Health Information systems: International lessons

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Executive summary

At present Ireland lacks really effective and usable health information systems.

The priorities listed in the draft ‘Information for Action’ report cannot be realised within the constraints of the existing systems. Our health information systems are not people centred; they do not facilitate assessment of quality; they make measurement of equity very hard; they do not support an adequate level of democratic or political accountability.

The current systems lack credibility with health service staff, at least partly because they seldom see any results from them. There is no adequate system for analysis of and reporting on most of the current Irish health information systems.

Despite these problems, components of our systems work well, and produce data of high quality. The Irish Cancer registry provides accurate, timely reports on cancer incidence in Ireland. The National Disease surveillance Centre does excellent work on the collection analysis and dissemination of infectious disease data. The quality of the data collected in the HIPE system by ESRI, and in the Vital Statistics system by the CSO are good. The national disability register works well. It is imperative that the existing systems are not broken in the attempt to bring in new systems.

There are many different models in Europe and elsewhere of working health information systems. We would particularly suggest that elements of the systems used in New Zealand, Finland, Scotland and Canada could provide models for further development in Ireland.

Specifically, New Zealand has a working model of an e-health Internet; Finland has a good model of a registry based system; Canada has a working model of systems using and analysing health data. Scotland has a very interesting system, with very close integration with primary care. This is a weakness of the Canadian, and especially the Finnish systems.

Devising a system based on the best elements of these systems would produce a very powerful tool indeed. It is also worth noting that such a system might lead to substantial opportunities for Irish IT companies here and abroad.

Key recommendations

Political support is a prerequisite for the establishment of effective health information systems. Unless there is a clear understanding and agreement amongst senior politicians and senior managers of the benefits and need for these systems, they will not be effective.

New health information systems must be adequately resourced. Present levels of funding are insufficient. Inadequately funded systems will not produce useful results.

A decision needs to be taken about the introduction of personal health identifiers and geocoding. We would strongly recommend that such systems be adopted in Ireland. In our view, postcodes on the UK model are not an appropriate solution for Irish geocoding. The Finnish approach of a register of addresses is more suitable for a small country.

The new systems must have clear guidelines on confidentiality, with explicit procedures for data use within the health service and data release outside the service, whether for research purposes, or for other reasons. New legislation will probably be needed.

It is imperative that new systems are built around the existing working systems. It is not acceptable to break existing systems in the hope of making a transition to better systems in the future.

At present investigating an urgent environmental public health concern, or a major health service problem would take several years and could cost several million pounds. This money would be better spent on building working systems now.

We propose that two projects, likely to produce rapid results, should be funded quickly. These are making the existing routine data available over the Internet, on the model of the WHO HFA databases; and preparing some simple analytical reports using the HIPE, birth and death data.

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Recommendations

Ireland now has a tremendous opportunity to introduce and develop a modrern health information system, and possibly a working health informatics system. There are many different models of good practice, and regrettably, almost as many different models of bad practice in the countries which we studied.

DATA USAGE

A recurrent theme is that data are collected, and kept in splendid isolation. Many motives, proprietorial interest, concerns about confidentiality, technical difficulties, political animosities and inter-organisational rivalries, perpetuate this unfortunate situation.

A strong view expressed by some Irish health information people is fear – specifically fear that their information will be misused, if it is released. There seems to be a strong concern that data released will be misinterpreted. While this fear is understandable, it is our view that education of potential users of this information is the way forward. Experience in other countries suggests that this is feasible.

To be of usable quality data must be used. There is a striking Irish example of this in the HIPE system, which achieved acceptable levels of completeness and quality only after it became a factor in hospital funding.

DATA COLLECTION

However use alone does not make acceptable quality data. The British Registrar-General in the early 1920's, John Stephenson, said 'you must always remember that the figures come from the Parish Clerk, and he, well, he just puts down whatever he likes'. This describes, far too accurately, many pieces of routinely collected data today.

What is needed is a way to involve those recording the data, and to motivate them more effectively. Experience in many countries would suggest that people will record data which is of use to them in their work. The best way of ensuring this is to have a proper health informatics structure in place.

