribing to provide a source of statistical information on prescriptions issued.

Computers were also used for gathering structured information. In this context the information was usually gathered in a bespoke software program in a rigid manner. This suited many surveillance and research based objectives. Prior to 1990 very few general practitioners (GPs) or health policy makers appeared to have woken up to the prospect of a computerised record as a fundamental tool for managing health services and providing good epidemiological data. Even among those who appreciated the technological possibilities of the computer, relatively few saw the primary record as an information tool. Conceptually it was not difficult to recognize but the prospect of getting large numbers of GPs to deliver such data reliably seemed remote to them. The use of the computer for gathering structured information has occurred in other fields of medical care especially in disease surveillance and as an aid to efficient laboratory investigation.

The computer industry approached the matter commercially. In the early days, there were no particular encouragements by the Department of Health in England either for the practices or the software companies. It responded on the one hand to the pressures from the pharmaceutical industry to obtain prescribing data and to the pressures from interested GPs to ensure the computer could be used to get the information they wanted. These requests were in general individually based and there was little collaborative strategic thinking behind computer developments. Until the mid 90s there was little potential for financial advantage from computer use in the UK. Because paper records had to be maintained alongside computer records there were often additional clerical costs involved in maintaining computerised systems. The situation for the general practitioner in the UK changed for two main reasons: firstly, the purchase of computers and relevant software was heavily subsidised by the Department of Health and secondly the requirement to continue with a paper based record was removed. The use of electronic records was further encouraged by the Department of Health in

the development of the Quality Outcome Framework in 2003 (Doran, Fullwood et al. 2006). In efforts to try and improve the quality of care given to patients with specified conditions, there was a need to obtain details on how patients were managed and to what extent target objectives were achieved. This requirement put pressure on GPs to collect information in a specified and structured way more or less forcing the practices to use computers. Though this did not mean they had to use computers for all records it had the effect of familiarizing them with computer routines. In the UK therefore, the computerised record has now all but replaced the paper record in primary care. Such paper based information as is still used is commonly stored on the patient record as scanned documents including, for example, the results of investigation procedures and letters from specialists. Data stored in this way however is not amenable to automated searches.

In 1994 the Department of Health in England commissioned a task force to develop standards for practice computing systems. At the time, these standards were developed out of what was seen to be desirable for health service information purposes rather than simply to fulfil practice administrative functions. In the development of these standards, attention was given to the experience of computer use to provide data for the Fourth Morbidity Study in General Practice (McCormick, Fleming et al. 1995). That study was particularly concerned with the capture of data to provide epidemiological information. Though there had been previous similar studies, data capture had been clerical with all relevant coding either done by the recording doctor or a practice clerk. For the fourth study it was decided to use primary data entry in coded form with computers in the practices. Not all computer systems could achieve these standards. Equally neither could all practices, especially so since this standard of recording was supplemental to the paper based record. The study was greatly facilitated by the use of the Read Thesaurus as a means of coding diagnostic data. The Read thesaurus was extensively tested during the fourth morbidity survey and was adopted by the Department and all computer software houses as the means of access to coding nomenclature (Chisholm 1990). Developments in practice computing in the Netherlands have similarly been stimulated by national morbidity surveys conducted by the NIVEL Institute in Utrecht (Westert, Schellevis et al. 2005).

In the past, no action was taken in any member state whereby the computer systems were designed at the outset to meet the needs of a national integrated record system oriented around individual persons. However, several member states (including the UK, Denmark, the Netherlands and France) have recognised the potential benefits of integrated records and are working towards this goal. In most countries there are many software suppliers and the possibility of merging data obtained in one system with another (as for example on patient transfer to another doctor in another district) is very limited. Even upgrades between the software systems of a

single supplier sometimes present difficulties. Data extraction routines are also different and subroutines for analysing the data are specific to particular software systems. The concept of an integrated record for primary and secondary care was not seriously addressed at the time of introducing the electronic record for primary care.

Project Aims

This project is concerned with the use of routine electronic medical records (EMR) in primary care and their potential for epidemiological purposes. The notion of the *routine record* is paramount. The study is not concerned with special records designed to meet specific objectives. There are many reports of studies undertaken in general practice in which computerised recording has been used to meet specific objectives. Here we are more interested in what needs to be observed in the recording process such that the record is useful for epidemiology. A sound epidemiological foundation in which individual demographic and disease/problem related data are recorded consistently provides the basis for using the record for other purpose: for example- to study therapeutic interventions; to examine patient flow between primary and secondary care sectors; to study co-morbidity. Disease specific data are essential for sensible interpretation of interventions such as prescribing.

The medical record is primarily a record of the interaction between patient and doctor on a particular occasion. It must contain the fact of the encounter; the reason the consultation takes place; a faithful record of the examination and investigation routines together with their results (including the negative findings); the basis for and details of interventions, advice and treatment. It has to be generated in a way that takes account of the time constraints and multiple problems commonly presented during typical consultations in primary care. The generation of an appropriate record is part of the GP's responsibility. The record is required not only to describe a current consultation but to provide the basis whereby the patient's progress in an illness can be assessed and if necessary to provide the basis of the doctor's defence against an allegation of negligence. There has been much recent discussion in relation to the patient's contribution to the record. However no healthcare system imposes a responsibility on a patient to maintain his own records. That the record is an accurate report of the consultation is important. Patients have the right to see their own records, but the medical record is usually constructed from the medical perspective.

The statement of the project aims and objectives made in the grant application is incorporated as Box 1:

The project aims to use data collected in EMR during operational routines in primary care, to provide data on four health indicator conditions (the incidence and prevalence of diabetes, the prevalence of ischaemic heart disease and the burden of mental illness presented to primary care). The Health Information Strand of the Public Health Programme under the previous EC Public Health Action Programme (1998-2002) defined a set of health indicators and reviewed the role of the sentinel practice networks in providing data. Data must be captured cost effectively. Many medical practices working in primary care settings use EMR in which morbidity data from all consultations are systematically computerised. **This project examines the data collected in practice networks to define the best recording practice.**

Existing successful data collections are used, because data from routine operational activity are available without further cost and data capture is manageable and sustainable without imposing the additional work normally associated with research projects.

The project moves the EU 'health monitoring programme' forward from the theoretical consideration of health indicators to the deliver of relevant data. We will examine recording procedures and make recommendations on best practice. We have identified a second priority area in the cost cutting themes (2.1.5: promoting best practices and effectiveness). Data from EMR are also currently used in relation to health threats and health determinants.

The project brings together practice networks willing to provide data from EMR for epidemiological purposes at no additional cost for data capture. We will define best practice by a comparative evaluation of recording methods (established on practice site visits and by assessment of the quality of data made available). The dissemination of best recording practices will involve representatives of practice networks moving towards routine and continuous registration of consultations in EMR.

Box 1: Project aims and objectives

Choice of Indicator diseases

The choice of indicator diseases evolved from the deliberations and report of a previous EC sponsored project (the ECHI project (Kramers 2003)). The report responded to the need to encourage a set of indicator diseases whereby the health status of the population of the member states could be compared. Indicators included obvious general demographic statistics such as birth and mortality rates but also some more specific indicators which were likely to inform on fundamental differences in the proclivity of some national populations to acquire certain diseases. These indicator conditions were also useful in the measurement of health inequalities or in some cases

inequalities in access to appropriate care. National differences provide insight into the cultural and diet related aetiology of disease.

From a primary care perspective we were particularly concerned with those conditions which other national data sources could only provide a limited picture. The attraction of primary care as a source of such information is chiefly cost based. In most countries, primary care is the first point of contact between patient and health service and is a pivotal point for collecting health related information from all sources. These data are available as part of routine records, the issues for primary care concern costs for data extraction and ethical constraints in relation to data acquisition and interpretation. The conditions chosen to test the capacity of networks obtaining data from routine electronic medical records were

- Diabetes – incidence and prevalence
- Ischaemic heart disease – prevalence (we also examined incidence)
- Mental illness – prevalence (in total and of selected disorders)

Diabetes was an obvious choice since most people with diabetes have type II (maturity onset) and are largely managed in primary care. Even where there is specialist input to management this is usually provided on a time limited basis (for example ophthalmological review or management of a complication). Ischaemic heart disease (IHD) is particularly important because of the resource implications for health services and because it is the cause of so many deaths. Persons with IHD often have this condition over many years and their demand on healthcare resources varies considerably during those years. For part of the time the subject may have little more than infrequent angina attacks: he may also experience complications such as a myocardial infarction or episode of heart failure: in addition, he may have a major surgical intervention such as by-pass graft. These events can be spread over several years and for this reason it is very difficult to estimate the numbers of persons involved from data sources which are time or intervention limited. The great advantage of a longitudinal patient specific record is the ability to interrogate it in ways that differentiate between event counts and person counts over long time periods. Mental illness presents a different set of problems. Most persons experiencing mental illness have intermittent episodes: comparatively few are chronically ill: most illness episodes are viewed as minor and most are contained within primary care. Nevertheless, because large numbers of persons are involved their total impact on individual and family life, on sickness absence, on health care costs and on the national economy is huge.

In short therefore we chose a set of indicator conditions which we consider will need to be obtained from primary care and which offered a suitable opportunity to explore the potential of EMR to deliver data in a variety of situations.

Chapter 2: PARTNERS, MATERIAL, METHODS AND WORK PLAN

In this chapter we describe the establishment of this project, the identification and selection of project partners and the program of work involved

Project Partners

Previous projects within the EC sponsored framework have provided opportunities for developing collaboration between networks and effective communication between key individuals. Though practice information networks had been established for specific purposes (e.g. the Weekly Returns Service in the UK (Fleming, Zambon et al. 1999), the Sentinel Practice Surveillance System in The Netherlands (Donker 2007), the Influenza Surveillance network in Belgium (Snacken, Lion et al. 1992) the influenza surveillance network in Portugal (Falcao, de Andrade et al. 1998) and the MORBUS Asthma network in Germany (Schlaud, Salje et al. 1998)), there had been no deliberate attempt to provide truly international comparative data. Several networks had been established primarily to undertake routine surveillance especially in the area of influenza and common infectious diseases.

Regular meetings between key persons within the context of the European General Practice Research Network (EGPRN) and within a series of primary care focused EC sponsored initiatives prompted the sharing of respective experiences and gave awareness of activities in neighbouring countries. These contacts were particularly significant in that most of the persons involved were active general practitioners familiar with the problems of capturing data in the consulting room and not simply with interrogating databases. From these contacts we were aware of developments in national networks and particularly from the previous project ('Health monitoring in sentinel practice networks'), aware of those networks capable of providing computerised data.

In the recruitment of partners to the project we were anxious to obtain a reasonable balance between the potential contribution of networks in differing member states. To achieve this, we had to be selective and focussed on a core group with long experience of computerised recording, though we did not confine recruitment to these partners. We were particularly interested in the use of EMR collected routinely and comprehensively. There are many projects undertaken in primary care which in effect require the general practitioner to deliver information additional to that routinely recorded. Such projects are usually time limited and rarely provide data which can be used for monitoring trends. Experience in the national morbidity surveys in England and Wales and in

the Netherlands have illustrated the importance of capturing relevant information from every consultation. Thus it was apparent that a sound discipline for the capture of routine information was essential.

These contacts led to a primary collaboration between England, the Netherlands, Belgium, France and Spain which were EU countries in which networks already existed. We were aware of embryonic developments in Portugal and Denmark and given the desirability of an expanding European involvement we were keen to include partners in the evolutionary stages of network development. In addition to these national networks within EC countries we had contacts with a Maltese network which though small had a particular experience in routine electronic recording. During the exploratory phase we identified a functioning network in Italy which joined the project.

By personal contact and from published material we were aware of other networks in these countries and though the project included a summary of their activities, we limited national participation to one network per country with the exception of England and Wales where two national systems were included; the Weekly Returns Service (WRS) of the Royal College of General Practitioners and QResearch (a joint enterprise between the University of Nottingham and EMIS, a GP computer system supplier, using volunteer EMIS practices throughout the UK (Smith, Hippisley-Cox et al. 2007)). The involvement of QResearch (database version 12) in the project was particularly important because of their experience in collecting data from ordinary service general practitioners with no declared interest in medical research; this was also the case with HealthSearch in Italy. All other participants involved networks of doctors actively associated with disease surveillance or monitoring.

As the project developed we became aware of other national initiatives regarding the use of routine data and reference will be made to these in appropriate places in this report.

Material

The material for this study came from three primary sources

Site visits
In order to understand what was done in each of the networks a program of site visits was organised. These visits involved a member of the research team visiting the network head quarters and interviewing representatives of the leadership ascertaining in structured interviews precise details explaining how the network operated. These were complemented by visits made mostly to two practices involved in the provision of data. These interviews were also semi structured and were designed to focus on what might be regarded as the difficult and confusing areas of recording disciplines.

Statistical data from the networks
Statistical data on the incidence and prevalence of selected diseases were obtained from the network representatives. These were aggregated data from the entire networks and not practice specific data. Data were obtained in relation to differing annual observation periods. We started by obtaining data that were readily available and collected according to their established protocols. Discussion of these results prompted a critical evaluation of the protocol definitions and harmonisation to a common definition. Further data were obtained concerning the results for the subsequent year gathered in accordance with the revised protocols.

Meetings of project partners
Recruited partners held five meetings concerned primarily with the execution of the project. The discussions during these meetings (main agenda points in Appendix 1) provided major contributions to the project. We aimed to make recommendations which were practicable in as many member states as possible. It was not our intention to deliver recommendations which were 'top-down' in their orientation: we took reasonable steps to ensure that the recommendations made were realistic in as many settings for healthcare delivery as were in use in the member states. These meetings also provided the opportunity for network representatives to inform on the situation in their countries with regard to other networks also using routine records and for the Project Monitor to report (Appendix 2). The Work plan as summarised in the grant application is shown in Box 2.

The methods of our enquiry are in effect summarised in the work plan. However, some additional points are appropriate in relation to the data collection and interpretation on the material of health indicators. In this study we were first concerned with establishing what was going on in the respective networks and gaining insight into the quality of the data. We were aware that there would be difficulty with regard to defining the indicator, not so much in terms appropriate for medical epidemiology but more so in ways that allowed us to extract data in accordance with that definition. For this reason particularly, our data on health indicators was obtained in two separate years. We were anxious to establish consistency of reporting but also to look at data from the year 2004 to see if any revision was necessary in the definition of health indicator to be used in the following year.

Each of the networks was already in a position of collecting data from routine medical records in the network practices. Although there were disciplines established in the practices there had not been an agreement to collect data on specific indicator diseases chosen in any particular consistent manner. As has been pointed out, we were very keen to obtain data from practice networks where data were collected routinely and not part of the research exercise.

Task 1 – to bring together practice networks capable of delivering epidemiological data from EMR. At the first meeting the initial group of participant networks will all share contact experience and try and recruit as many member states as possible (maximum of ten). Networks recruited will be required to produce sample data as a means of establishing credibility. Two networks collecting suitable data even if not collecting directly from EMR will be included in order to maintain input from networks in a developmental phase. Action – coordinator.

Task 2 – to disseminate information about the project to relevant potential additional collaborators who may be incorporated within the first twelve months. Action – coordinator.

Task 3 – to agree protocol for measuring the four health indicator conditions, recognising the problems of data collection in differing health care systems. Action – coordinator and research assistant-project team.

Task 4 – to arrange a programme of site visits to examine first hand the methods of data collection including their strengths and weaknesses. Action – research assistant.

Task 5 – report on site visits. Action – research assistant.

Task 6 – to provide continuing feedback for the networks and recording practices. Action – coordinator and research assistant.

Task 7 – project evaluation at 12 and 24 months. We intend to appoint an independent assessor to report on the project at twelve and twenty-four months. Action – coordinator and independent assessor.

Task 8 – to collect, analyse and interpret the first tranche of data. Action – project team.

Task 9 – to establish measures of data quality from the first twelve months data to be applied to the second tranche of data. Action – project team.

Task 10 - to organise meetings to disseminate best practice. Action – coordinator research assistant.

Task 11 – to collect and analyse the second tranche of data. Action – project partnership team.

Task 12 – final report. Action – coordinator and research assistant

Box 2: The project work plan

Chapter 3: SITE VISITS

Each national network organisation and representatives of the recruited GPs were visited in order to observe directly the organisation of the networks and the recording arrangements within the practices. We here summarize the main qualitative findings from these visits first as they concern the network organizations and then the recruited GPs.

Introduction

The project included visits to the participating networks in order to observe directly current practice and to determine the strengths and weaknesses of each system in providing health indicator data. The findings from these visits were used to assist in agreeing a protocol for measuring the four health indicators in the participating networks.

Method

The site visits consisted of visits to both the network administrative teams responsible for the organisation, collection and analysis of the data and to participating general practitioners (GPs) who were recording the data. Structured questionnaires were used to assist the interviews and to ensure consistency. The network questionnaire asked about the structure and setting up of the network, size and representativeness of the network, data collection and analyses, determination of the denominator, data quality measures, feedback and training for GPs, publications and the strengths and weaknesses of their network. The GP questionnaire asked about recording during consultations, data from other sources, diagnostic coding, data quality, providing data to and support from the network organisation, recording of the health indicators of interest and what they saw as the strengths and weaknesses of the recording and network systems. The questionnaires were piloted in the Netherlands network and revised, before the other site visits. The visits were conducted in English.

Eight networks in seven countries were visited. For these networks at least one GP providing data to the network was visited (13 in total) as well as the network organisation. Additionally, two other network organisations (but not their GPs) and one further GP (but not the corresponding network organisation).

Commentary on visits to network leaders

An overview is provided for each of the networks presented by country in alphabetical order using names which will be used throughout the report.

Descriptive information is provided covering the population monitored, the numbers of participant practices/GPs in 2005 when the project was undertaken.

Brief description of networks

Belgium (Intego) The network covers the Flanders area of Belgium and 55 GPs in 47 practices are currently contributing data. The yearly contact group for 2003 was 64,000 patients, which represents an estimated monitored population of approximately 80,000 persons. The network has been collecting data since 1994.

Catalonia Xarxa d'Investigadors Informatitzats en Atenció Primària-(XIIAP) is a regional network which covers the Catalonia Autonomous Community. In 2005 the data analysis covered 14 practices with 71 GPs and 52 nurses providing data for 422,254 persons.

Denmark Den Almenmedicinske Kvalitets Enhed-(DAK-E) is an expanding national network which in 2006 included 24 GPs in 9 practices. Electronic records have been kept by the practices since 1994 but the information network was established in 2004.

England-QRes is a national database chiefly based on practices in England with small contributions from Wales and Scotland. In 2005 data were obtained from 488 practices. The database was established in 2003 and currently collects data from 3.5 million persons. It is widely known in England as QRESEARCH.

England-WRS The Royal College of General Practitioners established a Research Unit in Birmingham in 1963. Initially it was involved in the surveillance of selected infectious diseases on a weekly basis (The Weekly Returns Service). Data have been collected exclusively from electronic medical records since 1994. In 2005 data were collected for all diagnoses from 73 practices (345 GPs) in England and Wales covering 650,000 persons.

France L'Observatoire de la Médecine Générale (OMG) is a national network of 96 GPs. It was established in 1993 and in 2005 collected data for 116,000 consulting patients.

Italy (Health Search) is a national network of 750 GPs who send data. Currently data from the 548 'best recorders' are included in the database which was established in 1998 and in 2005 contained data on 996,000 persons.

Malta The Transhis network collected data for Malta from 10 GPs in 2005 including approximately 15,000 patients operating in private practice. The network was established with the specific intention of generating an epidemiological database which could be used to research the consultation process and the evolution of disease.

Netherlands Landelijk Informatie Netwerk Huisartsenzorg- (LINH) is a national network of 120 GPs from 83 practices. They have been collecting full morbidity data since 2001 and in 2005 data were collected for roughly 327,000 persons. Previously (from 1996 to 2001) prescriptions and referrals with associated diagnoses were also collected.

Portugal There is a well established network of sentinel practices contributing to the surveillance of influenza and common infectious diseases. This network was recruited to the project in the anticipation that it would become functional during the course of the project. This expectation failed to materialise because of political changes in the anticipated support and thus this group had to withdraw.

Network Structures

The network central organisations varied in size and support. All had initiated procedures for considering the scientific validity of any proposed research which sometimes also considered ethical issues and how this fitted with the central organisation's objectives.

The networks were funded from a variety of sources including government health departments, health insurance organisations and the pharmaceutical industry. Some were funded, at least in part, from selling their services/data to others including government health departments and researchers. Some networks received funding from more than one source: two had been set up using government funding but were now reliant on the institution in which they were based to continue functioning. Most of the networks paid their GPs a small allowance for contributing their data but others relied on the beneficence of the GPs. The amount ranged from around €150 to €1500 per year per involved GP.

Ethical considerations

The main ethical consideration for networks in setting up their databases was in ensuring confidentiality for individual patients. This was achieved, primarily, by anonymising patient identification data and by not extracting other potentially identifiable data such as addresses or post codes. Most networks confined the data extraction to coded data and did not collect free text.

One network has a specific system to ensure the protection of confidentiality. This involves a unique patient identifier being encrypted in such a way that the encrypted number is always specific to that patient, but cannot be used to identify that patient at the practice level. This allows new data concerning that patient to be ascribed correctly while preserving patient anonymity.

Many countries have a government privacy authority which requires databases to be registered and follow guidelines. Ethical approval to set up the networks, extract the data and hold the database was usually required. Thus, ethical approval for individual studies based on the data collected was not always needed, though peer-review of study protocols was usually conducted within the network organisation.

Recruitment of GPs to the networks

Most networks reported that after the initial recruitment of GPs, the network remained stable with few changes from year to year. Volunteers were recruited by a mailing to potentially suitable practices, (for example to practices using particular software).

In some networks, the total data set provided by a practice was not always used for every research enquiry. Belgium and the Netherlands, for example, made an assessment of recording quality before including data. Italy extracted data from all volunteer practices but this was only then added to their research database if it met minimum quality standards. England-QRes and France accepted all volunteers and included all data in the database but applied data quality standards prior to including the practice data in specific research projects. Concerns about the representativeness of the network data also affected recruitment. England-WRS would look for a specific practice type (size, location, deprivation) so that their network remained representative of the population. Studies of network and practice representativeness are reported in the next chapter.

Practices were sometimes required to record specific additional items on the EMR. The Netherlands required the GPs to code their assessment plus episode type and prescriptions according to ICPC codes (WONCA International Classification Committee 1987; WONCA International Classification Committee 1998). In England, GPs were required to attach information relating to the quality of care (Quality indicators) and were rewarded financially. England- WRS required GPs to record episode type linked to diagnosis and Italy required GPs to link prescriptions to diagnoses. Most of the networks were capturing this type of information as a routine but the ‘mandatory’ status of the recording rules varied and thus the links between data items were not always clear when analysing the data in specified time periods.

Data recording and collection

All the networks which provided data collected data recorded on a continuous basis. All collected data at least yearly and some also collected the retrospective data in the EMRs of practices/GPs joining the network.

Six different coding systems were used across the seven networks:

- Read codes – (UK) a hierarchical thesaurus of conditions containing approximately 50,000 terms.
- ICPC – International Classification of Primary Care, (Belgium, Catalonia, Denmark, Netherlands) A classification system designed for primary care with around 700 codes including 300 diagnosis codes and additional symptom codes.
- ICPC-2-E – the revised edition of ICPC, with a similar number of codes but incorporating a number of important changes (Malta).
- ICD-9 – (Catalonia and Italy) the World Health Organisation's International Classification of Disease, containing approximately 4000 entry codes.
- ICD-10 – (Catalonia) the latest revision of ICD with around 8000 diagnostic entry codes.
- DCR – Dictionary of consultation results (France) (Braun 1979; Braun 1986; DCR 2007) a system designed for primary care which incorporates diagnostic details for around 280 codes which map to ICD-10.

These classifications systems are not easily transposed from one to the other, even with old and new versions of the same system. All the networks used one classification system excepting Catalonia which at first combined three software systems each of which use a different classification for diseases (ICPC-2, ICD-9 and ICD-10). In recent years the Catalan Institute of Health has decided to move to software with ICD-10 although a few health centres maintain software that uses ICPC-2. The Belgium software also used a coded system of definitions in the software coded both in ICD-10 and ICPC-2 so that analysis could be in either system. In England and in France the data were collected through one system but analysed after mapping to the ICD-10.

Most networks collected anonymised patient linked data which included all coded data from the patient record (consultations, diagnoses/assessments, prescriptions, referrals, etc). Some also collected limited free text data. England-WRS collected tabular summary data from all consultations.

Data Entry: menu driven software

Most networks were using data entry procedures which allowed the recorder to access relevant codes using conventional medical language. Little use was made of coding manuals and the groups felt strongly that a thesaurus approach was desirable. In France recording by the GP involved a preliminary choice of a DCR which gave access to an automated interrogative process to select the appropriate ICD-10 code and this incorporates a code qualifying the certainty of diagnosis. In England and Wales the Read Thesaurus (Chisholm 1990) was well established and had a particular advantage for the uninitiated doctor as an aid for data entry. In using Read codes for example, it was possible to use the word cough as a description of a patients symptom (reason for encounter) or as a diagnosis. In other words the term cough could carry a Read code which indicated that this was a patient symptom or a different code indicating that it was the doctor's chosen assessment label for that consultation and episode of illness. ICPC codes were mostly accessed through software driven menu Thesauruses incorporated in the software.

Prevalence, incidence and episode typing

The main statistics of epidemiological importance are prevalence and incidence. Prevalence is usually described as point prevalence though it is always necessary to determine how point prevalence is defined. For several conditions the need for continuing treatment is a useful indicator but it is certainly not an exclusive criterion. Many people with diabetes for example are managed solely on dietary regimes and could be excluded if prevalence was defined exclusively on the need for treatment with drugs (Hippisley-Cox and Pringle 2004). For some conditions the notion of ever prevalence may be useful. A person with a major malformation may contribute to prevalence over his entire lifetime but if the problem is completely untreatable he may well not appear in a prevalence estimate based on consultations. Even patients with acquired disabilities (e.g. blindness) may not be recorded because they may make no consultation relevant to this problem.

The term incidence is usually taken to describe first ever incidence. For any condition the first incidence and age at first incidence are of particular importance. In monitoring trends over time, a change in the age of incidence is an important health indicator. However, from a health service management perspective the concept of episode incidence can be more important. A person may have more than one heart attack, more than one admission to hospital for asthma, etc. The health service resource consequences thus relate more to the episode than to either the first incidence or prevalence. New episodes are not defined from unqualified consultation data. There are many episodes of illness which call for several consultations. Mental illness often prompts numerous consultations for

comparatively few episodes of illness though one person may have several episodes of depression over a space of a few years. Equally, a child may have an episode of otitis media in February and an independent further episode in November. For information systems recording data routinely from consultations it is important to distinguish those which relate to new episodes of illness as opposed to continuing and follow up consultations.

Episode incidence provides the best opportunity for comparison with data from other sources (such as hospital episode statistics and prescriptions) and is particularly valuable in connection with resource allocation. The timing of new episode incidence is needed for studying the seasonality of disease. Whilst this project was primarily focused on the provision of epidemiological data, we recognised that information systems in primary care were often used for routine surveillance where episode typing was particularly important. If data are to be used contemporaneously (as opposed to retrospective examination over long periods) it was important that the episode type be defined at the point of recording.

We report here on how each of the networks defined the episode type.

Belgium Intego has no specific episode registration but the first entry for a diagnosis can be identified from the database and thus diagnoses of chronic diseases such as diabetes can be examined as an episode. Diagnoses, prescriptions and laboratory results are linked by patient.

Catalonia Incidence was defined as a new case that was identified between January and December of the selected year. Episode typing is not mandatory for the main software used.

Denmark Episodes of care are defined as a series of contacts with a patient concerning the same health problem, according to the doctor (Schroll, Stovring et al. 2004).

England-QRes This network used data which were not episode specified. In the analysis of their data the definition incidence was based on new diagnoses identified in longitudinal datasets. In order to avoid confusion in the interpretation of new episodes in this way, incidence was only calculated when patients had been registered for a minimum of six months. A new entry after six months was counted as a new incident.

England-WRS The Weekly Returns Service of the RCGP requires the recording physician to describe the episode type at each consultation. Three options are available:
F (First ever) – the first consultation with a general practitioner for this condition.

N (New episode) – the first consultation in a new episode of illness (which had been experienced previously).
O (ongoing consultation) – second or subsequent consultation within an episode of illness.
This system had been successfully applied over more than twenty years and continuously within a framework of electronic recording during the last thirteen years.

France In France the Dictionary of Consultation Results requires the recording doctor to type episodes of illness either in new (N=nouveau) or persistent (P=persistant).

Italy The HS database, as far as the EHID activity period is concerned, does not allow episode registration if an episode is described as a "period of care related to a diagnostic code with a defined beginning and end date". Indeed, HS registration is "problem oriented" (i.e.: registration of a diagnostic code) and the problem may be defined either as "active", "inactive" or "chronic". Inactive problems could, to some extent, correspond to closed episodes. However an automated mechanism to achieve this is not yet implemented in the basic Millewin EHR which was used in the practice network.

Malta Episodes are either New (N – a health problem presenting for the first time to the doctor) or Pre-existing (X – a health problem presenting for the first time to the doctor, but pre-dating the registration period or period of observation). Follow-up consultations are linked to New or Pre-eXisting episodes, and labelled as O (consultation in an Ongoing episode of care).

Netherlands Episode typing is obligatory for each consultation diagnosis ('new' and 'existing'). ICPC codes and the episode typing suffix were used to construct episodes in which different contacts were grouped into episodes. In this procedure as an example, a symptom code of stomach ache may be linked to a subsequent diagnosis code of appendicitis. This method has been validated (Biermans, de Bakker et al. 2007).

Data quality measures

Measures of data quality included those related to whether records were being made and their completeness and also how these compared with external data sources. The networks all used a variety of assessments and these can be divided into two broad areas, internal and external measures. Examples of such measures used in the networks include:-

Internal assessments of data quality included:

- Completeness of the data – how does this upload compare with previous data from same practice/GP? Are there data from each week?

- Comparison of the number of contacts with network practice average.
- Mean number of diagnoses/assessments per contact.
- Mean number of new diagnoses/assessments per patient per year'
- Percentage of contacts with a coded diagnosis/assessment.
- Number of prescriptions per contact'
- Stability of patient registration in the practices (<5% of patients move in/ out of the practice in one year)
- Stability of recording rates for selected disorders or data aggregated at chapter level.
- Consistency of selected disease prevalence rates compared with other practices in the network.
- Consultation rates for specific conditions within 'normal' parameters (min, max, mean and SD of rates).
- Internal consistency checks – e.g. does every patient with an insulin prescription have a diabetes diagnosis? Are the patient's gender and disease compatible? Are the patient's age and disease compatible?
- Prescription and referral rates compared with other practices in the network.
- Proportion of prescriptions linked to a diagnosis.
- Completeness of records registering the death of the patient.

External assessments of data quality included:

- Comparison of yearly data with comparable health insurance data.
- Comparisons of incidences and prevalence with national data derived from other sources; (for example, other networks and published literature)
- Comparison with source records. As part of their initial process of validating the data uploads, the Catalonia network were able to compare the database record with the record at the GP surgery (their system allows reversal of the encryption process so that a GP can identify the patient).
- When involved in specific studies, networks conducted data quality checks appropriate to the requirements of the study.

Some of the networks assessed the quality of data as a routine, fed back the results so outliers could improve their recording and did not use data with apparently outlying results, without first discussing recording discipline with the recording practice (examples Italy and Belgium). Selective exclusion of data gives rise to problems in epidemiology if recording quality is judged in relation to the specific disease being monitored: for whatever reason the low level might be a true level. It is necessary to judge quality in relation to items other than those associated with specific indicator conditions. For example consistently low prevalence in a range of unrelated conditions would prompt concerns for the reliability of recording. Some networks had training days for practices to improve the quality of recording.

Training, feedback and input of GPs

Most networks provided the GPs with feedback including an annual report; personal report comparing their data with the network average; website access; the provision of software programs allowing them to run their own queries; network study days. The study days enabled the network to present their research, have discussions about recording discipline and provided an opportunity for GPs to raise any issues. Many networks had GP representatives on their management committees and some organised a helpline for individual queries to a named contact person at the network headquarters.

Network organisation opinions of strengths and weaknesses in the systems

The major strength identified by most was that the systems were user friendly in the context of maintaining ordinary clinical records. Information about chronic diseases was felt to be particularly well recorded. Most networks were able to link different information fields, for example, prescriptions issued with particular diseases. These were usually built around the recording discipline of the GP. Networks thought particular aspects of their systems were an advantage: such as the recording of episode type and the automation of coding procedures. Networks considered the involvement of GPs in the central organisation gave a realistic clinical view of the data and ensured that data analysis and interpretation were relevant. In the France network, the recording of the diagnosis was linked to specific criteria which meant that the data were standardised and recorded to the same definitions. The Belgium network felt that by their policy of excluding data from poor recording GPs the data were of higher quality. England-WRS was a contemporary data source (twice weekly) and was able to react quickly to new problems setting new information in the context of a very long time series (40 years).

All the systems were dependent on the quality of GP recording, but there were many other issues which could potentially affect the data. In some networks changes in the health system had influenced GP recording behaviour. There were also changes in the way patients could receive care, such as increased availability of medicines from pharmacies, care from others providing primary care services such as NHS Direct in the UK (Cooper and Chinemana 2004) or directly from secondary care providers as in France, Belgium, Italy and the Netherlands, though the extent to which this occurs is highly variable. Consultations outside the practice carried a risk of losing relevant data in the GP record. In Italy and in urban Catalonia paediatric care was provided by community paediatricians and unless separate arrangements were made to collect these data there were serious

limitations in the use of GP data for paediatric epidemiology. France and Belgium did not have registered age/gender specific population denominators. Networks also felt that potential changes in ethical and privacy regulations might affect future data collection and the research that could be conducted. Limitations also existed because of the inability to link with other datasets or track back to patients.

Some of the networks were collecting data from different software systems each with their individual strengths and weaknesses. Catalonia had observed that acute diagnoses were not as well recorded in two of their three systems since a diagnosis/assessment was not required for each contact. A diagnosis though no longer active would remain active in the Belgian, Danish and Catalan software unless the GP specifically recorded it as inactive; an action that could not readily be undertaken for someone who does not consult. Changes in software systems (or even lack of change) could affect quality of data recording. For example the way in which data on socio-economic characteristics and smoking status were recorded depended on practice inducements to obtain these data. Proxies could be used (for example, postcodes of residence and educational achievement have been used as proxies for socio-economic status) (Harcourt, Edwards et al. 2004; Westert, Schellevis et al. 2005; Coupland, Harcourt et al. 2007).

Findings from visits to participating GPs

Recording in GP computer systems

Most of the GPs visited had been using electronic medical records for at least 10 years, the exception being the Catalan GPs who had started more recently. All had ceased using paper records, although most held historical paper records and often recent letters were stored in paper form. In many cases the letters were stored as scanned documents but the relevant morbidity data was not always routinely coded into the EMR. All of the systems recorded similar clinical information, the majority following the principles though not the precise details of the SOAP system (symptoms, observations, assessment and plan) as the basis for recording (Weed 1969).

All the GPs reported that they aimed to record from all consultations and all diagnoses/problems considered. Omissions occurred; in particular when persons consulted with several problems, minor illnesses were sometimes not coded. The quality of recording from home visits was variable and was usually dependent on computer entry from paper notes. The use of laptop computers with all relevant data uploaded before making the home visit was increasing and will improve the quality of recording from home visits. Telephone consultations tended to be less well recorded, depending both on

the importance of the consultation and the location of the GP (at his computer or not) during the call.

Recording in EMR by persons other than the GP was more common in large practices, where locums, trainees, nurses, dieticians, dentists, social workers, etc. all entered relevant data. In single-handed practices this was less common; in some, even GP locums did not record in the EMR but left notes for the GP to enter later. Most GPs were happy for regular practice employees to record in the EMR but were more cautious about temporary staff.

The GPs generally found the classification/coding systems for diagnoses easy to use although a couple commented that it could sometimes be difficult to locate diagnoses in ICD-9/10 as there were so many possibilities. The diagnosis or doctor assessment is selected from a coded list or thesaurus in most systems. In the Netherlands coding was not a mandatory requirement; in Italy the GP is required to assign a coded ICD label to each problem/episode. The ICD coded label may then be complemented with free text as in most other systems used by eHID Partners.

The quality and discipline of recording was well established by most participating GPs. There were occasional problems where the content of the record appeared to be influenced by the wishes of the patient. Thus, for example a diagnosis of depression might be recorded as ‘stress’ or psychosomatic symptoms be described in pathological terms. There is a potential problem for epidemiological research if, for whatever reason, GPs deliberately choose diagnosis/problem labels to suit the patient rather than match the pathological process. Nevertheless this problem is likely to be foreseen when interrogating the database. These enquiries must be based on the reliability of the GP to record accurately.

Not all the software systems enabled the recording of episode type. In those systems where it was possible, the method of recording was not the same. In the two UK networks the episodes were categorised as first, new and on-going, although one England-QRes GP reported that recording episode type was an extra step and therefore was not completed as well as it should be. In the French network the episode types of new, on-going and revised (where an update diagnosis has been added) were used. Additionally in one UK software system the problem can be recorded as significant, or not, allowing a hierarchy in problem summaries and in the French software the certainty of the diagnosis can be recorded (symptom, syndrome, illness picture or full diagnosis).

Amendments to diagnoses were generally made in two ways. Firstly, where a new diagnosis was entered, the old diagnosis was either left or deleted (at least from what was seen in the record) and secondly, where the new

diagnosis is linked to the old diagnosis, to enable changes to be tracked. However some GPs were not sure which of these entries would be transferred to the network database – the amended entry only, or both the original and amended entry. Most systems can also cope with mistaken entries when deletions could be made and would not be available on screen.

Problems arose where patients were receiving care from multiple primary care sources. One example was where patients were mixing care from private and public health service providers, if the system of care or its characteristics influence the care process. In the Maltese and Catalan networks we learnt that patients might use the private sector initially but after being investigated and diagnosed transfer to the public sector for continuing treatment to gain the advantage of subsidised prescriptions. Additionally, some patients would consult network GPs for selected conditions (such as gynaecological problems) and see another GP either privately or within the state system for other conditions.

Maintaining the concept of active diagnoses/problems depended on whether records were structured according to diagnoses/problems or around the consultation. In some networks the concept of disease activity was recognized and diagnoses retained on the EMR until re-labelled 'inactive'. This re-labelling opportunity was not well performed in practice. In records based on consultations the diagnosis was considered active by the patient continuing to consult for that condition. The Transhis software used in Malta and the Millewin system used in Italy have automatic systems to support GPs in deleting inactive diagnoses, for example if no consultation had taken place over a period of time, from the problem list, but some major diagnoses were never deleted.

The GPs felt that all persons with diseases with sufficient diagnostic certainty that were presented to the GP were recorded reliably. Though most GPs summarized important diagnoses and entered them in a problem summary, we found considerable variability in the determination of a problem worthy of summary. So much so, that we did not see the Problem Summary as a useful instrument for epidemiological research.

All systems contained supplementary information recorded in free text. Some of the free text entries were attached to specific diagnoses/problems, but others were entered in the Journal section of the EMR and not linked to coded information. Free text entries were however dated and a link to other information recorded on the same date could be inferred. Free text information was often negative information and usually phrased in a specific way appropriate to the circumstances; eg 'son in hospital with asthma': 'father died from a stroke age 56'. The wide variety of phrases entered in this way defied routine analysis of free text records in a cost efficient way.

Furthermore, free text entries sometimes named persons who perhaps were disease contacts to be traced.

Recording for eHID indicator conditions

Diabetes Strict criteria for diagnosing new cases of diabetes were generally observed consistently across all the networks with two abnormal blood glucose tests in line with local, national and international guidelines. However the diagnostic information in patients already on treatment when joining the practice was often not available to the recording GP. Many GPs reported that they carried out diabetes screening in at risk groups and/or in the general population as part of general health checks.

Ischaemic Heart Disease (IHD) There was more variation in what would be required for a diagnosis of IHD. A history of acute myocardial infarction or diagnosis made by a cardiologist would result in the entry of an IHD diagnosis. However, in patients presenting with chest pain, doctors varied in their acceptance of differing levels of evidence before an angina/IHD diagnosis was accepted and recorded. Some GPs would record only chest pain before they had some objective evidence such as an ECG or exercise tolerance test to confirm the diagnosis, whereas others would record angina or IHD if the symptoms by themselves were sufficiently convincing.

Mental Illness Not surprisingly the GPs found this more difficult to diagnose consistently. Some recognized difficulties in their system in distinguishing between symptoms reflecting unhappiness and normal reactions to adverse life events (particularly in the early stages of mental illness) and diagnoses of psychological problems and mental illnesses. The diagnosis of illness in this context was a matter of professional judgement. Most mental illness is relatively minor and is diagnosed by the GP but for more serious mental illnesses, most GPs awaited the opinion of specialist psychiatrists, though this was not always easily available. Many were reluctant to diagnose dementia without a specialist opinion. GPs did comment that the perceived stigma of mental illness led to a reluctance to allocate a mental illness diagnosis. The GPs also encountered coding difficulties: there was a wide range and it could be difficult to find a suitable description.

GPs opinions of strengths and weaknesses in the systems

The principal strength identified by the GPs was the fact that the majority of the systems did not require any basic change to their routine recording behaviour and relied on ‘normal’ clinical records. The GPs from Belgium and Denmark were very positive about the study days run by the network organisation and felt this had improved the quality of their recording. Opportunities to meet their network GP colleagues and the receipt of feedback about their practices were welcomed by the GPs. Some of the

networks tried to improve consistency in recording by GPs by providing advice on recording diagnoses. User friendly methods for linking the different data fields were valued, in particular, the link between diagnosis and prescription.

The potential for inconsistent data entry by individual and between different GPs were perceived weaknesses. The use of coding procedures and the selection of preferred terms varied. There was some criticism of coding options but this came from opposite camps; some GPs considering these insufficient and others excessive. The influence of recording instructions for specific purposes had influenced recording and some GPs in England indicated that it was not easy to label every consultation with a diagnosis without triggering an investigation cycle designed to meet the objectives of the Quality Outcomes Framework (Doran, Fullwood et al. 2006). Delay in updating the prescribing database limited the use of the prescription record in France.

Networks requiring the entry of additional coded information over and above the minimum required for the routine maintenance of records needed to recognize that all additional key strokes are an additional opportunity for error as well as for enhanced meaning. The extra work involved in providing additional detail was criticised by some GPs. The maintenance of a computer record did not necessarily mean that the diagnostic information needed to be coded and in routine use in many countries, only some of the diagnostic information is stored in coded form suitable for automated analysis. Sometimes, although a facility for further detail was built into the software, it was not entered systematically in routine recording. Supplemental data for specific purposes which were not immediately related to the problem in hand (eg information on smoking habit or the BMI value) often led to variable recording quality. All systems allowed supplementary free text data entry and this was considered essential.

The growth of practice information networks

Prior to computerisation there were very few organised data collections from primary care. The need to monitor epidemic diseases provided the impetus for the development of information networks such as those established in Belgium, England and Wales, France, the Netherlands, and Portugal (Snacken, Lion et al. 1992; Fleming and Cohen 1996; Falcao, de Andrade et al. 1998; Fleming 1999; Donker 2007). These were initially paper based and their value was particularly apparent in the timely delivery of incidence data on persons presenting with illnesses such as influenza, acute bronchitis, gastro-enteritis, measles, chickenpox etc. The operation of these networks has been made easier by the introduction of computers into practices in which the computer has been used systematically to record diagnostic information. The converse - namely the exploitation of the computerised

record in order to provide an information system has encouraged the development of new practice networks over the last 25-20 years. Some of these systems are specific to a single software supplier. In the UK the General Practice Research Database (Hollowell 1997) and Qresearch (QResearch website 2008) have been developed around single software suppliers; in Scotland the continuous morbidity registration program has been developed around GPASS (Henderson, Taylor et al. 1995). In addition there are primary care based information networks providing other information, for example prescription information, or contact frequency. This experience in the UK is being replicated in many other countries. The relative size and growth of the eHID networks is shown in Table 3.1.