Data should be entered once, as close to the point of patient contact as possible. This was a guiding principle of the New Zealand system. Work in London maternity hospitals found that in some systems patient information was recorded four times for each admission. Besides the waste of time and resources, such systems invite error.

Pending the development of better systems, what can be done quickly, is to ensure that those who collect the data get something back. This may be as simple as a timely report. The report should be relevant to those doing the data collection, whether these be doctors, nurse, midwives, coding clerks, or managers.

DATA CONTENT

We would strongly urge that there should be a unique health service identifier, used throughout the system. This should be given out at birth. It should be used for registration of births and deaths, and for all health service contacts. There are wider issues, which we will not discuss, about the use of such an identifier in other situations. In some countries such multiple use systems work very well, in other countries health service only identifiers are the norm.

From a purely health service perspective it makes little difference, as long as the numbers are unique, and permit linkage of events. Note that the use of such numbers can solve many problems in health service manpower planning as well.

We also recommend the introduction of geocoding for all health service facilites, and for all patients. We advise against postcoding, or any address based system. Irish postal addresses outside cities, have a high degree of ambiguity. For An Post this is resolved easily enough by experienced local staff. The health service does not have access to this level of expertise. Instead we recommend a linkage between a register of houses, and a register of people on the Finnish model. This greatly simplifies an otherwise very difficult task.

Coding systems used should be appropriate to the needs at hand, and to the skills of the coders. Reliability of coding is paramount, and we urge the development of abbreviated code lists. This is especially critical if ICD-10 is used. We would recommend an urgent evaluation of primary care coding systems, including Read codes.

DATA COLLECTION SYSTEMS

At present there are three main national data collection systems in Ireland. These are the registration of births, stillbirths and deaths; the Hospital Inpatient Enquiry system which covers discharges from public hospitals; individual Child Health systems in each Health Board. There are quite a few other disease registers, including at least the national Cancer Registry, two sub-national Cerebral Palsy registers, a national Cardiac Surgery register, a national Disability register and a two sub-national register of Congenital Anomalies.

We advise that a single body should be established to deal with Health Information in Ireland. This should **not** take over the functions of all of the other systems. Rather it should have three specific roles –

- monitoring data quality of existing systems;
- making data available very quickly from the existing routine systems;

- preparing reports and analyses on some of the existing systems.

If the existing systems are unable to meet this requirement of timeliness they should be phased out and replaced. Note that the existing systems have an important role in providing definitive and final results. In the nature of things this can take a long time. This function should be maintained.

A significant practical issue is how to deal with problems like late registrations, changes of diagnosis, and deaths abroad. We recommend that the mortality database should be live, that is to say that it should be possible to add new information to entries at any time. For coroners' cases we recommend that the fact of death be entered immediately, and further details of causes should be added as these become available. Deaths of Irish citizens abroad should probably be registered here if they were usually resident in Ireland at the time of death.

LEGAL ISSUES

There is a project underway in the Department of Health and Children to review legal issues surrounding health information in these countries. Pending the conclusions of that work we tentatively suggest that new legislation will be required. We suggest the introduction of a new act covering registration of births, deaths and marriages, collection of health data from primary care, hospitals and other locations, the use of personal identifiers and geocoding. The act should provide for a transparent system of data collection, and data use, with appropriate protection for privacy.

IMPLEMENTATION

In our view the implementation of these proposals is urgent. We would recommend the establishment of a small group to drive forwards this agenda, with a larger consultative group representing the major stakeholders. We realise that the full implementation of this set of proposals would take some time.

Areas where rapid results could be obtained would include a specific project to make HIPE and perinatal data more readily available, and making birth and death data available over the Internet. There are several existing tools, notably from WHO which could accomplish this goal at minimal cost.

A second task, which could also produce rapid results, would be to prepare a series of analytical reports on HIPE, on Irish mortality and birth data, and on he perinatal data.

TECHNICAL ISSUES

Technical objections are often raised. Experience suggests that many commercial information systems are of very low quality. At a minimum, all systems should be able to produce individual records, and complete files of records, in a well defined text format.