In Table 3.1 we summarize information illustrating the recent expansion of the networks included in this study.

Networks	2005			2007		
	GPs	Practices	Persons	GPs	Practices	Persons
Belgium (Intego)	55	47	80,000	78	55	102,000
Catalonia (XIIAP)	71	14	422,254*			
Denmark (DAK-E)	24	9	8,680	160	60	
England Qres		488	3,500,000		525	4,000,000
England WRS	345	73	650,000	511	100	951,296
France (OMG)	96		116,000	153		653,000
Italy (Health Search)	750		996,000			
Malta (Transhis)	10		15,000	8		
Netherlands (LINH)	120	83	326,844	130	94	364,354

* includes persons consulting 52 nurses as well as the GPs

Table 3.1: The size of each participating network in 2005 and 2007

Chapter 4: ANALYSIS OF HEALTH INDICATOR DISEASES

Enquiry methods, protocols and results of the analysis of indicator disease incidence and prevalence are presented together with a brief discussion of the findings.

Introduction

As described in the previous chapters, all the European research networks in eHID were asked to provide data on four indicators – incidence and prevalence of diabetes mellitus, prevalence of ischaemic heart disease (IHD) and prevalence of doctor defined mental illness. In addition some provided data on the incidence of IHD and on the prevalence of selected mental illnesses – dementia, schizophrenia and affective psychosis.

Data were initially provided by the participating networks for the year 2004. In some, these data had already been collected as part of their routine and the methods of analysis were well established. Data for this year were obtained in two extracts. The first included the defined population or the person consulting data from which the monitored population was to be estimated. Some flexibility was given to each network in the way that these data for 2004 were processed. For example- not all networks provided data based on the exact calendar year; the definition of age group was not determined in identical ways. The second extract concerned the counts of persons with indicator conditions and these were defined in differing ways. Some networks included prescribing links in the disease definition, some networks sought evidence of prevalence in data collected before the specified year. These data for 2004 were used as a pilot to define the recording protocol to be adopted for the 2005 extraction. The data submitted for 2004 are summarised as age and gender specific incidence and prevalence rates in Appendix 4. These data formed the material of our initial discussions surrounding the definition of the common protocol for the extraction of data for the main analysis of the data for 2005.

Portugal, which was a provisional partner dependent on their being able to establish a network, found that it could not return any data in either year (see statement in Appendix 3). Denmark was unable to provide data in 2004 and data for 2005 were based on only four months recording. Therefore Danish data were only used to calculate the prevalence indicators and are presented in italics in the tables which follow. In 2005 the England-QRes database was only able to provide data on diabetes prevalence; Italy and Malta were unable to provide all the mental illness data.

Analysis protocols as specified for the year 2005

In the light of experience gained from discussing the results for 2004, we formulated more rigid and standardised protocols to be applied to data collection for the year 2005. The agreed protocol was finally presented as a set of reporting instructions as follows

Time period **–** calendar year - January 1 to December 31

Denominator data

Age **-** to be determined at mid point of study period.

Registered patient list (where possible)

Submit your denominator in 5 year age bands (0-4, 5-9, 10-14, ….. 90-94, 95-99), separately by gender based on the denominator at the mid point of the study year. If you are unable to generate data in this detail ensure that it is available in a form that allows analysis in the age groups 0-14, 15-44, 45-64, 65 years and over. Submit data for all age groups though we shall not include children in the main analysis. If you are in a network which has not got a registered patient list please make an estimate of the underlying denominator and explain exactly how that is derived.

Patients who are temporarily receiving medical services (e.g. because they are on holiday) should be excluded from denominator and numerator counts.

Patient consulting denominator (yearly contact group) if no registered list-

Submit these data by gender in 5 year age bands referable to the year 2004.

Disease codes

The following diseases (codes) are included in the analysis.

Disease groups	ICD10	ICD 9	Read	ICPC	
Diabetes	E10-E14	250	C10.. to C10zz	T89,T90	
Ischaemic Heart Disease	I20-I25	410-414	G3… to G3z..	K74-K76	
All mental illness problems				All Ch P	ICPC only
All doctor assessed mental illness (exclude patient symptom codes)	ChF	ChV	E…. to Ez…	P70-P99	
Dementia	F00-F03	290	E0… to E00z.	P70	
Schizophrenia schizo-typal and delusional disorders	F20-F29	295,297	E10.. to E10z. plus E12.. to E12z.	P72, P98	Difficulty in matching exercise. Persons using ICD9 are asked to submit grouped data for codes 295-299 in addition
Affective psychoses	F30-F39	296	E11.. to	P73,P76	Difficulty in entire

Numerator data

There are a maximum of 7 disease categories However, if you have a data set which can be processed using both ICD and ICPC please submit the data in both forms labelling it carefully.

Prevalence Definitions

Diabetes- A prevalent diabetic is a person identified in your records from an entered diagnostic label and/or in receipt of a particular drug or particular investigation; and who is known to be on your list of consulting patients during the study year. (You may only know this patient to be on your list because of a consultation for a condition which is not necessarily diabetes).

Ischaemic Heart Disease A prevalent case of IHD is a person identified in your records from an entered diagnosis and/or intervention specific procedure (e.g. coronary artery bypass graft) and/or in receipt of drugs such as nitrites which are specific for IHD (but not for drugs such as aspirin, beta blockers, ace inhibitors, etc, which are not specific for IHD).

Mental Illnesses A prevalent case is identified from your record exclusively on the basis of the diagnostic entry for the appropriate illness (illness group) in the 1 year recording period. For the purpose of this project, the diagnosis of mental illness cannot be based on prescribing information without evidence from the diagnostic entry. A consultation for the illness during the study period is a pre-requisite to know that the problem is active and not simply historical.

Incidence definitions

Submit numerator counts on incidence according to the following rules. Incidence can only be derived from diagnostic information. It cannot be derived from prescribing or intervention information. Where episode type has been recorded there are 2 types of incidence which can be considered.

First ever incidence This is the most useful measure if you have first incidence data submit this information for diabetes and ischaemic heart disease but state exactly how you (or your recorders) define first incidence.

New episode incidence If your dataset is defining new episodes of illness, submit your data for first ever and new episodes combined. We recognise the patient with diabetes or ischaemic heart disease can have a complicating factor (e.g. diabetic cataract, acute myocardial infarction respectively) which is entered in a recording system as a new episode of illness. For the mental illnesses submit your data on the basis of first and new episode incidence

Data extractions according to this protocol were undertaken during 2006 and sent to the project leaders for further analysis. In the analyses which are reported in the following tables data from each network have been standardised (direct standardisation) to the EU 15 countries adult population (Office for Official Publications of the European Communities 2002). Ninety-five per cent Confidence intervals (CIs) have been calculated according to the Altman method (Altman 1989). As a crude statistical indicator we have referred to differences based on non-overlapping CIs. The standardisation routine was initially applied to the male and female populations separately.

Results of the analyses of the 2005 data in respect of each health indicator disease are presented firstly as a tabular summary of age standardised rates and secondly as a figure to illustrate age related trends. Within each table we also present the rank order (high to low) for each set of statistics. The ranking is provided to facilitate easy comparisons and is used in the subsequent discussion of the results where Spearman coefficients of association have been used to illustrate particular points

Gender comparisons in the main health indicator conditions were made after standardisation to the combined male and female EU 15 adult population. This issue is addressed in a later section of the presentation of the results

Incidence of diabetes

Eight networks provided data on the incidence of diabetes. The overall age standardised incidence rates for females, males and all adults are given in Table 4.1 (as in all these tables, the data relates only to persons aged 15 or over). The presentation includes the standardised rate, the CI and ranked position among the networks. Information on crude age specific rates reported by the network (all adults) is shown in Figure 4.1.

	Belgium	Catalonia	England-QRes	England-WRS	France	Italy	Malta	Netherlands
FEMALE								
Rate	3.5	7.3	3.7	2.5	3.0	5.5	8.5	6.4
CI	3.0-4.1	6.9-7.7	3.6-3.8	2.3 - 2.7	2.4-3.6	5.2-5.7	4.1-12.9	5.8-7.1
Rank	6	2	5	8	7	4	1	3
MALE								
Rate	4.4	9.2	4.3	3.2	4.9	6.5	12.5	7.5
CI	3.7-5.0	8.1-9.7	4.2-4.4	3.0-3.4	4.2-5.7	6.2-6.8	6.9-18.1	6.8-8.2
Rank	6	2	7	8	5	4	1	3
FEMALE & MALE								
Rate	4.0	8.2	4.0	2.8	3.9	5.9	10.1	7.0
CI	3.6-4.4	7.9-8.6	3.9-4.1	2.7-3.0	3.4-4.4	5.7-6.1	6.7-13.5	6.5-7.5
Rank	5=	2	5=	8	7	4	1	3

Table 4.1: Incidence of diabetes: age standardised rates per 1000 adult population by practice network in 2005

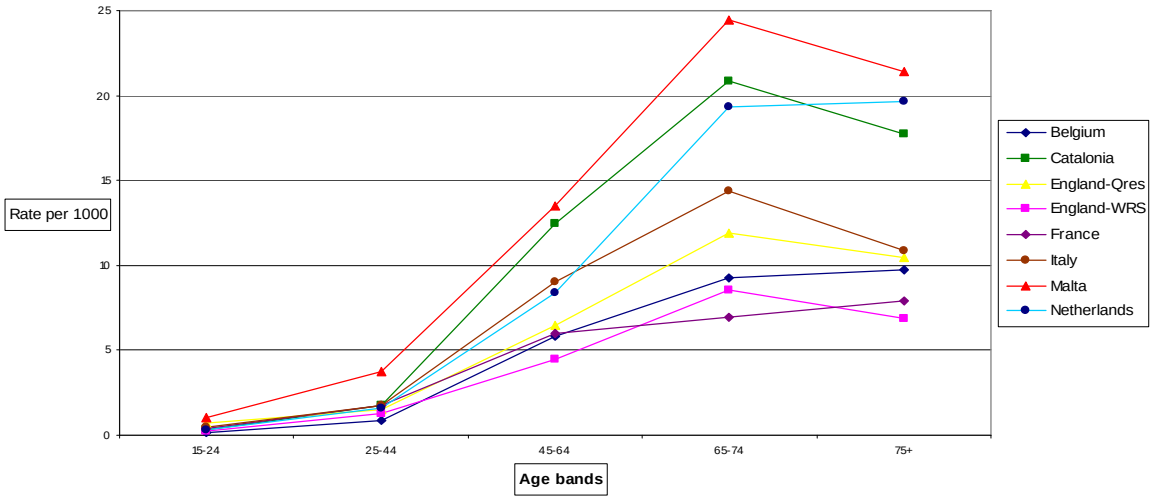

Figure 4.1: Incidence of diabetes per 1,000 by practice network and age band in 2005

Prevalence of diabetes

Nine networks provided data on the prevalence of diabetes including Denmark though the prevalence estimate was extrapolated from a four

month period of data collection and thus Danish data are presented in italics and this network is excluded from the ranking. The results are shown in Table 4.2 and Figure 4.2.

	Belgium	Catalonia	*Denmark*	England-QRes	England-WRS	France	Italy	Malta	Netherlands
FEMALE									
Rate	40.3	53.9	*28.9*	20.0	22.7	33.6	60.9	57.4	45.6
CI	38.4-42.2	52.7-55.0	*24.9-32.8*	19.8-20.3	22.1-23.2	31.7-35.7	60.1-61.8	45.4-69.4	43.9-47.4
Rank	5	3		8	7	6	1	2	4
MALE									
Rate	35.2	57.2	*49.8*	24.0	30.4	49.6	68.5	71.3	43.5
CI	35.0-35.3	56.0-58.4	*43.9-59.7*	23.7-24.2	29.7-31.0	47.1-52.0	67.6-69.5	57.3-85.2	41.8-45.2
Rank	6	3		8	7	4	2	1	5
FEMALE & MALE									
Rate	36.5	55.6	*37.9*	22.3	27.7	41.3	64.6	62.5	44.7
CI	36.4-36.6	54.7-56.3	*34.5-41.3*	22.0-22.5	27.4-28.1	39.7-42.8	63.9-65.2	53.5-71.5	43.5-45.9
Rank	6	3		8	7	5	1	2	4

Table 4.2: Prevalence of diabetes: age standardised rates per 1000 adult population by practice network in 2005

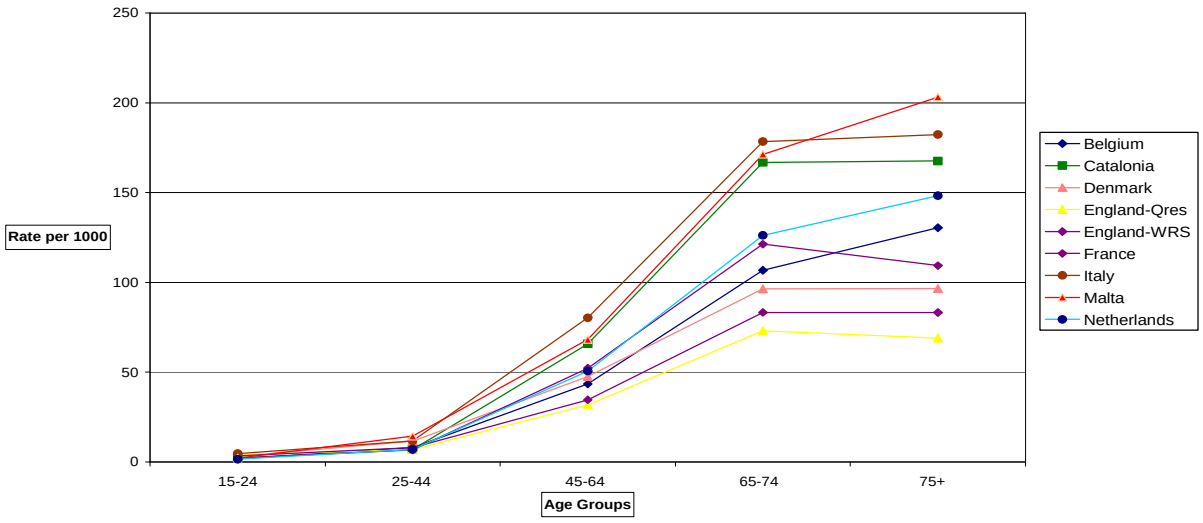

Figure 4.2: Prevalence of diabetes per 1000 by practice network and age band in 2005

Comments on results for diabetes

Incidence in Malta was considerably higher than in all other countries in both years. Incidence in males always exceeded that in females. The age specific pattern of incidence shown in figure 4.1 and of prevalence in figure 4.2 demonstrate consistency in the comparison between age groups. There are considerable differences between countries in reported incidence and prevalence. The two English networks reported rates lower than in the countries of mainland Europe. There are large numbers of diabetics and thus the confidence intervals indicate that most of the differences reported are statistically significant. The age specific data disclose a similarity of the relative prevalence in each age group.

The consistency of the age specific patterns of the data strongly suggest that the differences are not the result of recording bias in differing national healthcare systems. The Spearman coefficient of association between the incidence and prevalence rate of diabetes was strong in Males (0.90, $p<0.01$) but less so in Females (0.70, $p=0.05$). In general, higher incidence and prevalence was seen in the countries bordering on the Mediterranean which hints at differences in diet as a possible explanation.

The incidence and prevalence rates reported here reflect the wide variation between countries also found in other data sources as illustrated in material published by the WHO and Eurostat. The eHID prevalence data for 2005 are compared with data published by OECD (OECD Health Division 2007) and WHO (2008) in Table 4.3. The data from these sources are not consistent for any individual year and mostly vary between 2002 and 2004. For this reason the rank order comparisons have not been formally examined using statistical tests. Nevertheless the rank order comparisons demonstrate that the eHID data provide a similar overall picture to that obtainable from other sources of official statistics.

The results from the eHID project indicate the need for continued monitoring of diabetes. Incidence data reflect the current position; prevalence data describe the situation which has accumulated over several years whereas mortality data reflect the endpoint of a disease process which was initiated many years ago and is subject to the quality of the intervening medical management and possibly also to variability in the severity of illness related to geographical and socio-demographic factors.

	eHID 2005 Diabetes Prevalence		OECD Diabetes related deaths		Eurostats Diabetes related deaths	
Country	Per 10000	Rank order	Per 100000	Rank order	Per 100000	Rank order
Female						
Belgium	403	5	10.2	6	10.4	7
Catalonia/Spain	539	3	13.9	5	14.4	5=
Denmark	*289*	*7*	*20.1*	*1*	*21.3*	*2*
England QRes	200	9	8.5	7	8.8	8
England WRS	227	8	8.5	7	8.8	8
France	336	6	14.5	4	14.4	5=
Italy	609	1	17.8	3	18.4	4
Malta	574	2	n/a		27.0	1
Netherlands	456	4	17.9	2	18.7	3
Male						
Belgium	381	7	10.8	5	11.0	6
Catalonia/Spain	572	3	12.3	4	12.8	5
Denmark	*498*	*4*	*14.6*	*2=*	*15.1*	*3=*
England QRes	240	9	5.9	7	6.3	8
England WRS	278	8	5.9	7	6.3	8
France	496	5	9.9	6	9.5	7
Italy	685	2	15.0	1	15.5	2
Malta	713	1	n/a		20.5	1
Netherlands	435	6	14.6	2=	15.1	3=
Female and Male						
Belgium	393	6	10.8	6	7.9	7
Catalonia/Spain	556	3	13.2	4	11.1	6
Denmark	*379*	*7*	*17.1*	*1*	*15.1*	*1*
England QRes	223	9	7.1	7	5.8	8
England WRS	252	8	7.1	7	5.8	8
France	413	5	11.9	5	12.4	4=
Italy	646	1	16.4	2	14.3	3
Malta	625	2	n/a		15.0	2
Netherlands	447	4	16.3	3	12.4	4=

Table 4.3: Diabetes prevalence per 10,000, eHID (2005) compared with: death rates reported by OECD (2002 or 2004) and by WHO (2004). Rank order indicated (high to low)

Incidence of Ischaemic Heart Disease

Ischaemic heart disease (IHD) was an additional indicator for which six networks provided data. Six networks provided data (Table 4.4 and Figure 4.3).

	Belgium	England-WRS	France	Italy	Malta	Nether-lands
FEMALE						
Rate	1.7	1.2	0.7	3.4	2.6	5.7
CI	1.3-2.1	1.1-1.3	0.4-1.0	3.2-3.6	0.4-4.9	5.1-6.3
Rank	4	5	6	2	3	1
MALE						
Rate	2.6	1.7	2.6	5.1	10.7	9.5
CI	2.1- 3.1	1.6-1.9	2.0-3.1	4.8-5.4	5.2-16.2	8.7-10.3
Rank	4=	6	4=	3	1	2
FEMALE & MALE						
Rate	2.2	1.5	1.6	4.2	6.1	7.6
CI	1.8-2.5	1.4-1.6	1.3-1.9	4.1-4.4	3.4-8.8	7.1-8.1
Rank	2	6	5	3	2	1

Table 4.4: Incidence of Ischaemic heart disease: age standardised rates per 1000 adult population by practice network in 2005

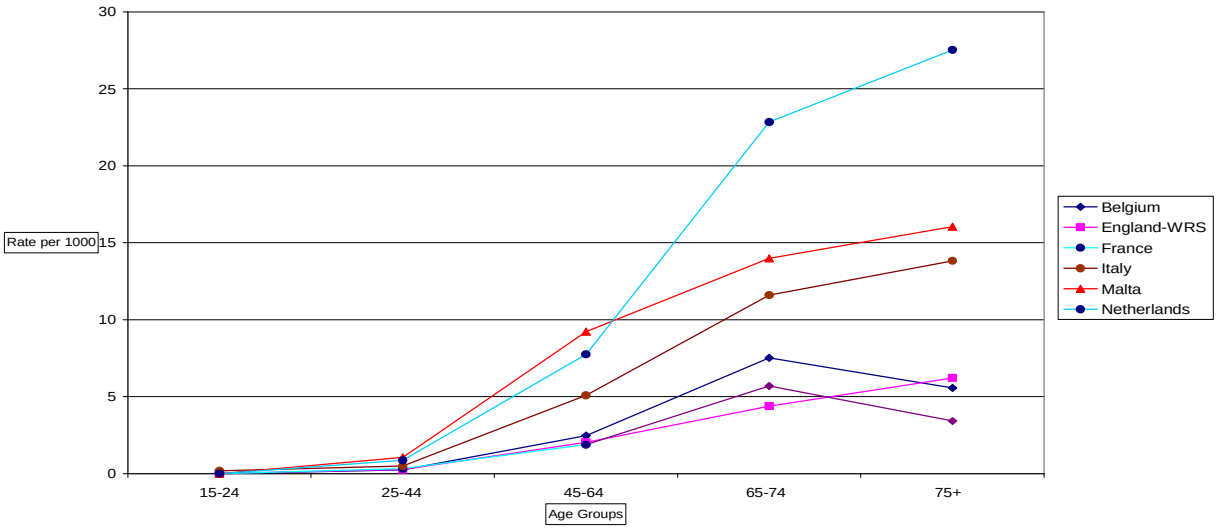

Figure 4.3: Incidence of ischaemic heart disease by practice network and age band in 2005.

There was considerable variation by country in the incidence estimates which were much lower in Belgium, England and France than in other countries. A male excess over females was consistent in all countries except Malta (small population sample). The age specific data show consistency in the ranking of incidence by age group; in two networks there were small reductions in incidence in age group 75+ compared with 65-74 years..

Prevalence of Ischaemic Heart Disease

Eight networks provided data on the prevalence of IHD. Age standardised rates are given in Table 4.5 and expressed graphically by age band in Figure 4.4.