International XML based standards exist for many components of the health record. We draw particular attention to the New Zealand system, and the GEHR record system. Systems capable of producing records in such formats can usually be made to interoperate at a reasonable cost.

Modern computer systems, if designed well, are far more secure than paper based systems. Technical advances in secure data transmission, especially in cryptographically secured VPN facilities like SSH, can provide very high levels of security. We recommend ‘Secrets and Lies’ by Bruce Schneier as a very good non-technical introduction to the real issues in computer security.

Methods

We secured a tender to carry out this work from the Irish Department of Health and Children in early September 2001. The report was completed by the end of September 2001.

We used two main sources of information. We obtained copies of relevant documents form agencies already known to us, and we sought out information on health information agencies in each of the countries over the World-Wide-Web. We interviewed by telephone, e-mail or in person, key informants from each of the countries studied. These interviews were the most important and useful part of our work, and it is from these that we have some understanding of how these different systems operate in practice.

We also e-mailed a questionnaire to several internet mailing lists used by epidemiologists and biostatisticians, namely the allstat mailing list in the UK, the epidemio-L and injury-L mailing lists in the United States. Although we are grateful to those who replied, too few replied to form a useful component of our investigation.

A resource of inestimable value for our work was the series of reports on Health Systems in Transition prepared for the European region of the World Health Organisation (WHO).

http://www.who.dk/country/country.htm

These are a series of reports on the history and organisation of the health services in Europe and Canada, written by experts from each country. It is not an exaggeration to say that without these reports we would not have been able to complete this project. We have quoted extensively, with permission, from these reports on the organisation of the services in each country covered by them. Regrettably, we were unable to find similar reports for Australia or New Zealand.

WHO also produce a series of health reports, available from
http://www.who.dk/country/country.htm

which we recommend. The IMF also have a useful series of links to national statistics offices at

http://dsbb.imf.org/country.htm .

These include contact details, and a brief outline of their operations.

The limits of our methods inevitably lead to limits in our results. We believe that we have identified most of the principle agencies involved at national or regional level, as specified, in each area. For each country, we have contacted local practitioners, either from public health, or from statistics bureaux, or both. By interviewing these people we have gained an appreciation of the operation of these systems.

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The authors alone are responsible for all errors of fact or interpretation in this report.

Issues

DEFINITION

A health information system is a set of tools designed to allow rapid access to timely information on the health status and use of services by a defined population. Fundamentally it is a decision support system to facilitate rapid and accurate making of decisions about health service provision for a population over some period of time.

STAKEHOLDERS

Such a system must meet the need of many different stakeholders, with divergent requirements. There has been a major exercise undertaken by the Department to clarify the needs for health services in Ireland. We give below a partial list of stakeholders with a brief outline of some of their anticipated major requirements.

MINISTERS

Ministers require timely, accurate information, both to respond to urgent political issues, and to ensure that their policies are being implemented, and being effective. They need correct, and politically and professionally defensible, analyses and interpretations of the data. These are needed as the data are released.

GENERAL PUBLIC

The general public requires access to timely accurate and understandable information, with appropriate analysis and commentary. This is a key role for any health information system. The providers of this information must be trusted, and this trust should not be compromised.

Furthermore, the public need local information, applying to their own area, and to their own local services. It is of little interest to a woman expecting a baby to know national figures, what she needs are local figures, as part of the basis for her decisions about her health and her child's health.

PATIENT INTEREST GROUPS

These require accurate and specific information to measure the need for services of particular groups, the services actually provided, and their uptake of services. They need to trust the information provided, and they need help in understanding the origins of variation in the services provided.

DEPARTMENT OF HEALTH AND CHILDREN

The Department needs accurate prompt information, equal in quality and timeliness to its financial information needs. This information must be reliable, and relevant, accompanied by pertinent analysis and commentary.

Health Boards/Authorities

Health boards need information for planning, to assess and monitor service delivery, to monitor population health, and to respond to public concerns and needs. The capacity to undertake health needs assessment and health impact assessment quickly is becoming more important.

Service providers

Above all else people providing health care need feedback. They need accurate, easily accessible information on their own activity and outcomes, and information to allow them to place these results in a broader context. Without this wider context audit activities are unbalanced, furthermore without this feedback data quality will suffer.