	Belgium	Catalonia	*Denmark*	England-WRS	France	Italy	Malta	Nether-lands
FEMALE								
Rate	26.7	10.7	*12.4*	14.0	14.6	46.5	21.2	20.6
CI	25.2-28.2	10.2-11.2	*9.9-14.8*	13.6-14.4	13.3-15.9	45.8-47.2	13.7-28.7	19.4-21.8
Rank	2	7		6	5	1	3	4
MALE								
Rate	40.0	21.7	*22.5*	22.9	32.2	57.1	37.4	30.8
CI	38.1-41.8	21.0-22.4	*18.8-26.2*	22.3-23.4	30.3-34.2	56.2-57.9	26.8-48.1	29.4-32.3
Rank	2	7		6	4	1	3	5
FEMALE & MALE								
Rate	33.6	16.1	*17.0*	18.4	23.1	51.5	27.9	25.8
CI	32.4-34.8	15.7-16.5	*14.8-19.1*	18.1-18.8	22.0-24.3	51.0-52.1	21.7-34.2	24.9-26.8
Rank	2	7		6	5	1	3	4

Table 4.5: Prevalence of Ischaemic heart disease: age standardised rates per 1000 adult population by practice network in 2005

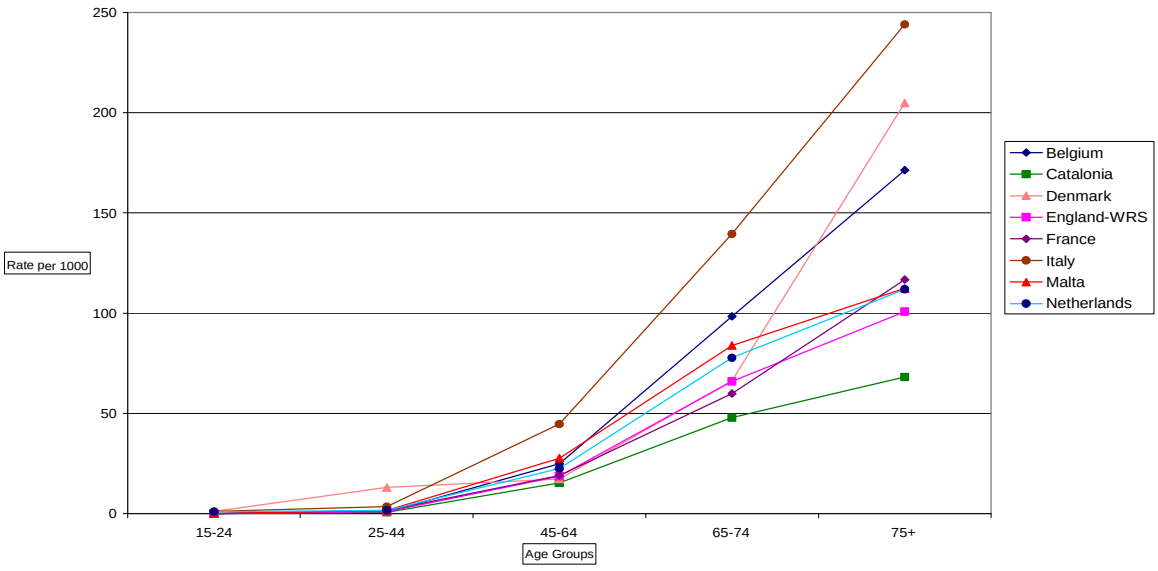

Figure 4.4: Prevalence of ischaemic heart disease per 1,000 by practice network and age band in 2005.

Prevalence was highest in Italy: otherwise there was an approximate twofold variation in prevalence. Estimates by age group show relative consistency of increasing prevalence by age in all countries.

Comments on results for ischaemic heart disease

The project was not specifically concerned with the incidence of IHD because of the difficulty of defining incident IHD. When first diagnosed, people often present with chest pain of uncertain origin and the true diagnosis is only established later. Many persons currently being managed in their practices on the basis of a diagnosis of IHD experienced their first infarction many years ago and the basis of diagnosis is no longer available. Furthermore sometimes, it is only retrospectively (and sometimes after an interval of years) that the significance of an unexplained episode of chest pain can be properly interpreted correctly. There was a good though not statistically significant association between incidence and prevalence rates in the data for males and females combined (R_s 0.60).

The prevalence data are more robust. Today, if not the case 15 or 20 years ago, most people with recognised heart disease are receiving treatment and thus, provided there is a suitable system to capture the data, the point of management is an appropriate source for capturing the data. In Table 4.6 a comparison is made between the eHID prevalence data for 2005 and WHO data on deaths- males and females combined.

	eHID 2005 IHD Prevalence		WHO IHD related deaths 2004	
Country	Per 10000	Rank order	Per 10000	Rank order
Belgium	336	2	70.1	4
Catalonia/Spain	161	8	54.1	7
Denmark	*170*	*7*	*87.2*	*3*
England WRS	184	6	99.3	2
France	231	5	36.9	8
Italy	515	1	68.2	5
Malta	279	3	125.4	1
Netherlands	258	4	67.8	6

Table 4.6: Ischaemic Heart Disease prevalence in eHID (2005) and IHD deaths published by WHO (2004) - (Males and Females combined)

The association between the prevalence of IHD and published death rates is weaker than that shown for the comparison in diabetes. Again the distinction

between the endpoint of a disease situation and contemporary prevalence needs to be considered carefully. Deaths attributable to IHD include many sudden deaths including deaths among people in whom the manifestation of IHD was exclusively a terminal event and also some in whom the diagnosis is made at autopsy simply on the evidence of finding coronary artery damage at post-mortem in the absence of any other more obvious cause of death.

Prevalence of doctor assessed mental illness

Mental illness was chosen as an eHID marker condition because it presents special challenges:-

- Is it recorded in a consistent and accurate manner?
- Can it be meaningfully analysed? ;
- What is the perspective of clinicians regarding the recognition and description of mental illness? ;
- Does the organisation of mental health care vary between countries?

Seven networks provided data on the prevalence of all doctor-assessed mental illness. This definition was carefully chosen to estimate the prevalence of mental illnesses in persons presenting, recognised and recorded specifically as such by doctors.

	Belgium	Catalonia	*Denmark*	England-WRS	France	Malta	Netherlands
FEMALE							
Rate	23.7	131.6	*62.7*	83.9	221.3	135.7	68.2
CI	22.2-25.2	129.9-133.4	*56.5-68.9*	82.8-84.9	216.5-226.1	122.4-149.0	66.2-70.2
Rank	6	3		4	1	2	5
MALE							
Rate	12.6	87.3	*42.9*	56.6	175.1	66.3	37.5
CI	11.5- 13.6	85.9-88.7	*37.0-48.9*	55.7-57.5	170.5-179.6	55.4-77.2	36.0-39.0
Rank	6	2		4	1	3	5
FEMALE & MALE							
Rate	18.1	109.5	*54.4*	70.5	199.5	106.0	53.1
CI	17.2-19.0	108.4-110.6	*50.0-58.7*	69.8-71.2	196.2-202.9	97.1-115.0	51.9-54.4
Rank	6	2		4	1	3	5

Table 4.7: Prevalence of doctor assessed mental illness: age standardised rates per 1000 adult population by practice network in 2005

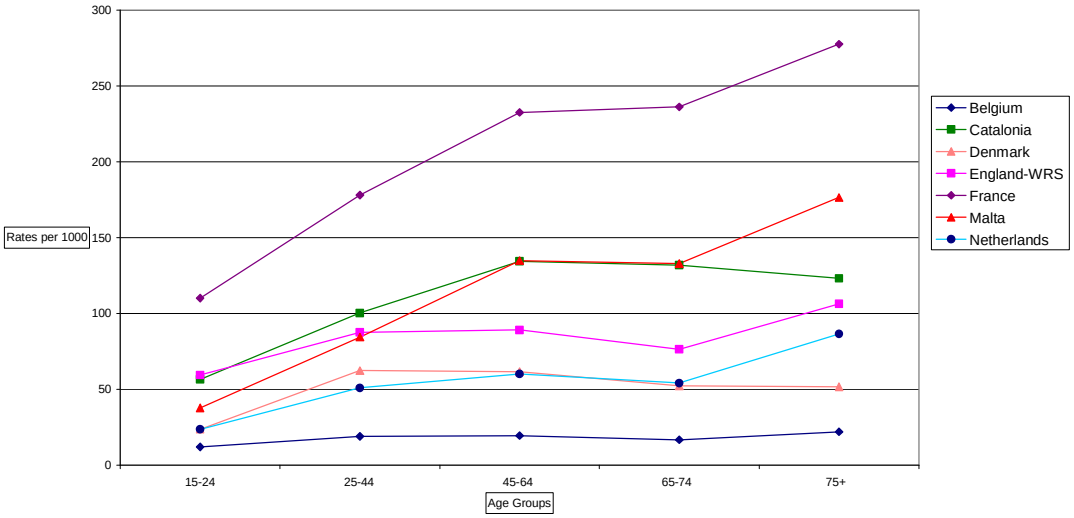

Figure 4.5: Prevalence of doctor assessed mental illness per 1000 by practice network and age band in 2005.

There were substantial differences between countries with particularly high estimates made in France and Catalonia and low estimates in Belgium. The age specific patterns disclosed in the figure show a similar relativity by age in all networks.

Prevalence of dementia

Seven networks provided prevalence data for dementia (Table 4.8 and Figure 4.6).

	Belgium	Catalonia	*Denmark*	England-WRS	France	Italy	Netherlands
FEMALE							
Rate	6.4	3.8	*2.7*	2.3	5.3	5.5	2.9
CI	5.7-7.1	3.5-4.1	*1.6 -3.8*	2.1-2.5	4.6-6.1	5.2-5.7	2.5-3.4
Rank	1	4		6	3	2	5
MALE							
Rate	2.6	2.0	*1.9*	1.1	2.4	2.7	1.9
CI	2.1-3.0	1.8–2.2	*1.0-2.9*	1.0-1.2	1.9-2.9	2.5-2.9	1.6-2.3
Rank	2	4		6	3	1	5
FEMALE & MALE							
Rate	4.5	2.9	*2.3*	1.7	3.9	4.1	2.4
CI	4.1-4.9	2.7-3.1	*1.6 -3.1*	1.6-1.8	3.4-4.4	4.0-4.3	2.1-2.7
Rank	1	4		6	3	2	5

Table 4.8: Prevalence of dementia: age standardised rates per 1000 adult population by practice network in 2005

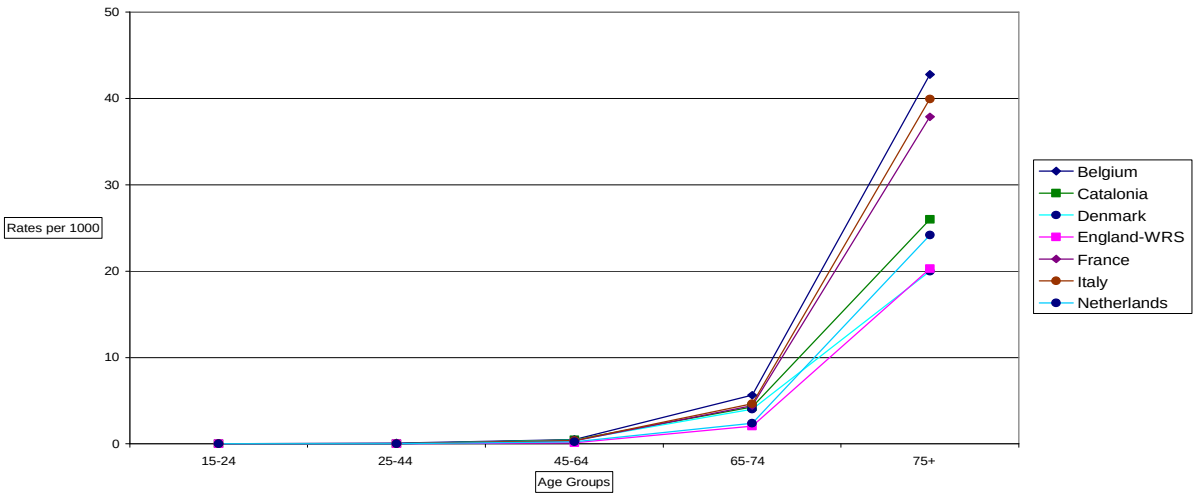

Figure 4.6: Prevalence of dementia by practice network and age band in 2005

Estimates of prevalence were less variable than those for total mental illness described above. The age specific data shown in the figure disclose similar relative estimates in each network in the age groups 65-74 and 75+years with as might be expected a sharp rise above age 65 years.

Prevalence of schizophrenia

Seven networks provided data on the prevalence of schizophrenia (Table 4.9; Figure 4.7).

	Belgium	Catalonia	*Denmark*	England-WRS	France	Italy	Netherlands
FEMALE							
Rate	0.7	2.6	*3.6*	1.4	0.1	1.6	1.8
CI	0.5-1.0	2.3-2.8	*2.1 - 5.1*	1.26-1.54	0.0-0.1	1.4-1.7	1.5-2.1
Rank	5	1		4	6	3	2
MALE							
Rate	0.6	3.5	*3.4*	1.9	0.3	2.2	1.7
CI	0.4-0.8	3.2 -3.7	*1.7-5.1*	1.8-2.1	0.1-0.5	2.1-2.4	1.4-2.0
Rank	5	1		3	6	2	4
FEMALE & MALE							
Rate	0.7	3.2	*3.5*	1.7	0.2	1.9	1.8
CI	0.5-0.8	3.0-3.4	*2.4 -4.6*	1.5-1.8	0.1-0.2	1.8-2.0	1.5-2.0
Rank	5	1		4	6	2	3

Table 4.9: Prevalence of schizophrenia: age standardised rates per 1000 adult population by practice network in 2005

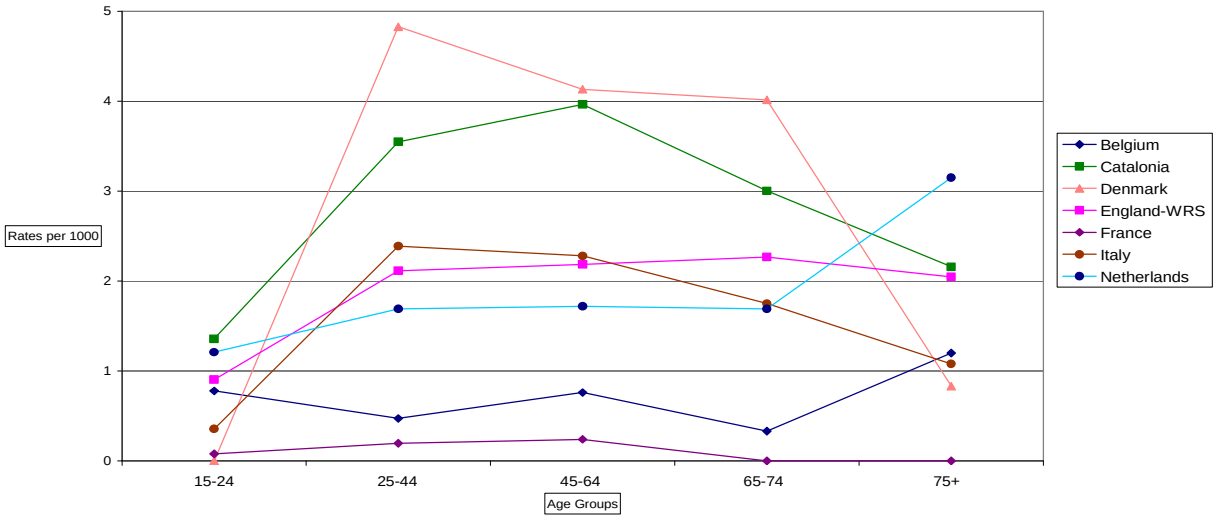

Figure 4.7: Prevalence of schizophrenia per 1,000 by practice network and age band in 2005.

Prevalence was low in France. The rate for Denmark was high but this may reflect the extrapolation from the limited data set of four months. The age specific pattern shows an inverted 'U' shaped pattern with maximum prevalence in the age groups 15-44 and 25-44 years.

Prevalence of affective psychoses

Eight networks provided data for this diagnostic category (Table 4.10 and Figure 4.8).

	Belgium	Catalonia	*Denmark*	England-WRS	France	Italy	Malta	Netherlands
FEMALE								
Rate	14.4	41.6	*50.0*	6.4	70.7	2.5	65.7	37.3
CI	13.2-15.6	40.6-42.6	*44.4-55.5*	6.1-6.7	68.0-73.5	2.4-2.7	54.8-76.7	35.8-38.8
Rank	5	3		6	1	7	2	4
MALE								
Rate	6.5	31.8	*34.1*	3.1	32.0	1.9	31.5	17.9
CI	5.7-7.2	30.9-32.7	*28.8-39.4*	2.9-3.3	30.1-34.0	1.7-2.1	23.1-39.9	16.9-18.9
Rank	5	2		6	1	7	3	4
FEMALE & MALE								
Rate	10.4	36.6	*43.3*	4.8	52.6	2.2	51.1	28.0
CI	9.7-11.2	36.0-37.3	*39.4-47.2*	4.6-4.9	50.9-54.3	2.1-2.4	43.9-58.2	27.1-28.9
Rank	5	3		6	1	7	2	4

Table 4.10: Prevalence of affective psychoses: age standardised rates per 1000 adult population by practice network in 2005

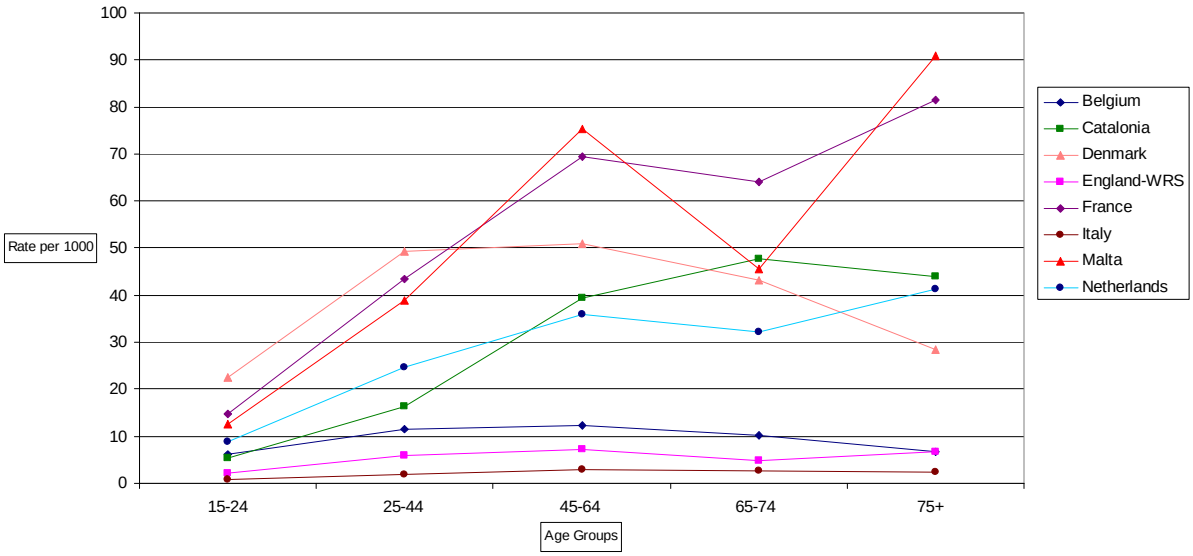

Figure 4.8: Prevalence of affective psychoses per 1,000 by network and age band in 2005

In all networks rates were higher in females than males (generally around twice). There were particularly large differences between the estimates.

Comments on results for mental illnesses

As we anticipated the prevalence of mental illnesses provided the greatest problems for interpretation. However the remarkable consistency in the relative male and female rankings for all the conditions presented is an encouraging indicator of recording quality. There is not much comparable material published in medical literature. Among the various mental illness groups considered, it was only for dementia that there was any consistency between the prevalence estimates. Since it is unlikely that there are large differences in the prevalence of these conditions in European countries we believe that most of the apparent differences here are due to different cultural perceptions and differences in recording behaviour. We elaborate some of these points below.

Perception of mental illness- there are large cultural differences in the acceptance of mental illness and as to whether it should be described in terms that are less pejorative. In the third national morbidity survey in England and Wales (McCormick and Rosenbaum 1989), we observed that rates of illness described as due to anxiety showed a social gradient which

was opposite to that seen for depression but if the diseases were combined there was almost no social gradient. Stress related illnesses and symptoms which might have a psychosomatic origin were sometimes reported using physical illness terminology e.g. migraine as opposed to tension headache, palpitations as opposed to panic reaction.

The recording process- Where emphasis is placed on the reason for encounter, the person's presenting symptoms may be entered exclusively without proceeding to enter a medical diagnosis. The distinction between person reported symptoms and doctor assessment diagnosis is made elsewhere in this report and though these are different pieces of information, GPs are likely to make a record which they see as best facilitating patient management and switch between these recording emphases. In the assembly of episodes of care the data can be linked and the analyst can choose the latter as the more specific diagnosis, provided it is entered.

A spin-off from differing approaches to classification arises from the way diseases are grouped. Sequential consultations ostensibly from one episode of illness may embrace codes from differing chapters of the classification system and lead to difficulty in defining the classification chapter to which a particular episode of illness should be assigned. This applies particularly to the interpretation of data about mental illness. ICPC includes within the chapter on psychological problems a number of vague symptom diagnoses such as sadness and feeling lonely which may not indicate mental illness. The ICD collects diagnoses which at the mental illness chapter level include anxiety and similar syndromes but non-specific symptoms are mostly classified in chapter XVI 'Symptoms, signs and ill-defined conditions'. For this reason the comparison between networks using ICD and ICPC is of limited value when considering the totality of mental illness though that is not the case when comparing individual diagnoses.

Source of care- In some countries (e.g. France) major mental illnesses such as schizophrenia are not generally treated or even patients given prescriptions by GPs, nor are they routinely informed about such illnesses in the people they are treating for physical conditions. In most countries persons with major mental illness are referred to specialists but the GP will be kept informed and may often be responsible for prescribing his drug therapy.