Researchers and Academics

They need easy access, with good rules on confidentiality, to individual level geocoded and linked data. At present, such data are very scarce in Ireland, and hence most Irish health services research and epidemiological research requires special data collections. This is slow and costly. The Scandinavian countries show what can be done with good population based routine data, while maintaining strict confidentiality.

Media

The media need reliable data with credible, prompt, timely interpretation. They need careful and meticulous explanations of technical issues, to help them present the reality of health services to their readers and viewers. They need to trust those who provide them with health service information, and the confidence to approach the data providers for clarification of technical points, obscure issues, or apparent anomalies.

International community

The Irish Government is required to provide various items of information to the European Union, to WHO and to the UN. The information required is limited, and includes data on births, deaths and notifiable infectious diseases. This is presently done by the Vital Statistics section of the CSO. With the development of the EU competency in public health the breadth of information requested is likely to increase.

Purposes

Information for what? Information for whom? These are the two key questions, which must be resolved before an information system is designed.

FINANCIAL CONTROL

The differences between the management challenges facing a typical private sector organisation and a typical health service provider are sufficiently well known. However, rigorous financial control is required in both. There are three primary reasons for this. The first is to prevent outright fraud and theft. The second is to control cash flow. The third, and the area in which most health services fail badly, is to link expenditure and results.

The first two issues fall outside our direct remit in this report, but should not be forgotten. Linking financial information and health information is a crucial part of any effective management information system for the health services.

The third area cuts to the heart of our topic. A common theme in modern management, especially for large organisations, is the timely availability of relevant information at the pint at which decisions are made. Organisations, which make decisions based on inaccurate or out-of-date information, do poorly. Information is by no means the only issue – for example decision making authority must be sufficiently devolved, and a culture of trust developed – but it is an important issue.

At present, rather few health services think in terms of matching expenditure and outcomes. Expenditure is matched to activity to some degree in most systems, including our own. This is usual in secondary care services, and common in primary care services. Note that linking expenditure and outcomes is required if health investment in health and social gain is intended to drive health expenditure.

INFORMATION FOR SERVICE USERS

There are two separate issues here. The first is access to activity and outcome information, which is the main topic of this report. In our view, this is important both for motivating data collection, and more importantly for getting service providers to act on the results.

The second issue is the use of electronic techniques for such purposes as transfer of information, access to results, booking of investigations, OPD visits and so on. It is possible to link service users electronically. Most hospitals are now developing GP access to their information systems over the web. Unfortunately each hospital is developing their own system, which forces GP's to learn to use a multiplicity of different systems. There is a need for a national decision – do we intend to have a national e-health system, with the various attendant advantages and efficiencies associated with such systems. There are working models of this type of system, in Canada, New Zealand and Finland for example.

PLANNING OF SERVICES

Needs assessment and knowledge of current activity levels are the keys places where information informs planning. At present both of these fundamental activities are too slow, too expensive, and too unreliable. Many key decisions in health service provision are made in the absence of usable and reliable data. This leads to two problems. First, the wrong decisions get made. Secondly, it is not possible to set intelligent targets to be reached as a means of monitoring the impact of specific decisions.

In these circumstances the only sensible decisions are small, incremental ones. The hope is that these small decisions will slowly lead the service somewhere useful. Irish health service managers and staff deserve better. Irish patients deserve better.

MONITORING OF SERVICE DELIVERY

The core of service delivery monitoring is of course audit, conducted locally in each service location. If this isn't working, regional and national monitoring will accomplish little. For various reasons, it is exceptionally hard to use routine data to monitor service performance. The reasons for this are technical, but essentially, it is because the main source of variation between institutions in performance is the individual mix of patients.

Having said this there is an important role for routine data in monitoring the performance of entire services, rather than individual service providers. There are a number of indicators of performance, which can be extracted from routine data. Examples include the measures of in-hospital mortality for specified conditions, and the occurrence of exceptional or sentinel events.

SURVEILLANCE OF POPULATION HEALTH

At present population health monitoring in Ireland is limited. There are a number of special surveys, and limited use is made of mortality and birth data. Cancer incidence data and infectious disease data are specifically monitored. There are also a number of well developed projects in the ERHA area. Every organisation embarking on this activity has to develop its own systems. This is inefficient, and expensive, It is also not working well.

We need, urgently, to establish tools capable of monitoring population health at a small area level, where there is a capacity to respond to identified health problems. This problem faces every health board, and each seems to be pursuing their own solution. This is probably not the right way to solve the problem.

We also need to routinely monitor our population's health at a national level. The Irish Cancer Registry and the NDSC show what could be done with reasonable resources. While the efforts of the Vital Statistics section of the CSO are commendable, they are severely under-resourced for their task. There seems to be no national monitoring of HIPE data at present. The perinatal reporting system has not produced a report since their report on 1994 births. This is not satisfactory.

ADDRESSING SPECIFIC ISSUES OF CONCERN

A key political requirement for a health information system in a modern state is the capacity to respond promptly to issues of major public concern. This is not presently possible in Ireland, as the Askeaton investigations clearly showed. It took nearly six years and several million pounds to conclude that there was no evidence of poor human health in the area. The residents of Askeaton had, we believe, a reasonable expectation of having their concerns addressed a bit faster than this. If something like the Shipman affair, or the Bristol Royal Infirmary enquiry were to take place in Ireland, our existing health information systems would be unable to respond in a reasonable timescale.

RESEARCH

In general countries with effective health information systems are able to use these systems to carry out a wide range of epidemiological, health service research and audit projects. This represents a major source of added value from such systems. For such systems to be useful for research, they must be accurate and accessible.

STRUCTURES

DATA LIFECYCLE

It is helpful to think of the ‘lifecycle’ of an item of data from the time when the event occurs, to the time when a final record of the event is placed in a data store somewhere. This approach emphasises the mutability of items of health data. It is frequently necessary to secure additional information before an event can be finalised. Critically, it is not necessary to finalise the record of an event before using it.

A data lifecycle has several distinct phases. These include occurrence, recording, abstracting, coding, querying, cleaning, and deposition. These phases may occur in different places, and in different organisations. To make this discussion concrete I shall consider the Irish Hospital Inpatients Enquiry in the light of this model.

The basic function of this system is to record the occurrence, duration and certain other attributes of hospital inpatient stays in Ireland. For the purposes of simplicity, I shall ignore the possibility of an admission, which crosses a year boundary.

A stay begins when someone is admitted as an inpatient, but only becomes an episode in the system when the person is discharged. At some time after this the hospital record is returned to the medical records department. A clerical officer is employed and specifically trained in coding and abstraction. Details for this admission are abstracted. This can be easy enough if the records are well structured, and discharge letter are uniformly structured, and up to date. The admission is then coded, by the same person who has done the abstraction.

The coded records are sent, usually monthly, to ESRI in Dublin. Here some consistency checks are done, and the record is entered on to the HIPE database. Queries can arise at any stage of abstraction, coding, and checking. The database is heavily used by the Department of Health and Children, but is otherwise little used. Limited work on data quality of the finalised database has been done, and these suggest that internal data quality is reasonably good. No external quality assessment has been published on this system.

SOURCES OF DATA

Health information is created during an encounter between a patient and someone in the health services. Traditionally this is written down in medical nursing or other professional’s records, and stored on shelves. The problems with medical records managed like this are well known, but fall outside our remit. Our concern is with an abstract of information representing the key actions or decisions in each patient encounter.

These can be captured on several levels. For example a cancer registry usually only records the initial diagnosis of cancer, and a limited subset of the information leading to that diagnosis, typically in the form of a pathology report. They record very limited treatment information, and, usually, the outcome is recorded only as alive, or dead. A birth registry might merely record the fact of birth, but most record substantially more information than this. A notable exception to this generalisation is the French birth registry. A hospital discharge register usually records dates of admission and discharge, age, sex, place of residence, a couple of diagnoses, and any major surgical procedures carried out. It would not usually record other treatments, such as radiotherapy, physiotherapy, counselling, antibiotics, etc..