Concern about the record content- we have previously made the point that some doctors are particularly concerned about entering information in the medical records which they fear could in some circumstances disadvantage the person concerned (e.g. where records might be used by another doctor to provide an employment medical report). Though apparent to some extent in all countries, it was not equally so.

Gender differences

We examined gender differences in all conditions reported. We first report gender specific standardised rates to the combined female and male EU 15 country adult population (Table 4.11).

	Diabetes Incidence		Diabetes Prevalence		IHD Prevalence		All Dr Assessed Mental Illnesses	
	SR	CI	SR	CI	SR	CI	SR	CI
FEMALE								
Belgium	2.5	2.0-3.1	25.9	24.2-27.6	11.4	10.0-12.7	21.5	20.0-23.0
Catalonia	7.0	6.6-7.4	50.4	49.4-51.5	9.7	9.2-10.1	130.7	129.0-132.4
Denmark			*27.2*	*23.4-31.0*	*11.2*	*8.9-13.4*	*62.8*	*56.5-69.0*
England-QRes	3.5	3.4-3.6	18.9	18.7-19.1				
England-WRS	2.4	2.2-2.6	21.3	20.7-21.8	12.6	12.1-13.0	83.0	81-9-84.0
France	2.9	2.3-3.4	31.7	29.8-33.5	12.9	11.8-14.0	218.4	213.7-223.1
Italy	5.2	5.0-5.5	57.4	56.6-58.2	42.0	41.4-42.7		
Malta	10.6	6.0-15.3	63.6	52.0-75.4	19.3	12.6-26.0		
Netherlands	4.4	3.9-4.9	42.5	40.9-44.2	18.7	17.6-19.8	67.5	65-5-69.5
MALE								
Belgium	3.7	3.0-4.3	30.0	28.0-31.9	25.8	23.8-27.8	11.2	10.1-12.3
Catalonia	9.6	9.1-10.1	61.0	59.7-62.2	23.7	23.0-24.5	87.5	86.1-88.9
Denmark			*52.0*	*46.0-58.1*	*24.7*	*20.7-28.7*	*43.0*	*37.1-48.9*
England-QRes	4.5	4.4-4.6	25.6	25.4-25.9				
England-WRS	3.3	3.1-3.5	29.8	29.1-30.4	25.4	24.8-26.1	57.5	56.6-58.4
France	5.1	4.3-5.9	52.5	49.9-55.1	35.5	33.3-37.6	176.4	171.8-181.0
Italy	6.7	6.4-7.0	72.6	71.6-73.6	62.7	61.8-63.6		
Malta	15.8	8.5-23.1	79.5	63.5-95.5	40.5	28.6-52.4		
Netherlands	5.8	5.1-6.4	46.5	44.6-48.3	33.9	32.2-35.5	38.3	36.8-39.9

Table 4.11: Gender differences found in 2005 per 1000 adult population within each participating network after standardisation to the male and female combined adult EU 15 population

These data confirm that diabetes has a consistently higher incidence and prevalence in males than females; that ischaemic heart disease also has a consistently higher prevalence in males than females; but that females experience a consistently higher prevalence of Doctor Assessed Mental Illness in all participating networks.

The rank association coefficients between the female and male standardized rates for the four main indicators were for diabetes incidence Rs 0.96; diabetes prevalence Rs 0.99; ischaemic heart disease prevalence Rs 0.95; mental illness rank orders were identical (Rs 1.0). The p values were all

highly significant ($p>0.01$) and provide evidence of the reliability of data capture in the networks.

Overall discussion of the results

All data recorded for one purpose must be used with caution when used for a second purpose. In all the eHID participating networks the primary purpose for the data was to record clinical care. Several of the networks had recruited and trained practices to record data for epidemiological purposes, so their data could be said to have a joint purpose.

The eHID project has demonstrated that data can be extracted and compared in a range of European countries, and that such data are reliable and valid. Furthermore, these results were obtained at low cost from routinely maintained records. The results emphasize the considerable difference between countries in a wide range of health indicators and draw attention to the need for international research initiatives seeking to investigate the underlying causes.

For minor and less specific diagnoses the interpretation of data from primary care needs to be understood in the context of national arrangements for the delivery of healthcare;- for example, the arrangements for prescription reimbursement; the rules governing sickness certification, the conventions regarding access to specialist care. Estimates of prevalence derived from primary care, even for some major illnesses will not be directly comparable if the arrangements for providing care are substantially different (as for example in the care of persons with major psychiatric illness which scarcely involves French GPs).

Chapter 5: CRITICAL ISSUES FOR EPIDEMIOLOGICAL INVESTIGATION

In this chapter we comment on observations from the site visits and the results of the investigation of indicator diseases which impinge on the interpretation of epidemiological information as obtained from routine EMR

The project had two purposes; first to provide health indicator data for selected conditions and second to use the experience gained from these analyses to make recommendations on optimum recording practice. Optimum in this sense is applied to the routine use of EMR for epidemiological purposes. We have established that for some conditions (diabetes for example), data accumulated from routine consultations can be used for epidemiological purposes in both major collaborating practice networks and in one instance (England QRes) from all practices.

Given that the EMR has not been structured specifically around the provision of epidemiological data, this project has been conducted mainly within practice based networks where recording discipline has been established. The networks have different recording routines and from this variety of experience we have been able to examine critically feature which may bear on the estimates derived.

Denominator issues

Epidemiology is based on populations: hence defined populations are needed. In some countries this is achieved by a formal patient register in a single practice. Where patient registration is linked to general practice reimbursement arrangements, the denominator is very secure. Such arrangements are nationally administered and the likelihood of a patient being registered in more than one practice at a given time is remote. Duplicate registration only arises if a clerical mistake has been made or a person is deliberately using more than one name. Formal patient registration provides the basis for defining the denominator in Catalonia, Denmark, England-QRes, England-WRS, Italy and the Netherlands

Since epidemiological investigation always requires age specific estimates there needs to be agreement on the definition of age groups. These have mostly been taken from long established statistical practice in describing deaths and demographic statistics. From the perspective of the EMR there is no real issue as data can be processed in any arbitrary age groups. There are often short delays in registration of birth and sometimes also on death, which produce small errors in the estimation of the registered population in the youngest and oldest age groups. These are not significant when making

all-age estimates of prevalence or incidence. However they must be borne in mind when making relevant age specific estimates. Delays in re-registration following change of address may theoretically influence the calculation of the denominator estimate but these are effectively balanced between those persons leaving the practice and those newly arriving. A practice experiencing rapid expansion or contraction may have widely differing numbers of patients registered at different times in an annual period. In the UK based practice morbidity surveys, denominators were estimated from patient days of registration and the concept of person-years at risk established. This is of course an ideal and it should theoretically be applied to numerator as well as denominator. For most international comparative studies this ideal cannot exist since it involves a higher degree of registration accuracy than is usually available.

In some countries, for example Belgium, a decision has been taken to define patient record location. This is based on patient choice and practice agreement and, provided arrangements are made covering the possibility that a patient may choose not to have his record located anywhere, the denominator can be defined satisfactorily according to the records held. The estimates of the non-consulting population in Belgium have been derived from comparing insurance based data with practice based consulting data. These are added to data covering the consulting population to estimate the population at risk (Bartholomeeusen, Kim et al. 2005). The opportunity to use this method of estimation depends on the willingness of health insurance companies to make available data on consultation frequency, which in some situations might be considered as commercially sensitive information.

Finally, there are countries in which the practice cannot move readily from the true consulting population to the at risk population. This applies particularly where primary health care is provided for large groups of the population in private practice. In these circumstances there is very limited information available whereby the underlying practice or network denominator population can be estimated. Denominators based on persons consulting are subject to the considerable bias from differing consultation frequency which may be as much determined by the doctor as by the patient.

As part of our investigation we found other ways for estimating the denominator applicable to a group of doctors where there is no formal patient registration.

Estimation from the number of participating general practitioners

Where there are no specific features which suggest an unusual grouping of GPs/practices and where the number of active GPs in the area is known,

the average population per GP can be used as a crude denominator estimate. There are limitations in the use of the method where national lists of available practitioners do not adequately discriminate between active doctors still working and those who are part time or even retired.

Estimation from the total number of consultations

Where available, the total number of consultations (age specific) provided by a group of GPs/practices can be proportionately related to a nationally equivalent figure. For example, if a primary care health service is predominantly financed through health insurance the claims made by the network GPs in respect of age and gender groups can be related proportionately to the national equivalent values to estimate the population coverage. (This method is applied in the Switzerland sentinel surveillance scheme (Bollag, Cloetta et al. 1999)). Such a system works effectively where this is the universal system for providing primary care and where the claims system is sufficiently robust in its execution. In many ways this method is similar to that described by Bartholomeeusen but does not carry the same age specific and regional detailed adjustments to estimate the non-consulting population.

Numerator issues

Many issues relating to the estimation of the denominator apply equally to the numerator. Epidemiological enquiry involves counting all relevant persons in a defined cohort. The interpretation of the count involves the calculation of a rate which may be standardised to a common population when making comparisons.

Free Text data

Free text entries are made as a supplement to coded diagnostic data or as an ‘aide memoire’ for the doctor of particular risk situations. (eg, “This child seems to have a lot of injuries.” “This man’s wife does not know that he has a history of major psychotic illness.” “This man is now complaining about two specialists to whom he has been referred.” “This woman is being ill-treated by her husband but she refuses to do anything about it.”) These data will always be retained as free text entries. We emphasise the importance of coded data for epidemiology and believe that free text data are unnecessary for epidemiological analyses where appropriate recording discipline is established. Free text data cannot be used in a cost efficient way and furthermore, free text entries might occasionally name other persons including doctors consulted or contacts who should be traced as part of good medical care. Accordingly we do not believe the numerator should include free text data

Undiagnosed persons

There is a well recognised difference between known diabetes and total diabetes reflecting those persons in the community who are not diagnosed and in some cases, even not yet symptomatic. All disorders include sufferers in the early undiagnosed stages and the question for epidemiological and health care management is 'how important is the group of undiagnosed patients?' The undiagnosed fraction changes over time depending on the effectiveness of the health care system in identifying all the people with raised blood glucose levels. Particular programmes to seek and identify an illness in the early stages will always make some differences to the estimate of prevalence, reflecting the places where these have been undertaken. However, in the context of health care management, persons not yet diagnosed, do not impose costs on the health care system. That is not to challenge the need for population screening for a few highly selected disorders in order to make the diagnosis as early as possible and maximise treatment benefit. To justify this action there have to be effective, acceptable and cost efficient methods of investigation and treatment available.

Continuing disease activity

When defining the numerator, the concern on the one hand is not to miss persons and, on the other, not to include those whose problem is resolved. The problem is maximal in the context of those chronic diseases which have long periods of relapse. As a health indicator, the important statistic concerns persons who actually have a problem. Persons with a resolved problem cannot be defined from a practice database other than by default. We therefore need consistency in the way problems are defined. In studies using practice databases, ad hoc arrangements have been made in order to address this issue. The commonest is to assume the disease is no longer active if no consultation has occurred over a given period or sometimes if no relevant prescription has been issued. This has some limitations since persons may continue to have a condition but no longer consult for it. They may also continue to receive medication for a condition which they no longer experience (e.g. epilepsy where some people continue on medication for the protection of their driving licence even though they have not had a fit for several years). For analysis there are many situations in which prescribing or procedural codes are melded with diagnostic codes in order to define disease activity. This is only possible where a prescription or procedure is uniquely linked to a particular disease. If a practice based recording system is dependent on this type of linkage in order to define prevalence, it will be severely compromised in estimating the prevalence of most diseases.

The inference of activity can be defined from the consultation record using arbitrary criteria. For example, a disorder might be considered inactive if it

does not prompt a consultation or contact with the practice in a one year period. Though this 'rule' may be suitable for most conditions it might miss significant numbers of persons whose disease remains active but who experience intermittent illnesses with long periods of remission in between, e.g. multiple sclerosis. In order to cover this situation databases can be searched for longer periods seeking a relevant diagnostic entry over perhaps a three year period (Van Eijkelenburg-Waterreus, Schellevis et al. 2001). However, in systems which do not have formal patient registration the practice cannot make inference on continuing disease activity because the patient may have moved away or be consulting another doctor and thus should be excluded from both numerator and denominator.

Within this project, we investigated the difference in the prevalence of diabetes using data collected in one year with that in an extended period (England-QRes, the EMR lifetime: in the Netherlands the previous three years). Additionally we investigated the effect of including prescribing criteria within the search definition (Table 5.1). In the data from England QRes, estimates of prevalence and incidence based on one year were considerably greater if prescribing data were included but these differences were much less evident in the EMR extended periods estimates. Estimates in 2005 were consistently greater by a small amount than those for 2004. The estimates in data from the Netherlands also showed small increases in 2005 compared with 2004. The addition of prescription information for drugs only prescribed for the relevant diagnosis increased the prevalence estimates but by a smaller margin than that seen in England QRes. These differences are based on recording procedures on which we make recommendations elsewhere. It should be noted however that both these networks are based on registered population lists.

Network	Diabetes prevalence Annual 2004	Diabetes prevalence Extended record period 2004	Diabetes prevalence Annual 2005	Diabetes prevalence Extended record period 2005
England-Qres without prescriptions	25.2	39.5	26.0	42.2
England-Qres including prescriptions	37.1	40.9	39.2	43.6
Netherlands without prescriptions	33.7	40.5		
Netherlands including prescriptions	38.2		39.5	

Table 5.1: Comparison of prevalence per 1000 adult population calculated with and without prescription data and in a single year or over a period in two networks in 2004 and 2005

Opting out

This issue potentially influences both numerators and denominators. Increasing opportunities are being given for persons to 'opt out' of arrangements for anonymous interrogation of their EMR. Interestingly this option is not available in Denmark or Catalonia. The programme of site visits disclosed that this option was often stated in information publicity on the use of data for research and was sometimes displayed as a poster in the GP's waiting room. Enquiry suggested that such opt out was infrequent. This choice is made by some patients because of personal sensitivity about their health record, but generally reflects a suspicion that confidentiality might be breached. The right to opt out has been established legally in England (NHS Summary Care Record 2008) and was available in most but not all countries. A person may also choose not to allow the use of identifiable data. He may also choose not to permit the sharing of information with other healthcare providers. The means whereby information is protected is based on an exclusion code in the EMR which prevents record search. The concept of a 'sealed envelope' containing sensitive information has been suggested as a means of giving extra security.

In England, the use of anonymised data is governed by a facility called the Secondary Uses Service and individuals cannot opt out of this (Information Centre 2008). In this context, anonymisation involves the destruction of any means whereby the identity of the person can be reconstructed, though it does not negate the possibility of accumulating data about an individual in sequential data extractions. In brief the single patient identifier is encrypted consistently so that new data relating to that patient can be associated with their previous data, but the encrypted identifier cannot be applied to the original source to identify the particular patient.

Similar guidance on the use of EMR is given by most member state governments and the interpretation of data from whatever source has to be made in the light of the bias it may cause. In most countries the patient's right as to the content of the record is a) to see it; b) to request removal of inaccurate information; and c) to refuse to allow its use for any other purpose save that of immediate medical management by the doctor who generated the record. It is the third right which presents the problem for the use of records for epidemiology and applies whether the limitation is total or selective. If it is total, interrogation programmes have to be written to exclude data from the person opting out and these affect both the numerator and denominator in any rate calculation. If it is selective, the complexities of determining which data entries or laboratory test results are excluded cannot be accommodated in analytical routines to measure rates. The primary issue surrounding the transfer of data is the potential to harm the patient and that

cannot happen if the data are truly anonymised and information entered in free text is not transferred to research institutes,

Some of the issues surrounding confidentiality are illustrated by the example of a person from whom a specimen is taken for establishing influenza diagnosis by virology. He may be willing for data about influenza illnesses to be included in some collective analyses but be quite unwilling for information regarding HIV infection to be included. However, if the influenza specimen was shown to contain a drug resistant influenza virus, it is vitally important from a public health perspective that information relevant to an immune compromised state can be identified. Selective data sets at the minimum produce bias; failure to record information may lead to patient safety being compromised; the lack of critical information because of ungrounded fears about breaching confidentiality prevents accurate assessment of problems for public health management.

Apart from the issues surrounding procedures to allow individual patient opt-out, the program of site visits disclosed a tendency for some doctors to be sensitive to patient pressure in the way selected items of information were recorded. Such pressure may be exerted for advantages with regard to claims for sickness insurance or for personal gain. Equally there are dangers from doctors maintaining records in ways that are also related to personal gain perhaps in justifying the costs of further investigation or even achieving treatment targets by such manoeuvres as preferentially recording information on favourable results and suppressing unfavourable ones. It is fundamental to efficient use of the records that we can be united on the purpose of the record and the basis for which it is constructed. For the purpose of this project we need to work on the basis that the EMR is a true and reliable record of doctor-patient interaction. However we flag up the dangers inherent in allowing the record to be substantially influenced by secondary issues.

Diagnostic definition

The science of epidemiology requires conditions to be defined. Mostly, definitions are based on objective criteria, illustrated as an example by the precise glucose levels appropriate to diagnosing diabetes (Deckers, Schellevis et al. 2006). In practice however, many patients consult who have been diagnosed elsewhere and who may be already on treatment. The criteria on which the diagnosis was based may not be available to the recording doctor. It is therefore necessary for doctors when registering problems in the practice EMR to make a decision based on the evidence before them rather than what might be considered gold standard evidence.

The diagnosis of an acute infection such as influenza illustrates other considerations. If we wish to investigate the value of a treatment for influenza it is essential that part of the clinical investigation is based on laboratory confirmed influenza. If we want to estimate the overall impact of influenza infection it is equally important that we take a wider view. Not every person with clinically symptomatic influenza infection presents for care. Among those who do, many are well into the course of the illness when the classical features are no longer observable by the doctor and it is already beyond the time that recovery of virus is likely (Ross, Kai et al. 2000). The costs of establishing the diagnosis using laboratory confirmed methods are often not justifiable. Mental illnesses pose even more problems. The interpretation of psychological symptoms depends more on the assessment made by the doctor than on the symptoms presented. Persons recovering from major illness, or experiencing traumatic situations such as bereavement, marital breakdown or employment redundancy often experience and report symptoms similar to those of a person who is mentally ill, though it is inappropriate to assign a mental illness label to the clinical situation.

These examples illustrate several problems in the application of diagnostic criteria in general practice and when interpreting practice based data. Patients are seen in a ten minute consultation and sometimes this is the only opportunity to label the illness. A person may provide strong evidence supporting a particular diagnosis but at the point of consultation, typical criteria are not present: (for example, a temperature based criterion - a patient might have felt feverish all night but not have an elevated temperature when seen). Most treatment in general practice is empirically based. However notwithstanding this limitations there is good evidence of matching between laboratory diagnoses of influenza with influenza like illness (Fleming, Zambon et al. 1999), and of asthma attacks reported in primary care and in hospital episode statistical data (Fleming, Cross et al. 2000).

In order to improve the quality of diagnosis WONCA introduced diagnostic criteria for use in conjunction with the ICPC (ICHPPC2-Defined) (WONCA Classification Committee 1983). This was a laudable attempt to rationalise a very difficult area and few would disagree with the intent. Indeed they can be used to record key symptoms effectively. The difficulties arise when the symptoms are used to code symptom as indicators of diagnoses. For example it is time consuming to code all symptoms associated with a clinical diagnosis of hypothyroidism or of influenza. There are two difficulties for the recorder – firstly the routine application of criteria to all the diagnostic labels used in general practice is excessively time consuming and, secondly there are so many clinical situations in which the patient’s problems fall short of the criteria as specified and the recorder is left without a suitable diagnostic label.

From a practical perspective GPs generally conform to accepted diagnostic definitions (Deckers, Schellevis et al. 2006): cancer is diagnosed on the basis of histology, myocardial infarction on the basis of ECG and cardiac enzyme studies which are contained in specialist reports. For acute and less serious conditions most diagnoses are made clinically. When considering data from general practice it is logical to take account of the diagnostic process appropriate to providing medical care in a general practice setting. However welcome objective diagnostic criteria are, in the final analysis the use of the criteria and the adherence of the recorders to those criteria needs to be validated.

The importance of episode typing already considered in Chapter 3 is emphasised again in the context of diagnostic definition, especially distinguishing consultations describing new episodes from ongoing consultations.

The GP as gatekeeper

In some countries access to secondary healthcare has traditionally been controlled by general practitioners. In this situation, the GP is theoretically consulted by all persons who might be included in the numerator. However for information to be accessible for epidemiology the relevant diagnostic data reported in letters from specialists have to be routinely entered in the EMR in coded form. As the importance of 'gate keeping' has diminished and persons increasingly receive primary care from sources outside general practice, there are increasing possibilities for loss of data and thus of underestimating the numerator. Disciplined practice recording routines are needed to ensure suitably coded data are entered from all sources including home visits and out of hours care. Where there is no formal person registration, agreement on the location of the record and responsibility for data entry need to be established.

In all countries, but much more so in some than in others, patients may be receiving their primary medical care from more than one source and sometimes more than one source for the same condition. The potential for error when including counts of these patients can be minimised by effective, consistent and detailed communication between the differing providers but this is not always realistic. Accordingly this potential must always be considered when analysing and interpreting data. The specific diagnosis and the country concerned will always be relevant.

Disease Classification

From the primary care perspective few doctors involved in the networks have any appreciation of the underlying structure and development of classification systems. The critical step for them was how to transfer their descriptive labels to usable coded data. When classification systems were developed, the primary concern was the ability to analyse medical diagnostic and allied data. For routine patient management the electronic record needs an efficient and structured means for storing and retrieving data. It is important that medical data are held at the highest level of specific detail even though they may more appropriately be analysed at a less specific level.

The networks have analysed their data either on the basis of the ICD classification (versions 9 or 10) or the ICPC Classification. In most networks the classification process involved the use of an intermediary interface. The French network had been collecting information using the Dictionary of Consultation Results (DCR) as the means of summarising the content of consultations with a terminology which is mapped to ICD10 for analysis. The English networks processed data using the ICD with data entry based on the Read thesaurus. The other countries used ICPC for both data entry and analysis. Perhaps inevitably, network members had become strong advocates for their chosen systems of accessing respective classification systems. The problems surrounding comparisons of data from differing classification systems were confined to the chapter based analysis of mental illness as a grouped category.

The Dictionary of Consultation Results (DCR)

This system has been used in France since 1983 and is based on the work of an Austrian general practitioner- Robert Braun. The result of consultation sometimes produces a diagnosis but may also produce no more than a reasonable basis for action. The DCR is a compendium of 277 terms usually presented alphabetically which are descriptors of the most commonly encountered terms in routine general medical practice (Braun 1979; Braun 1986; DCR 2007). These terms are optimally applied at the end of a consultation and before the results of further investigation are available. The terms can be qualified as a diagnosis (D), disease picture(C), a syndrome (B) or cardinal symptom (A).The use of the terminology is supported by specified inclusion criteria and the number of these which are to be present (ranging between 1, 2, 3 and all of them) before particular consultation result labels are to be applied. Finally the term can be complemented to provide an indication of episode type – N ‘new’ being the first time this consultation result has been reported: ‘ P ’persistent: R ‘revised ‘ for use when a consultation result is updated. The combination of DCR and its qualifiers is automatically mapped to ICD10 for analysis.

The International Classification of Disease

The ICD has a long history based originally on a desire to classify deaths in a way that national comparisons of mortality could be made (Registrar General of England and Wales 1856). It was introduced following the work of Farr in London and D'Espine of Geneva in the eighteen fifties (WHO 1977) and is now in its 10th revision (WHO 1992). National statistical data on deaths and hospital episodes are mainly presented using ICD codes but there are often considerable differences between one version of the ICD and its successors. In the presentation of national statistical data, it is important to note carefully which revision of the ICD is being used. Although the ICD is updated regularly, there is no consistency among the member states and there statistical agencies in the timing of the adoption of each revision.

The use of ICD is based predominantly on the recorder's decision as to the chosen diagnosis. However, in the practice situation, network representatives were aware that many hospital based episode statistics were allocated by clerks on the basis of the free text records left by the clinician. Project partners were very conscious of this weakness in coding procedures.

The ICD system could involve double coding where a disease may have anatomical characteristics (e.g. conjunctivitis) and an aetiological agent such as *adenovirus*. It was possible and even desirable that doctors could enter diagnostic information in more than one coded location, e.g. in Chapter I Infections – 'other adenoviral conjunctivitis' and in Chapter VI Nervous system and sense organs – acute conjunctivitis. Optimal use of a recording system favours the use of a single entry of information even if the software for the data entry procedure subsequently allocates a label to more than one code.

Although the ICD is predominantly a classification of diseases, one of the 18 chapters of the classification is concerned with *'Symptoms Signs and ill defined conditions'*. It was therefore possible and indeed common for information derived at a consultation to be entered at a symptom level. Allocation of a symptom at this level had both advantages and disadvantages. By grouping the symptoms together estimates could be made of the quantity of ill defined illness from the perspective of the recorder. Symptoms were not directly linked to any disease chapter based category though there were some broad links with disease clusters. For example, symptoms could be loosely described as skin symptoms and these could easily be linked for analysis with the chapter on skin diseases. The structure of the ICD is less conducive to following the course of a disease episode in which several diagnostic labels have been used.

International Classification of Primary Care (ICPC)

ICPC (WONCA International Classification Committee 1987) has evolved over the last thirty years from a classification system developed mainly for the analysis of data in a limited number of rubrics to a much more detailed classification which can be mapped to the ICD, though infrequently occurring diseases are described in free text links to broader diagnostic categories. It is designed to provide for coding of the patients reason for encounter through codes describing the investigation procedures, the process of care and conventional medical diagnosis labels including symptom diagnoses.

Conceptually it covers all aspects of the consultation process and many codes may be applied to one episode of illness. For example, these might include patient symptoms which constitute the reason for encounter, (e.g. rash, pain and poor sleep) and the doctor's chosen diagnosis following examination and/or investigation, (e.g. shingles). Increased diagnostic detail including the final diagnosis sometimes only emerges in the second or subsequent consultation. For the purpose of the patient record there are many illnesses in which the comprehensive nature of the ICPC codes is an advantage but it can present problems for analysis. The symptom code 'rash' is linked to the skin chapter, 'pain' is linked according to the anatomical location and 'sleeplessness' to the chapter for psychological problems: the diagnosis of 'shingles' is coded within the skin chapter. (In ICD by contrast, shingles is allocated to the virus infection chapter.)

The multiple codes available in ICPC accurately describe the picture of shingles but there is a risk of inappropriate entry in the allocation of symptom based codes. ICPC has been refined to incorporate problem definitions which minimise the risk of coding error, but the complexity of rubric definitions especially when criteria are only partially met and the comprehensive recording details can be a source of confusion for some recorders. Problem definitions are more specific for serious and major illnesses and more flexible for minor conditions. Our observations suggest that in the majority of practices, coding behaviour is resolved in a practical way using the classification to record the diagnosis (including symptom diagnoses) rather than simply reporting the presenting symptoms.This is the way in which ICPC has been used in the Dutch National Morbidity Surveys and in the Netherlands (Westert, Schellevis et al. 2005) .

The chapter based structure of ICPC differs from ICD in being anatomically rather than pathologically based, though critical links are retained: for example, malignant diseases are allocated into each anatomically based section but allocated to a consistent reference range of numeric codes at position 71.

The Primary-Secondary care interface

There was a unanimous view that the primary care electronic record should be integrated (or at least linked) with the secondary care record. Initial steps in that direction had been taken in England (NHS Summary Care Record 2008) and Scotland (Scottish Government 2008); in the Netherlands where a facility is being developed whereby EMR from one source can be read from a secondary source on the basis of the 'need to know' for individual patient management; and in France where secondary care summaries are often available in primary care, but not vice-versa. These steps have prompted consideration of the use of a classification system applicable to both primary and secondary care. In England a decision had been taken to use SNOMED CT as a thesaurus and thus permit all medical terms to be allocated to either ICD or ICPC (NHS Connecting for Health 2008). In France the need for an integrated record had prompted the decision to use ICD which was reached in primary care by using the DCR.

Chapter 6: PRACTICE BASED NETWORKS

This project has been mainly based on the EMR in use in practice based sentinel networks. We here consider those issues which concern the function of dedicated practice networks: both the historical and development aspects and those relating to current activity

The role of sentinel practice networks

Most of the project partners represented recording groups of GPs/practices committed to the provision of data suitable for use in epidemiological research. If EMRs maintained by all general practitioners met the standards aspired to in the eHID project, dedicated information networks involving specifically committed GPs/practices would not be needed as all relevant information would be available in routine records involving all general practices (and ultimately all sources of health care). However it is equally important to establish methods whereby the EMR can be interrogated efficiently.; an aspect of EMR which highlights the importance of recording networks. Though the ultimate goal includes both a high quality record and an infrastructure for using it , there is much work still to be done in order to harness the potential of the record a comprehensive tool for health care management. The eHID project has concentrated primarily on the importance of diagnostic information. It has touched marginally on prescribing information and all issues raised in regard to the reliability and completeness of recording are equally relevant to prescription and other data.

A record suitable for automated interrogation must contain all the appropriate linkages. Many of these are made at the point of data entry and require the software to be in place and the recorder to use it correctly. Some of these linkages are already established; for example the link between prescription and disease, but these are not exclusive and it is possible in most networks to record a prescription which is attached to a free text entry and not available for epidemiological research. In the study of the prevalence of diabetes (reported in Table 5.1) there were lower estimates of prevalence when the databases were interrogated exclusively by disease code as compared with a combination of disease and prescription codes. Thus prescription data were not always systematically linked to the underlying diagnosis.

In many networks, data entry does not include the results of laboratory tests. Information from pathology laboratories or hospital reports are entered onto the EMR as scanned documents and the contents are not coded. Specific

actions have been taken in connection with quality initiatives to ensure consistent capture of selected information, for example blood pressure level and information on smoking habit. However, the potential value for epidemiological purposes depends on consistent capture of all information with linkages retained and not just on items selected for a particular purpose.

New types of linkage need to be developed. Issues surrounding antibiotic resistance provide a good example; if resistance information is to be obtained from EMR, the results from microbiological investigation including the results of antibacterial resistance examinations need to be entered in a coded, consistent and usable form. Antibiotic resistance is a serious threat to public health and the issues are similar in all countries. At this stage of development of EMR there is a great opportunity to harmonise on the entry of such data onto EMR. There has been no serious developmental work along these lines and the opportunity to advance on the common pathway may not be available again. The enhancement of the record will be a continuous process and new developments will need to be piloted in practices already organised to provide comprehensive and consistent.

There are other important linkages to be developed: surgical procedures to diagnosis; sickness absence certification to diagnosis; prescriptions to diagnosis/problem and to all other prescriptions: laboratory results to problem investigated and to relevant diagnoses. These examples serve to illustrate the work needed in the continuing development and realisation of the potential of EMR in which dedicated networks have an important role.

Networks have an important role in benchmarking the quality of information from primary care. Except for small scale specific enquiries it would never be realistic in an economic sense to audit the quality of information collected across the board in large scale primary care based EMR. If however, a network is used as a test bed in which all aspects of data completeness and quality can be measured, in the context of a specified diagnosis, similarity of the results observed in a dedicated network compared with those more widely available gives credibility to the latter. Networks can pioneer the addition of critical data to the EMR which would allow the automation of interrogative procedures whereby diagnoses based on laboratory criteria can be investigated.

Networks will also be required to test new communication strategies not the least, the communication of information in an electronic form from laboratories, specialists and others directly to the EMR. This project has concentrated on acquisition of data from EMR in primary care. There are also matters relating to the dissemination of information to primary care and here the consolidated information processed from dedicated networks can be used to provide information of value to healthcare planning and to

informing healthcare policy decisions (Miller, Fleming et al. 2000; Chapman, Cross et al. 2003; Fleming and Elliot 2006; Olowokure, Clark et al. 2007).

Network aims

Historically the networks had different roots. Some evolved out of paper based recording systems used for disease surveillance; others had grown out of sponsorship by the pharmaceutical industry interested in obtaining data on prescribing and sometimes setting up the computer equipment for the purpose; others had emerged from the use of specific computer recording to engage in a clinical investigation or to monitor billing arrangements; and others had built the network around what was available in EMRs rather than influenced the design of the software. Those networks concerned with surveillance emphasised the importance of episode typing; those concerned with prescribing the importance of the accuracy of the prescribing data sometimes not even concerning the links between prescription and disease; where billing was an important use of the record, entries had to relate to costing and the main focus of accuracy was monetary. These varying emphases rubbed off in the software design and recording practice of the GPs which were later reflected in the results of interrogation. These differential effects tend to be minimal for serious disease of which diabetes is a good example and maximal in minor illness requiring no treatment.

Where networks were primarily financed for the provision of specific items of data for which they were commissioned or received payment, there was an obvious desire to ensure that the information provided was based on the notion of ‘best quality’. Some networks only analysed data from GPs they had assessed as being ‘good recorders’. There were difficulties in deciding what constituted unsatisfactory recording but, if such a practice is to be followed, recording quality needed to be assessed on a range of measures and not on the specific indicator disease item.

Payment to GPs was another factor influencing quality. There were firstly the payments for involvement in the recording process and secondly the payments made as part of a Quality Indicator target. The payments to the GPs for their involvement was not likely to bias the data received and indeed was likely to enhance the quality of the network provided potential omissions were monitored in some way. Payments for specific items of information presented the possibility that GPs might record data bringing financial advantage in a different way from those potentially disadvantageous. In England-WRS it had been noted that the repeat recording of ‘cerebrovascular accident’ as the diagnostic problem at each consultation prompted a programme of patient investigation as though this was always a first diagnosis, resulting in this label being avoided when recording ongoing consultations for this condition.

Differences in the arrangements for data transfer also influenced the results. The major problem here was seen in networks which did not have automated routines for data transfer. Failure to transfer at a particular time could lead to gaps in the longitudinal data applicable to some patients. Some systems allowed the collection of retrospective data collected within the practices prior to their participation in the network. Whilst the availability of retrospective data might be useful to many studies, the quality of retrospective data tended to be very variable and thus the use of it would be questionable.

Representativeness of networks

Networks had investigated how representative their database population were of the national or regional population. For many this could only be done at a broad level such as age and gender, as other potential data were either not recorded in the EMR or not transmitted to the network. Networks usually achieved a representative population (by age and gender) but the GPs were not always representative of GPs nationally. The databases were collecting data on the illnesses experienced by persons rather than the interventions of GPs and thus representativeness of the GPs was less important. We here present a summary of the activity of the networks in establishing representativeness.

Belgium– patients were representative of the Flanders population in terms of age and gender and they also had a similar mean taxable income. However they were not evenly distributed across the region. The GPs were mostly aged 40 to 59 and male.

Catalonia– patients were representative of the Catalonian region of Spain in terms of gender and age. No data for socio-economic comparisons or ethnicity were available. Only gender for the GPs could be demonstrated and this showed that 71% were female.

Denmark– This network was in its infancy and as yet had not examined its representativeness.

England-QRes– patients were representative of the UK population in terms of age/gender structure, levels of deprivation, birth and death rates, consultation rates, prescription rates and referral rates. The GPs were representative except in respect of practice partnership size where they were from larger practices than the UK average (QResearch website 2008)

England-WRS– The network population was well distributed across England and Wales and representative by age and gender. In a detailed study carried

out in 1991 (McCormick, Fleming et al. 1995), persons were representative for England and Wales compared with the 1991 census in terms of age, gender, marital status, urban/rural residence, housing tenure, employment status and smoking. The findings of a recent study (Harcourt, Edwards et al. 2004) disclosing under-representation in deprived areas in the north and over-representation in affluent areas in the south was followed by a programme of selected recruitment. GPs in the WRS were slightly younger than the national average and the practices were also larger.

France– consulting patients were representative in terms of age and gender when compared with national equivalent data from Échantillon Permanante Des Assures Sociaux (EPAS- Permanent sample of the socially insured population). Socio-economic data were poorly recorded by GPs and ethnic group, religion and sexual preference data were not allowed in databases in France. The GPs who contributed to France were older and more likely to be male (IRDES 2007).

Italy– patients were representative of the national population in terms of age and gender. Socio-economic and ethnicity data are not transmitted due to privacy regulations. Representativeness of the population was sought in the 21 regions of Italy. The health system in Italy, where children up to age 6 see a paediatrician and from 7 to 14 see a GP or a paediatrician, presents problems for estimating the true denominator in children. Women GPs were under-represented and GPs aged 40 to 60 years were over-represented.

Malta– the network database contains information on all persons who have consulted. The concept of active status based on the most recent consultation is used to describe the population currently receiving services from the practices. Temporary patients such as tourists are excluded from the database. However, the network is exclusively based in private practice and is separate from the public health system in Malta. For that reason the network is not representative of the Maltese population and the GPs not representative of GPs in Malta. Nevertheless all data are available in age and gender specific groups and thus provide an indication of disease activity which can be compared with age related trends in other countries and networks.

Netherlands– patients were representative in terms of age, gender and insurance type and comprised 2% of the national population. The GPs were representative in terms of urbanisation and computer systems but not currently of practice type (more GPs working in health centres)

Network organisation

Disciplined recording networks are needed in order to interpret data more widely available from all practices. The main purpose of a network is to

ensure consistent recording and to undertake studies in which the validity of data can be checked. There are only limited opportunities to make such checks in all practices. Recommendations of this project which are specific to practice based information networks are summarised here.

1. Networks should be able to demonstrate representativeness in socio-demographic and regional distribution and in other key variables. However, it was more important (and more practicable than actually achieving representativeness) that networks collected data appropriate to examining their representativeness, weighting their results to the index population.
2. Practices to be recruited to networks should meet minimum recording standards. These are determined by the recommendations we offer here subject to specific limitations applicable in the country concerned.
3. Data quality checks are important, particularly those concerned with the accuracy and completeness of the data.

Network Recruitment Criteria

We encourage a strengthening of information networks in primary care and make the following recommendations in relation to network operation and concerning the suitability of a practice to join in such a network.

1. It is preferable for patient registration with general practitioners, since this allows population based analyses. If this is not available practices and networks should collect sufficient information to derive a reliable estimate of the population at risk
2. The doctor's assessment of the problems or diagnoses presented at each consultation need to be recorded using appropriate codes (including home visits and telephone calls). This is preferably achieved by appropriate construction of software linkage of all data to the underlying problem entry
3. Before practices are included in a network, the routine capture of non-consultation data needs to be established (e.g. key items from specialist letters; the results of investigations and biometric data, etc.), which need to be linked to all relevant problem titles
4. Network participants must ensure updating of the EMR with appropriately coded information in circumstances where locums or deputies provide care for registered patients.
5. Practices must be willing to cooperate in data extraction analysis routines executed corporately in the network.
6. Practices need to be willing to collaborate in the further development of information systems in primary care.
7. Software designers must support the recording of episode type and practices must be willing to use it.

Chapter 7: RECOMMENDATIONS

The recommendations made here are presented in summary format and are based on observations during site visits, practical experience gained in collecting and sharing data and the deliberations of the project partners. Future developments are suggested

This summary of recommendations arising out of the eHID Project is presented with a focus on EMR for epidemiological purposes. These recommendations are directed towards the key players involved, ranging from the healthcare system managers to the individual recording GPs and on to the data analysts. The recommendations derive from the deliberations of the project partners in relation to the findings on site visits, the observations of recording doctors, the results and discussions between the partners on the analyses of the indicator diseases.

Computer software

Commercially it was inevitable that there should be several computer companies involved in providing software in any one country. However, there are some areas in which there has to be consistency of software design in order that data can be extracted consistently. These include:

1. Clear and separate fields identifying the presenting problems and doctor assessment diagnoses.

2. Common classification systems for morbidity and interventions for use in each country should extend across primary and secondary care. Data collected in coded form should be capable of mapping across classification systems. Relevant information supplied in one classification system should service the needs of other health care providers, even when using a different classification system. The coded data in EMR (but not free text information) from both primary and secondary care sources should be capable of examination by healthcare providers in both care sectors. (This recommendation should not be taken to exclude the use of free text as an item of specific and intended communication between collaborating care providers).

3. Every consultation or service provided for a patient is to be linked to the underlying problem or diagnosis to which it relates.

4. Natural data linkages need to be maintained. Date and identity are insufficient by themselves to provide linkage. All data entries whether made at a consultation or at other times, whether relating to a problem, prescription or intervention need to be linked to the underlying diagnosis or problem. Links between data items need to be established through automated software programmes and not simply inferred.

5. The software must be capable of defining the list of registered or consulting patients at any one time or in any one period (see discussion on denominator in the data analysis section).

6. Codes for data storage need to be accessed via a thesaurus in a user friendly way.

7. The registration status of the patient is essential (e.g. registered listed patient, temporary resident, insured patient, private patient etc.). At the minimum, registration should include unique name, date of birth, gender and post coded address.

8. The opportunity for the recorder to attach the episode or consultation type to every morbidity entry is essential.

9. An audit trail is needed whereby diagnostic updating and revisions are retained for analytical purposes.

Recorder tasks

Many of these recommendations stem from the needs of consistent and reliable data entry. They are made in the context of the GP recording environment where the key task is to provide a code(s) labelling the consultation firstly for ongoing patient management and secondly for analytical purposes. That exercise must be undertaken in an environment in which the record provides a true and reliable record of the consultation. The consultation is necessarily limited to one short time period and is often independent of other consultations for that patient.

1. All persons involved in delivering primary healthcare (including nurses etc) should be appropriately trained in recording principles and methods of data entry.

2. All entries to be recorded under a coded problem title. Problem titles should be an assessment diagnosis wherever possible. Where there is no clear assessment diagnosis the most important or significant symptom should be selected.

3. When recording patient reported symptoms as well as assessment diagnoses, both should be recorded consistently.

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4. All entries relating to prescribing or interventions should be linked to the assessment diagnosis.

5. Episode definition is essential in electronic records. At a minimum, the distinction between a new episode of illness and ongoing consultation should be made by the recording doctor at each consultation and for each individual health problem reported.

6. Free text entries should be seen only as supplements to coded information and never a substitute. We should aim at the epidemiological content of the record being completely coded with no need to access free text.

Confidentiality and Data Transfer Procedures

The EMR needs to be an accurate record of the consultation and the problems presented. As such it will contain personally sensitive information. The diagnostic information is usually in coded form but the content of free text is highly variable and sometimes includes extremely sensitive information.

1. The EMR must be comprehensive and accurate and not be subjected to selective exclusion of critical data (by doctors). Selective omission may in some circumstances compromise patient safety.

2. The ability of persons to opt out of data transfer arrangements should be discouraged. It introduces bias, and is operationally impracticable on a selected information basis.

3. True anonymisation (random encryption of patient identification) is the preferred method for use in epidemiological research in order to ensure complete protection of individual patient privacy. Methods of

anonymising data must not preclude the addition of new data to a specific patient in the epidemiological database.

4. The ownership or custodianship of the record needs to be defined unequivocally, and this might be considered separately for different parts of the record.

5. The transfer of free text data is not needed for most epidemiological research.

6. The approval of an Ethics Committee should be sought prior to transferring data from the practice and data transferred should be limited to that required for the defined epidemiological purpose.

Classification and Diagnosis Definition

The differing Classification systems were well established in the different networks and generally GPs were happy with the system with which they had become familiar. Accordingly, the group did not feel it was necessary to recommend the use of one or other classification system. We summarize points relevant to these issues:-.

1. In order to integrate the EMR from primary and secondary care, a single classification system is preferable, but the ability for all authorised persons to read and use all data available is of primary importance. We strongly favour a thesaurus approach to accessing clinical and diagnostic codes.

2. The interpretation of data from routine records should be set within their context. The records made by GPs in routine practice are appropriate to their purpose and for most common conditions are not based on rigid diagnostic criteria.

3. A simple statement summarising the important health events is a key file for medical management. However, there was so much variation in the choice of entries for inclusion in problem summaries that their use for epidemiological research is limited. Epidemiological enquiries need to involve the entire record

Denominator definition

Whilst formal individual registration is usual in some countries, it is not always available and is unlikely to become the norm in all member states. The definition of the denominator is primarily determined at individual practice level but sometimes it can only be reasonably estimated at the level of a network.

1. A population denominator is essential for epidemiological analysis. Where the healthcare registration system is sufficiently robust, we recommend the measurement of person days at risk to derive an estimate of person-years for use as the denominator.

2. In descriptive epidemiology based on primary care, annual prevalence is recommended to describe prevalence. It has the particular advantage of avoiding inclusion in the estimate of persons no longer attending the practice and of persons who no longer experience the specified disease.

3. Ideally, populations need to be defined in age and gender specific groups in each practice individually and network populations to be aggregated from these values.

4. Age needs to be determined consistently and we favour the mid point of the study period. We support the conclusion of a previous project (Health Monitoring in Sentinel Practice Networks) that specific breakpoints in the analysis of data should be observed -12 months, 5, 15, 25, 45, 65 and 75 years.

5. Where a registered list is not available we considered the denominator should be defined in age/gender groups in each practice individually according to the method described by Bartholomeussen based on persons consulting (Bartholomeeusen, Kim et al. 2005).

6. Where the numbers of persons consulting in a practice can be defined over an annual period, but the level of detail available from insurance companies or other information sources does not allow the application of the Bartholomeeusen method to each practice individually, the underlying population of a group of practices should be estimated using the best available national or private insurance registration data..

7. If there is not a robust method for estimating the number of persons monitored and of relating it to the national population, national estimates of disease incidence/ prevalence cannot be made

Further developments

Looking to the future there will perhaps be more opportunities to establish diagnoses reliably. The extension of near patient tests and more objective assessment of patients according to guidelines will gradually improve the reliability of diagnoses. When considering the new incidence of diseases, objective criteria are likely to be better observed if only because of the increasing pressure on doctors to record as accurately and precisely as possible is in the interest of data accuracy and computer legislation. We envisage the following as priority tasks

1. The incorporation into EMR of coded data covering the results of laboratory investigation.

2. The establishment of links between important diagnoses and the evidence on which the diagnosis was made.

3. Enhancement of the links between the evidence base for reporting incidence applied seamlessly as relevant diagnostic information is entered.

4. Automated analysis of output in relation to selected management guidelines.

5. The development of standardised and validated data extraction tools.

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Appendix 1: AGENDA POINTS AT eHID MEETINGS

5 meetings of the eHID partners were held during the duration of the project and the main agenda points are summarised below:

1. Birmingham September 2004
   - EC contract
   - Funding issues
   - Role of the monitor
   - Project commitments and timetable

2. Utrecht April 2005
   - Budget report
   - Monitor's report
   - Sample data received
   - Partners' reports on data , ethical issues, validation procedures
   - Preliminary report on site visits

3. Paris November 2005
   - Discussion of criteria for analysis of 2004 data
   - Financial update
   - Site visits update
   - Data received
   - Diabetes analysis
   - Reports from national representatives
   - Monitor's report

4. Barcelona June 2006
   - Presentations and discussion of 2004 data from all networks
   - Discussions on matters relating to quality and development of quality protocol
   - Preparation for presentation workshops
   - Financial update
   - Monitor's report
   - Discussions on dissemination, publications and further projects

5. Lisbon February 2007
   - Presentation of 2005 data results
   - Short reports on presentation at international meetings
   - Discussion of format and content of final report
   - Further dissemination strategy
   - Further projects
   - Financial update

Appendix 2: REPORTS FROM THE eHID PROJECT MONITOR: José Marinho Falcão

First Report – March 2005

1. Project start date

The original start date proposed in the contract was 1 December 2003 but the signature took place on 1 July 2004. Due to delays in collecting signatures of the partners, funds from the Commission were available only in the autumn.

2. Meetings

Meetings were held as planned. Two general meetings were already organised.
The first meeting took place in Brussels 11-12 Feb 2004, before the project was formally signed. This was an important meeting, getting together all participants and recognizing the feasibility of the project. A second meeting was held in Birmingham 23-24 Sept 2004 where further progresses were accomplished on participating GP networks and organisational issues.

3. Research assistant

The early recruitment of a research assistant was a main condition for the adequate development of eHID. Due to administrative difficulties, a research assistant (Helen Boardman) was hired and took office from 1 February, 2005, only. This recruitment delay was the major setback in the project, as some tasks were conducted as planned, specially, the program of site visits. Both the project leader (Douglas Fleming) and the research assistant are confident that all the tasks will be completed in the appropriate time. As project monitor I share the same point of view.

4. Site visits

As noticed before, the program of site visits has not started, formally. However, visits and contacts took place between the project leader and networks operating in several Member States. At least, these included visits to Portugal, Malta and the Netherlands, as far as I was informed. During the visit to Malta, the Project leader was able to identify several networks that can be candidates for participation in eHID. These visits show clearly that the project is now **very active** concerning one of its major component: site visits and recruitment of networks activities are catching up from a situation of delay.

5. Conclusions

Although recognizing that eHID had a delay caused by a late recruitment of the research assistant it should be emphasize that all activities are now being very actively developed, as planned. **I anticipate that there will be no adverse consequences from this delay and results will be successfully obtained and reported in due time.**

6. Recommendations

According to the information provided on the progress of eHID I recommend that:

a. the project leader and the research assistant keep their strong efforts and commitment to the project;
b. the current participating networks work together with the project co-ordinators, providing their expertise, experience and data, as deep and as timely as possible;
c. the involvement of other networks using emr data is promoted, provided that such expansion of the project will not disturb its natural progression;
d. the project co-ordinators continue providing the project monitor, on a regular basis with all information on activities, successes and failures that they consider important for the progress of eHID .

Second Report – November 2005

1. Research Assistant

eHID faced some delay in the first months of its activities due to the difficulties in recruiting a research assistant. As soon as Helen Boardman took her post, a very strong increase in the activities was noticed, starting by her active and efficient participation in the April meeting in Utrecht and confirmed by a successful accomplishment of the project work plan

2. Meetings

The meeting scheduled for 7-8 April 2005, in Utrecht, was successfully held as planned. In this meeting, some data on the health indicators under study

obtained from a few networks were shown, providing evidence that such data could be gathered. It should be emphasized that networks from Norway and Germany participated in the meeting, expressing their interest in the project.

3. Site visits

Site visits were one of the main activities of the project between April and October 2005. Helen Boardman visited 10 networks in 8 countries (The Netherlands, Belgium, United Kingdom, France, Italy, Spain, Malta and Germany), A detailed report on these visits was prepared and distributed to eHID participants by the end of October. This report contain a list of important issues, including: 1. Brief descriptions of the visited networks; 2. Recording in GP systems; 3. Recording for eHID indicator conditions; 4. GPs opinions of strengths and weaknesses in the systems; 5. Network structures; 6. Ethical considerations; 7.Recruitment of GP to the network; 6. Representativeness of the networks; 7. Data recording and collection; 8. Denominator; 9. Data quality measures; 10. Training, feedback and input of GPs; 11. Network organisation opinions of strengths and weaknesses in the systems. The report also describes and discusses "potential issues affecting disease measurement". It should be noticed the excellent and concise structure and content of the report. It provides a very good basis for discussion during the next Paris meeting.

4. Identification of emr networks not included in eHID

This task was successful conducted, leading to the identification of potential emr networks in Sweden, Finland, Hungary and Turkey.

5. Replacement of the research assistant

Helen Boardman reported that she will leave eHID on October 31th. This event is not good news for the project as Helen was performing an excellent job. She will be replaced by Catherine Elliot from December 1st.

6. Conclusions

As already anticipated in the 1st report from the monitor there was no "*adverse consequences from this delay (recruitment of the research assistant) and results will be successfully obtained and reported in due time*. Since April, progress was completely adequate both in the programme of site visits, in obtaining data on the four indicators and in identifying new emr networks. Therefore and so far, eHID is in an excellent position to achieve the objectives for which it was designed.

7. Recommendations

According to the information provided I recommend that:

a. the new research assistant be adequately integrated in eHID activities, minimizing the difficulties that are unavoidable when a replacement at the middle stage of a project occurs, independently of the skill of the person recruited.

b. all network co-ordinators recognise such difficulties and do their best to facilitate the tasks of the new research assistant.

c. the involvement of other emr networks be accepted, whenever possible, provided that such expansion of the project will not disturb its natural progression;

d. the project co-ordinators and the research assistant continue providing the project monitor with all information on activities, successes and failures that they consider important for the progress of eHID .

Third Report – May 2006

1. Research Assistant

Helen Boardman, the first research assistant of eHID, had to leave her post due to other professional responsibilities. In spite of this drawback, the project co-ordinators were able to select a new research assistant, Catherine Elliot, within a short period of time. Catherine Elliot started her responsibilities by the time of the eHID Paris meeting in November 2005. It must be recognised that she joined the project at a difficult stage. In fact, most of the activities were in progress and, specially, the site visits had already been conducted. However, eHID has progressed at the planned pace and Catherine has had an important contribution to such progress. According to my best knowledge, the replacement of the research assistant has not caused any major inconvenience for the project.

2. Meetings

The meeting scheduled for 17-18 November 2005, in Paris, was successfully held. The main subjects approached included:

1. a detailed report on the site visits and other related information;
2. the presentation of emr data from several participating networks;

3. discussions on coding instruments and procedures;
4. discussions on the interpretation of similarities and differences in the estimates found between networks, specially for diabetes prevalence.
5. discussions on the ways quality and comparability of data and estimates could be addressed and, hopefully, improved.

3. Work progress – December 2005 to May 2006

The activities conducted during this period were essentially concentrated on

1. 2004 data delivery from networks for the 4 conditions under study

2. quality and comparability of estimates calculated from different networks.

On April 27th the monitor asked all participants to report on difficulties and solutions they have faced since the Paris meeting. The feed-back was poor and does not allow the drawing of a complete picture of the activities developed by national networks.

Data delivery
The research assistant reported that, till recently, at least two networks had not delivered its data to the co-ordinating centre. This will make the analysis of data and interpretation of results difficult to be accomplished before the next Barcelona meeting. The project co-oordinator, Douglas Fleming reported that the major difficulty Weekly Return Service (WRS) faced was related to episode typing, specially the concept of "new" episode ("new to the recording system or new in a medical sense"). Grouping of diseases (and double counting) was foreseen as possible difficulties to be discussed. A more complete picture of the work done in 2006 will be, certainly, obtained during the Barcelona meeting.

Quality and comparability
On the subject quality and comparability, the project co-ordinator distributed a series of templates covering several aspects of issues related to quality and comparability of data to be addressed by the representative of each network at the Barcelona meeting. This is expected to be of great value to stimulate and organise the answers. Meanwhile a short paper on comparability was written by the monitor in order to facilitate the discussions on this subject.

4. Conclusions

1. The project overcame easily the consequences of the replacement of the research assistant. In fact, the monitor could not identify any relevant delay or trouble associated with this replacement.

2. Some networks had difficulties in delivering data in time. It is possible that such delays will not preclude a complete analysis and interpretation of the global results to be discussed in Barcelona.

3. Quality and comparability of data and estimates has been developed, mainly on the selection and calculation of indicators. It is foreseen that a major progress on these subjects will be shown in Barcelona by the participant networks, leading to more concentrated efforts during the next months.

4. Since the Paris meeting, eHID has progress according to the work plan and is in a good position to achieve the proposed objectives, as scheduled.

5. Recommendations

According to the information provided, the monitor recommends that:

a. all network co-ordinators recognise the importance of each national contribution for the project as a whole, trying to avoid delays in data reporting.

b. all networks do their best to identify, calculate and provide data regarding quality and comparability.

c. the project co-ordinators and the research assistant continue providing the project monitor with all information on activities, successes and failures that they consider important for the progress of eHID..

d. all network co-coordinators provide the monitor with the best information they can in order that he can have a timely picture of the progress of eHID in their networks.

Fourth Report – April 2007

1. The meeting and the participants

The meeting was held in Lisboa a few weeks later than usually. In fact, before, a eHID meeting had been always held before the end of the year. This change was intentionally planned in order, not only to have available the 2005 data from all networks, but also for allowing time enough for data analysis and comparisons. The change was not caused by any organizational difficulties of the project. It shall be emphasized that all

networks representatives were deeply involved in the discussions, showing an increased commitment and interest with the project.

2. Data delivery and internal presentation of results

Presentation of 2005 results provided by the networks showed that their activities leading to the availability of data was thoroughly and carefully accomplished. Only very few networks were not able to comply with the deadline. However, those delays didn't preclude a very good presentation of the results. These included all the four subjects under study: diabetes prevalence and incidence, and prevalence of ischaemic heart and mental health diseases. As with 2004 data, differences between networks were very large in some instances and, probably, they were explained not only by real differences in the populations but also associated to bias induced by a number of situations, as diagnostic criteria, coding procedures, different access of patients to GP, etc. Comparisons between 2005 and 2004 data were carefully assessed and presented showing a good consistency in each network. However, large differences between networks continued to be found, as stressed before. It shall be emphasized that, as expected, the largest differences between networks were found in the prevalence of mental health diseases. This suggests that mental health data is especially difficult to collect through GPs in a harmonized manner. Much research has to be done, certainly after eHID is finished, in order to address and correct estimates of prevalence of mental health conditions.

3. Giving visibility to the project

The scientific co-ordinators of eHID took an important initiative in order to introduce eHID to scientific audiences, in several meetings. Some network participants were also deeply involved in this initiative and contributed to its success. Therefore, the project were presented at several events, especially at 1.WONCA 2006 meeting, in Florence; 2. EUPHA 2006 Annual meeting,in Montreux and 3. International Meeting on Health Sentinel Networks I, Leon, Spain.

4. Quality issues

Activities during the period preceding the Lisboa meeting included issues related to quality of data and estimates. As in previous meetings, data quality was once again at the centre of the discussions. Going a step beyond earlier discussions, participants were asked to address a number of specified quality issues and quality indicators. Between others, these included the description of how the lists of GPs are a good representation of the underlying populations; the distribution of the number of weeks the practices were actively recording or how the estimates yielded by each network compare with available estimates from the country or region. It is

expected that the networks will generate a maximum set of quality indicators to be included in the final report. This activity will allow not only the description of the quality of the data but will also contribute to identify the major weaknesses of both each network and the overall system.

5. Structure of the final report

During the period covered by this report, careful attention has been paid to the structure and content of eHID final report. This turned out to be a very useful initiative of the scientific co-ordinators, allowing participants to discuss each of the planned sections that will be included in the final report. These discussions raised the need that all networks have to contribute for the preparation of the report.

6. Conclusions

1. The project progressed smoothly since May 2006, accomplishing all relevant tasks that were planned. It shall be underlined the successful efforts made to conduct a very good analysis of the 2005 data for all conditions under study, as well as the comparisons with 2004 data.

2. Representatives of the networks were deeply involved in the discussion of the results, adding important contributions for further analysis. Delays of a few networks in providing the 2005 data on time caused difficulties for analysis, although such difficulties were overcome by a considerable extra effort of the research assistant, Cathy Elliott and the other members of the co-ordination group.

3. Currently, eHID is already at a stage that guarantees a successful end of the project.

7. Recommendations

At the current stage of eHID the monitor wishes to recommend that:

a. all network co-ordinators participate actively and timely in the preparation of the final report, giving all the support to the co-ordination team;

b. the initiatives to give visibility to eHID continue using other scientific meetings, especially events in countries and regions where a potencial for adopting *emr* methods has been recognised.

c. the content of the final report includes not only the description of the activities, the results obtained and the strengths and weaknesses of *emr* to provide health indicators, but also the proposal of a set of

solutions for the difficulties already identified, in order to assist other networks that will intend, in the future, to start *emr* use for epidemiological purposes.

Final Report – February 2008

The eHID Project is coming to its end. The project monitor wishes to express some general opinions and comments about the project and its results.

1. The co-ordinating team was able to plan and conduct the project with an outstanding quality. All planned data collections, analysis and results were completed without delay and interim reports and deliverables were prepared according to timetables. The team was able to overcome the unavoidable problems and difficulties raised during the project, solving them appropriately for the good progress of the work.

2. GP networks participating in eHID accomplished all their responsibilities, although with different levels of difficulties. Most of difficulties faced by some networks were related to their structure and organisation which could be, in general, overcome by their own efforts and by a strong support of the co-ordinating team.

3. The results obtained by the project showed that GP networks, using routine electronic medical records (*emr*), were able to work together and could deliver estimates of prevalence and incidence of the diseases under study. Certainly, the validity of such estimates was not perfect but it was demonstrate that networks can improve the quality of estimates through the participation in regularly organised, cooperative, on-going activities, at European level.

4. The conclusions and the recommendations proposed by the project will be extremely important to guide all *emr* based European networks in the task of providing data with good quality for epidemiological purposes.

At the end of eHID, I wish to strongly recommend that further support should be provided by EU Institutions to future projects aimed both at enlarging the number of *emr* networks and improving the standardisation of definitions and procedures. In fact, the fulfilment of the maximum potential of *emr* use for delivering epidemiological estimates, at European level, is largely dependent on such support.

Lisboa, 5.3.2008

José Marinho Falcão
(Project monitor)

Special Monitor's Report : How can comparisons of incidence and Prevalence between countries /populations be validated? – February 2006

The eHID project is intended to explore routine data from electronic medical records to calculate estimates of incidence and prevalence, on a population basis and compare these measures of frequency of disease between participating countries / populations. Given the differences, both structural and operational, existing between networks in different countries the project has put emphasis in harmonising the methods used by networks. However, it is recognised that a perfect harmonisation is not possible to achieve during the lifetime of eHID. Therefore, at the end of the project, the differences between populations (countries or regions) expected to be found in the estimates shall be carefully interpreted. This short text describes a few considerations about the possible meaning of those expected differences. Let us elaborate a little on the reasons that can explain the differences expected to be found in the **estimates** of incidence and prevalence calculated for different countries / populations.

1. TRUE DIFFERENCES IN INCIDENCE AND PREVALENCE RATES

Of course, ideally, **true differences** in the rates of incidence and prevalence in the countries / populations should be the first and only explanation for the differences found in the corresponding eHID estimates. However, this explanation should only be assumed if other causes for the differences are excluded or taken into account. Such possible alternative explanations are discussed ahead.

2. PRECISION OF THE ESTIMATES

The problem
One of the aims of eHID is the comparison of estimates which will lead to report, for instance, that "prevalence of condition D is higher in England than in Spain". For this purpose, it must be recognised that the estimates are calculated on **samples** of patients and **inference** will be made for larger **populations**. Although the eHID samples are large, in general, a sampling error will exist and will be random in its nature.

The solution

Calculation of confidence intervals for the estimates will provide an assessment about how relevant sampling errors are for explaining the differences obtained in the estimates. It should be anticipated that with large samples, as those provided by the networks participating in eHID, the sampling error should not be a problem, except for estimation on sub-groups with a small number of individuals (for instance, a specific age group).

3. BIAS

The problem

Biases (systematic errors) are the most undesirable causes of differences in the estimates. Both incidence and prevalence of the conditions studied by eHID are strongly, positively, associated with **age**. **Gender** is also strongly associated with some of the conditions (ischemic heart disease and mental ilness). Therefore, differen-ces in the crude estimates of different countries / populations can possibly be explained by different age and gender structures. To avoid bias associated with age and gender com-parisons of estimates of incidence or prevalence of eHID conditions between countries / populations should be conducted after the effects of different age and gender structures are removed. A large number of **other bias** can be foreseen when data is provided by networks operating in different health systems, with different primary health care types of organisation, through GPs with differences in consultation procedures, in case definition, in diagnostic criteria, in recording relevant events, in coding procedures, etc. Such sources of possible bias can be dealt with by eHID efforts of harmonisation only to a certain extend (for instance, coding procedures). Realistically, in its lifetime, eHID will not be able to remove or even to recognise all relevant sources of bias.

The solution(s)

a. Age and gender

Use of **specific age and gender estimates** allow comparisons without the effects of these variables. However, the sample sizes for each of those specific comparisons will be smaller than the “all ages and gender” comparisons and, therefore, the precision of the estimates will be lower, confidence intervals larger, raising the question described in 2. If comparisons between countries / populations are to be made through **unique point estimates**, the effects of different age and gender structures should be dealt with by **direct standardisation** of rates (probably using the European standard population).

b. Overall validation of estimates

b.1. Inter-validation of incidence and prevalence

In eHID, estimates of both incidence and prevalence are calculated for diabetes (although not for the other two conditions). Again, differences will be found in the estimates of incidence and prevalence of diabetes for different countries / populations. The validity of the comparisons in two (or more) countries / populations could be approached by the corresponding **ratios prevalence / incidence**. In absence of other factors, it could be assumed that finding approximately the same ratio in the countries /populations under comparison would mean unbiased estimates and unbiased comparisons between populations and different ratios would mean biased estimates and comparisons. However, at least one factor, mortality, can invalidate this reasoning. In fact, for the same incidence, different "all causes" mortality rates (not only diabetes mortality rate) of diabetics in the populations under comparison will influence prevalence. If "all causes" mortality in diabetics is high, prevalence will be lower; if mortality is low prevalence will be higher. Therefore, the use of the **ratio prevalence / incidence** for assessing the unbiasedness of estimates and comparisons depends on evidence that the crude and the specific age and gender "all causes" mortality of diabetics in each country / population are similar. If differences are found in the "all causes" mortality rates of diabetics of the countries / populations under comparison, modelling the ratio prevalence / incidence adjusting it for mortality can be useful (if data on mortality of diabetics is available).

b.2 - Assessing disease frequency in different countries / populations through other sources of routine data

Validity of the incidence of diabetes and prevalence of IHD, mental illness and diabetes and of their comparisons between countries / populations can be assessed comparing measures of disease frequency obtained through other sources of routine data, namely mortality and hospital discharge statistics.

b.2.1 Mortality statistics

If eHID find differences between countries/populations it is expected that differences in the same direction will be found in the corresponding mortality statistics. This is probably true for conditions with a relevant case-fatality rate as **IHD**: countries / populations having high eHID estimates of prevalence are expected to have higher mortality rates. For **diabetes** the use of mortality statistics is less clear. In fact, a high percenta-ge of diabetics die with conditions other than diabetes and diabetes will not be reported in the death certificate, at least in a number of countries/populations. If the procedures used to ascertain, report and code causes of death *(namely diabetes)* are different between countries /populations, mortality rates will be

a poor indicator of the frequency of disease. For **mental illness**, the use of mortality statistics is, probably, not useful for assessing the validity of comparisons between countries / populations, given the very low case-fatality rate of the most important mental illnesses: the exception could be, perhaps, suicide. Even recognising the weaknesses described above, mortality should be carefully used for assessing the validity of comparisons, given the fact that national and regional statistics are readily available in most countries.

b.2.2 Hospital discharge statistics

As mortality, hospital discharge statistics are available in most countries and can be useful for the purpose of comparing countries / populations, using frequency of hospital admissions as an indicator of disease frequency. In general, hospital discharge statistics include not only the main cause for admission but also the conditions or episodes that occurred or were relevant during hospital stay. Most of diabetics in Europe will not have hospital admissions directly caused by **diabetes**. However, the frequency of hospital admissions related to diabetes is expected to be higher in countries / populations with high incidence and prevalence than in those with a low frequency of disease. It should be stressed that in a hospital setting, diabetes can be recognised not only by its acute complications but also by procedures related with its late effects (amputations, haemodialysis, kidney transplant, etc). The validity of differences in eHID comparisons of **IHD** prevalence between countries / populations can be approached by assessing differences in hospital discharge statistics associated with IHD (acute myocardial infarction, unstable angina, coronary surgery, etc). As for mortality, validity of eHID comparisons for **mental illnesses** is difficult to be assessed by hospital discharge statistics, given the low percentage of patients needing hospital admission and possible large differences in admission policies between countries. However, some causes of admission should be tried (suicide attempt, severe depression, etc). Certainly, differences in characteristics of health systems and hospital admission policies will make debatable, in general, the use of hospital discharge statistics to validate differences of eHID estimates between countries / populations.

b.3 - Integrated assessment of validity of eHID estimates for comparisons between countries / populations

Probably, none of the methods and sources of data described before provide, by itself, adequate ways for validating eHID estimates and comparisons between countries / populations for the diseases under study. Nevertheless, both mortality and hospital discharge statistics, as well as relationships between incidence and prevalence (for diabetes) should be used, whenever possible. If their results are inconsistent with each other

they cannot contribute to validate eHID comparisons between countries /populations. Otherwise, if those sources provide results consistent with each other and with the eHID comparisons, they can be important arguments in order to consider that comparisons are valid.

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Conclusions

Comparison of eHID estimates of diabetes, IHD and mental illness frequencies between countries / population covered by participating networks is one main objectives of the project. As described above, there is a large potential for bias to affect those comparisons. Many of these biases cannot be specifically confirmed or dealt with, one by one, during eHID lifetime. Therefore, validation of comparisons between countries / populations should be attempted, not only using internal estimates provided by eHID, but also using national and regional figures obtained from routine sources like **mortality** and **hospital discharge statistics**, readily available in most countries.

Appendix 3: PORTUGAL REPORT

SHORT REPORT ON PORTUGUESE COLLABORATION AS A SECONDARY PARTNER IN THE E-HID PROJECT

1- The situation of the GPs in Portugal related with electronic medical records

In 2005 I contacted GPs in several Portuguese health centres throughout the whole country trying to understand the situation related with the use of any kinds of software in health centres for a continuous and routine record of the information on their patients. I understood that most of the GP did not have PC on their desks at that time and consequently they were not using electronic medical records in their consultations. The records were, in general, on paper.

2- An opportunity for a development of the Portuguese collaboration en e-hid project

Nevertheless, I was told that software called SAM (help service to the GP) was being installed by the Regional Health Administrations of Portugal in every health centre, which could be very convenient for the e-hid project.
By the end of 2005 more than 50 Health Centres of Portugal had already SAM installed (about 15% of the Portuguese Health Centres, most of them in the north region of Portugal).

SAM has been developed only for prescription and administrative purposes; to participate in the e-hid project we needed more, we needed questions that could be useful for epidemiological purposes. As GPs were asking for the development of a statistic module, and SAM was going to be modified with this objective, I thought that it could be the moment to include other items/questions to answer to the e-hid project, such as the record of the first ever case of some diseases, etc. I talked with those in charge with the SAM development in order to ask them if that would be possible, and the answer has been affirmative. And I started to wait for a contact on this subject.

3- A change in the Portuguese political situation

At this time, the regional health administrations were willing to install SAM in every health centre in Portugal, which could be very useful for the e-HID project. So, we have been in contact with the institute responsible for SAM development, but meanwhile the political situation has changed, that institute

has been extinguished, the SAM development has stopped and we heard that it will be not be installed in any other health centres. That's why I've agreed with the project leaders of the e-hid project we should discontinue the Portuguese collaboration as a partner.

4- A new opportunity in the near future

Recently at the end of 2006 we heard again about SAM and that it will be finally developed. Anyway, it will not be useful any more for the participation of Portugal in the e-hid project, which will be ended in 2007.

Lisbon, 12/02/07

Isabel Marinho Falcão

Appendix 4: DATA RETURNS FROM THE PARTICIPANT NETWORKS FOR 2004 AND 2005

	COUNTRY									
	Belgium	Catalonia	Denmark	England-WRS	England-Qres	France	Italy	Malta	Nether-lands	Portugal
Incidence of Diabetes										
2004	✔			✔	✔	✔	✔	✔	✔	
2005	✔	✔		✔	✔	✔	✔	✔	✔	
Prevalence of Diabetes										
2004	✔	✔		✔	✔	✔	✔	✔	✔	
2005	✔	✔	✔	✔	✔	✔	✔	✔	✔	
Incidence of IHD										
2004	✔			✔	✔	✔	✔	✔	✔	
2005	✔			✔		✔	✔	✔	✔	
Prevalence of IHD										
2004	✔	✔		✔	✔	✔	✔	✔	✔	
2005	✔	✔	✔	✔		✔	✔	✔	✔	
Prevalence of all doctor assessed mental illness										
2004	✔	✔		✔		✔			✔	
2005	✔	✔	✔	✔		✔			✔	
Prevalence of Dementia										
2004	✔	✔		✔		✔	✔		✔	
2005	✔	✔	✔	✔		✔	✔		✔	
Prevalence of Schizophrenia										
2004	✔	✔		✔		✔	✔		✔	
2005	✔	✔	✔	✔		✔	✔		✔	
Prevalence of affective psychoses										
2004	✔	✔		✔		✔	✔	✔	✔	
2005	✔	✔	✔	✔		✔	✔	✔	✔	

Appendix Table 1: The return of usable data by country and eHID indicator, in 2004 and 2005 [NOTE: Denmark's data only contained prevalence for four months in 2005]

	Diabetes Incidence			Diabetes Prevalence			IHD Incidence			IHD Prevalence		
Age bands	M	F	M&F	M	F	M&F	M	F	M&F	M	F	M&F
15-24	0.53	0.76	0.64	1.24	2.87	2.02	0.53	0.76	0.64	0.18	0.00	0.09
25-44	1.03	1.51	1.26	6.47	8.82	7.60	1.03	1.51	1.26	1.54	0.24	0.92
45-64	5.19	4.67	4.94	47.62	31.03	39.66	5.19	4.67	4.94	37.65	12.36	25.51
65-74	9.85	8.89	9.36	99.23	96.17	97.66	9.85	8.89	9.36	136.47	71.56	103.16
75+	7.31	8.80	8.20	112.09	131.86	123.91	7.31	8.80	8.20	221.75	150.08	178.89
Total adults	3.25	3.61	3.93	32.48	35.10	38.83	3.25	3.61	3.93	39.31	26.91	38.30
	All Mental Illness Prevalence			Dementia Prevalence			Schizophrenia Prevalence			Affective Psychosis Prevalence		
Age bands	M	F	M&F	M	F	M&F	M	F	M&F	M	F	M&F
15-24	10.79	19.31	14.88	0.00	0.00	0.00	0.35	0.57	0.46	4.95	9.56	7.17
25-44	15.37	34.65	24.64	0.07	0.08	0.08	0.66	0.79	0.73	9.78	21.54	15.43
45-64	14.84	26.88	20.62	0.56	0.69	0.62	0.40	0.61	0.50	10.85	20.31	15.39
65-74	12.97	23.25	18.25	3.12	7.98	5.61	0.48	1.82	1.17	9.13	14.31	11.70
75+	18.58	28.46	24.49	39.29	46.27	42.24	0.91	3.48	2.45	6.70	12.08	9.92
Total adults	13.37	24.93	21.31	3.29	6.09	5.26	0.54	1.16	0.85	7.86	15.34	13.28

Appendix Table: 2004 data supplied by national network: Belgium

	Diabetes Incidence			Diabetes Prevalence			IHD Incidence			IHD Prevalence		
Age bands	M	F	M&F	M	F	M&F	M	F	M&F	M	F	M&F
15-24				2.36	1.94	2.15				0.04	0.00	0.02
25-44				7.13	5.78	6.51				0.82	0.32	0.59
45-64				73.88	51.61	62.80				23.78	6.18	15.02
65-74				175.99	153.99	164.46				69.38	27.85	47.63
75+				179.23	168.61	172.64				100.05	52.96	70.82
Total adults				49.93	50.33	50.13				19.39	10.62	15.05
	All Mental Illness Prevalence			Dementia Prevalence			Schizophrenia Prevalence			Affective Psychosis Prevalence		
Age bands	M	F	M&F	M	F	M&F	M	F	M&F	M	F	M&F
15-24	113.05	125.50	119.21	0.00	0.00	0.00	1.41	0.72	1.07	0.79	1.64	1.21
25-44	196.27	215.05	204.92	0.01	0.01	0.03	3.96	2.25	3.17	2.25	6.37	4.15
45-64	266.59	246.44	256.56	0.73	0.41	0.65	4.34	2.94	3.64	4.13	15.87	9.97
65-74	242.49	192.15	216.12	4.23	6.99	5.65	2.56	3.20	2.90	4.42	16.84	10.92
75+	155.38	166.70	162.40	24.61	39.45	41.84	1.83	2.19	2.05	4.19	15.42	11.16
Total adults	204.19	203.45	203.83	2.30	5.45	3.86	3.45	2.31	2.88	2.86	10.24	6.52

Appendix Table: 2004 data supplied by national network: Catalonia (Spain)

	Diabetes Incidence			Diabetes Prevalence			IHD Incidence			IHD Prevalence		
Age bands	M	F	M&F	M	F	M&F	M	F	M&F	M	F	M&F
15-24	0.31	0.59	0.45	3.77	4.44	4.09	0.02	0.01	0.02	0.12	0.13	0.12
25-44	1.27	1.61	1.43	11.29	11.14	11.22	0.67	0.30	0.49	3.06	1.34	2.23
45-64	6.75	4.67	5.73	50.93	35.31	43.27	6.21	3.36	4.81	56.18	26.53	41.64
65-74	13.07	10.37	11.67	119.44	88.68	103.52	15.18	9.45	12.21	196.42	110.60	152.01
75+	10.20	8.73	9.29	117.91	87.39	99.12	16.80	13.27	14.63	265.21	190.72	219.34
Total adults	4.05	3.64	4.51	42.42	35.63	39.00	4.28	3.23	4.47	50.60	37.90	52.62
	All Mental Illness Prevalence			Dementia Prevalence			Schizophrenia Prevalence			Affective Psychosis Prevalence		
Age bands	M	F	M&F	M	F	M&F	M	F	M&F	M	F	M&F
15-24												
25-44												
45-64												
65-74												
75+												
Total adults												

Appendix Table: 2004 data supplied by national network: England QRES

	Diabetes Incidence			Diabetes Prevalence			IHD Incidence			IHD Prevalence		
Age bands	M	F	M&F	M	F	M&F	M	F	M&F	M	F	M&F
15-24	0.36	0.36	0.36	4.30	2.60	3.44	0.00	0.00	0.00	0.00	0.00	0.00
25-44	1.52	1.11	1.32	9.70	7.20	8.47	0.35	0.08	0.22	1.60	0.40	1.02
45-64	5.80	4.03	4.92	45.80	31.00	38.48	3.58	1.63	2.62	33.70	13.40	23.65
65-74	10.77	7.58	9.10	105.90	79.90	92.19	6.37	4.66	5.47	115.20	57.50	84.79
75+	10.13	7.77	8.67	107.00	80.50	90.59	8.76	6.97	7.65	161.10	104.10	125.84
Total adults	3.41	2.70	3.68	35.34	23.60	31.78	1.99	1.43	2.08	26.20	17.00	26.31
	All Mental Illness Prevalence			Dementia Prevalence			Schizophrenia Prevalence			Affective Psychosis Prevalence		
Age bands	M	F	M&F	M	F	M&F	M	F	M&F	M	F	M&F
15-24	52.60	91.18	71.74	0.00	0.00	0.00	1.60	0.28	0.94	1.60	3.70	2.64
25-44	78.09	127.30	102.35	0.00	0.00	0.00	3.40	1.38	2.41	5.60	11.10	8.31
45-64	88.79	122.89	105.67	0.21	0.20	0.20	2.80	2.31	2.56	6.49	12.60	9.51
65-74	82.87	99.73	91.76	1.67	2.80	2.26	1.90	3.20	2.59	4.94	10.01	7.61
75+	103.95	139.59	126.00	17.43	25.00	22.12	1.90	2.50	2.26	6.36	10.27	8.78
Total adults	68.97	100.63	99.62	1.10	2.40	2.14	2.20	1.48	2.23	4.26	8.47	7.78

Appendix Table: 2004 data supplied by national network: England WRS

	Diabetes Incidence			Diabetes Prevalence			IHD Incidence			IHD Prevalence		
Age bands	M	F	M&F	M	F	M&F	M	F	M&F	M	F	M&F
15-24	0.32	0.25	0.28	2.21	1.53	1.82	0.00	0.00	0.00	0.00	0.00	0.00
25-44	1.30	1.33	1.32	7.35	6.35	6.79	0.61	0.13	0.35	2.22	0.51	1.28
45-64	8.25	4.13	6.07	69.32	36.87	52.21	2.66	0.95	1.80	35.66	6.88	20.60
65-74	10.57	10.17	10.33	151.65	98.65	123.42	4.97	3.57	4.22	102.24	35.45	66.66
75+	10.68	4.77	6.97	132.52	91.39	106.78	7.12	5.97	6.38	169.70	112.62	133.62
Total adults	3.61	2.45	3.73	35.98	24.40	37.33	1.51	0.97	1.54	25.12	13.07	23.45
	All Mental Illness Prevalence			Dementia Prevalence			Schizophrenia Prevalence			Affective Psychosis Prevalence		
Age bands	M	F	M&F	M	F	M&F	M	F	M&F	M	F	M&F
15-24	89.00	132.72	112.67	0.00	0.00	0.00	0.32	0.00	0.14	9.61	22.88	16.89
25-44	182.12	210.27	197.41	0.08	0.00	0.03	0.46	0.06	0.24	29.33	62.95	47.75
45-64	220.39	270.84	246.74	0.57	0.09	0.31	0.19	0.09	0.13	48.46	103.15	77.17
65-74	213.18	266.28	241.16	5.28	3.85	4.51	0.00	0.00	0.00	41.95	89.04	66.80
75+	225.87	331.42	291.86	25.32	41.99	35.59	0.00	0.00	0.00	61.31	107.85	90.17
Total adults	147.18	191.81	207.79	1.90	3.62	3.53	0.22	0.04	0.15	27.24	59.90	55.71

Appendix Table: 2004 data supplied by national network: France

	Diabetes Incidence			Diabetes Prevalence			IHD Incidence			IHD Prevalence		
Age bands	M	F	M&F	M	F	M&F	M	F	M&F	M	F	M&F
15-24	0.30	0.12	0.21	3.16	5.00	4.06	0.04	0.04	0.04	0.53	0.64	0.58
25-44	1.09	0.82	0.96	10.39	10.46	10.43	0.39	0.23	0.31	3.88	2.19	3.02
45-64	7.46	4.47	5.93	87.44	58.12	72.44	4.98	1.74	3.33	57.43	25.84	41.27
65-74	11.26	8.70	9.87	191.37	148.95	168.40	10.40	6.11	8.08	166.57	104.75	133.09
75+	8.64	8.48	8.54	182.62	173.02	176.60	12.23	8.59	9.95	265.61	220.33	237.16
Total adults	4.88	3.92	4.37	71.18	64.96	67.90	4.09	2.62	3.31	62.55	54.02	59.06
	All Mental Illness Prevalence			Dementia Prevalence			Schizophrenia Prevalence			Affective Psychosis Prevalence		
Age bands	M	F	M&F	M	F	M&F	M	F	M&F	M	F	M&F
15-24				0.00	0.00	0.00	0.49	0.20	0.35	0.79	0.56	0.68
25-44				0.00	0.05	0.02	3.08	1.55	2.30	1.68	1.68	1.68
45-64				0.30	0.30	0.29	2.23	2.22	2.22	2.03	3.51	2.79
65-74				3.30	4.20	3.44	1.57	2.16	1.89	2.24	3.52	2.93
75+				25.98	68.51	35.25	1.29	1.12	1.18	1.84	3.06	2.61
Total adults				2.94	7.13	4.93	2.15	1.62	1.87	1.70	2.53	2.17

Appendix Table: 2004 data supplied by national network: Italy

	Diabetes Incidence			Diabetes Prevalence			IHD Incidence			IHD Prevalence		
Age bands	M	F	M&F	M	F	M&F	M	F	M&F	M	F	M&F
15-24	0.00	0.00	0.00	2.66	0.00	1.09	0.00	0.00	0.00	0.00	0.00	0.00
25-44	2.48	4.77	3.77	18.56	11.47	14.55	3.71	0.00	1.62	3.71	0.95	2.16
45-64	22.56	12.10	16.46	95.86	64.60	77.59	7.52	5.38	6.27	35.71	21.51	27.43
65-74	20.20	25.32	23.35	222.22	234.18	229.57	20.20	18.99	19.46	161.62	44.30	89.49
75+	67.80	28.85	42.94	220.34	163.46	184.05	0.00	28.85	18.40	118.64	86.54	98.16
Total adults	7.96	6.35	9.18	39.04	34.80	48.37	3.41	3.02	4.25	17.05	9.97	17.47
	All Mental Illness Prevalence			Dementia Prevalence			Schizophrenia Prevalence			Affective Psychosis Prevalence		
Age bands	M	F	M&F	M	F	M&F	M	F	M&F	M	F	M&F
15-24										5.32	24.16	16.41
25-44										25.99	64.89	47.95
45-64										54.51	65.86	61.13
65-74										50.51	113.92	89.49
75+										169.49	115.38	134.97
Total adults										49.48	61.73	50.83

Appendix Table: 2004 data supplied by national network: Malta

	Diabetes Incidence			Diabetes Prevalence			IHD Incidence			IHD Prevalence		
Age bands	M	F	M&F	M	F	M&F	M	F	M&F	M	F	M&F
15-24	0.25	0.40	0.32	2.31	2.14	2.22	0.00	0.00	0.00	0.00	0.00	0.00
25-44	1.67	1.50	1.59	7.97	7.38	7.68	1.06	0.30	0.69	3.30	1.13	2.24
45-64	8.07	6.27	7.20	57.87	46.54	52.36	7.45	4.04	5.79	35.88	15.64	26.04
65-74	14.01	17.87	16.06	126.25	133.31	129.99	17.55	12.01	14.61	107.62	57.99	81.31
75+	14.74	17.11	16.23	135.15	162.37	152.26	21.98	18.14	19.57	142.14	101.02	116.28
Total adults	4.24	4.63	5.37	32.06	35.29	40.98	4.35	3.23	4.64	23.40	15.49	23.77
	All Mental Illness Prevalence			Dementia Prevalence			Schizophrenia Prevalence			Affective Psychosis Prevalence		
Age bands	M	F	M&F	M	F	M&F	M	F	M&F	M	F	M&F
15-24	19.05	40.26	29.87	0.00	0.00	0.00	1.65	1.03	1.33	5.85	17.64	11.87
25-44	37.12	72.05	54.22	0.00	0.00	0.00	2.15	1.70	1.93	16.56	36.61	26.38
45-64	46.64	76.00	60.90	0.23	0.25	0.24	1.95	2.02	1.98	25.31	46.21	35.46
65-74	35.41	63.99	50.56	2.93	3.27	3.11	1.08	2.18	1.66	20.02	39.30	30.24
75+	64.70	89.81	80.49	21.98	24.78	23.74	2.75	3.24	3.06	27.73	45.57	38.95
Total adults	32.43	57.54	53.99	1.15	2.01	1.94	1.77	1.62	1.91	15.18	30.95	28.14

Appendix Table: 2004 data supplied by national network: Netherlands

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LIST OF ABBREVIATIONS

Dak-E	Den Almenmedicinske Kvalitets Enhed
DCR	Dictionary of Consultation Results
EC	European Commission
eHID	Electronic Health Indicator Data
EMR	Electronic medical record
EUPHA	European Public Health Association
F	First ever (episode)
GP	General Practitioner in UK, family doctor in Europe
ICD	International Classification of Disease
ICPC	International Classification of Primary Care
IHD	Ischaemic Heart Disease
LINH	Landelijk Informatie Network Huisartsbezorg
N	New (episode)
NHS	National Health Service
NIVEL	Nederlands instituut voor onderzoeg van de gezondheidszorg
O	ongoing consultation
OECD	Overseas Economic Development Council
OMG	Observatoire de la Médecine Générale
QRes	QRESEARCH
READ	Coding system used throughout the UK
SAPC	Society of Academics in Primary Care
SOAP	symptoms, observations, assessment and plan
UK	United Kingdom
WHO	World Health Organisation
WONCA	World organisation of family doctors
WRS	Weekly Returns Service
XIIAP	Xarxa d'Investigadors Informatitzats en Atenció Primàri