DATA QUALITY ISSUES

There are two aspects to data quality – credibility and efficiency.

Put simply data sources thought, rightly or wrongly, to be of poor quality will not be believed. People will not act on suspect information. Instead of acting on anomalies shown by routine data collection, they will assume that the anomaly arises from errors in the data. They may be right, but they may not. Thus, suspect data is of limited use as a tool with which to change behaviour, alter priorities or affect policy and practice.

The second issues is that poor data quality both adds enormously to the costs of using data, and severely limits what can be done with the data. The bulk of the time required to carry out many health service research projects is spent cleaning the data, coming to terms with its problems, and working around them. This introduces an unnecessary delay, often amounting to many months, in making decisions based on facts. The costs of this to the health service, both in wasted hours of staff time, and incorrect decisions are probably very large indeed.

DATA HANDLING

There is now a body of work showing that data collected at the point of care, as part of the process of care, and which are useful to the person collecting it, are data of high quality. Unpublished work from a study carried out by us in London has shown very clearly the severe impact of unsuitable data systems on data quality in midwifery systems. Several participants in our project commented on the importance of this factor. Failure to adhere to these principles is a major cause of the failure of health information projects.

ACCESSIBILITY

Data must be accessible if it is to be used. Data which requires complex and time consuming steps to access it will not be accessed. Very often health information needs are for immediate answers to pressing and urgent questions. Many existing Irish systems require several months work before the data are usable. Clearly this is of no value whatever for many public health needs.

DIMENSIONS

The choice of items to record in a health information system can be very contentious. There has been a lively discussion in England over the last 20 years about the issues of a ‘minimum’ or ‘common’ data set for maternity services. The idea is to produce a list of items which every system will record. Organisations are intended to be free to record far more than this minimum for their own internal purposes. One of our informants said that ‘everyone can agree on the first twenty items, it’s the last two or three that people can’t agree on’. The lesson for Irish common data sets seems clear – if ever there was a case of the best being the enemy of the good it’s in the area of health information systems.

One strategy to consider is the range of dimensions which should be recorded on each category of health event. Systems with common dimensions are easier to use together than systems lacking such dimensions. There is also a strong case to be made for recording the dimensions in the same way throughout the entire system. One possible classification is given here.

TIME

The fundamental dimensions of time for health information systems are the date of occurrence of the event, and the age of the person at the time of the event. Recording these is usually unproblematic, though certain sources, for example Irish death certificates, do not permit the recording of date of birth, instead requiring age. This is usually a mistake, as age can be reconstructed from date of birth, but not vice-versa.

PLACE

Although this sounds simple enough, there are some problems affecting the recording of place. A good example in the Irish context is the registration of deaths to Irish residents occurring abroad. At present Irish people who die while abroad on holidays are not registered in the Irish death data. Some EU countries, Portugal for example, only register deaths to their own citizens occurring in their own territory. Sweden and Finland have different rules for registering deaths to non-nationals in their boundaries.

The issue here is not a technical problem, rather it is the result of a failure to carefully consider the function of a death registration system. If it was felt to be inappropriate to register deaths of Irish residents abroad, a health information system might see a need to record these events anyway.

PERSON

Again this is usually unproblematic. A striking counter-example and one which causes problems for many systems is the handling of multiple births. Many birth registration systems are baby-centred, which makes figures on deliveries hard to achieve. Some are mother centred, which pose the reverse problem. Hospital information systems are often very bad at this, for example failing to distinguish between admissions to give birth, and admissions due to being born in hospital.

EVENT

The decision as to what constitutes a codable event is often arbitrary. In different systems admissions, discharges, transfers of care between consultants and consultant contacts are all recorded as ‘hospital inpatient information’. Rather obviously, these systems will not provide comparable information.

Special issues arise in maternity services, where, usually, one person is admitted and two, or more, are discharged. There are also major variations in dealing with deaths in hospital, transfers between hospitals, and with psychiatric admissions. Admissions spanning a financial reporting period, say over the New Year, also cause problems.

In primary care, many systems only record contacts with the doctor. This can give rise to major anomalies. In the Irish system doctors play the central role. In Finland, for example, the first contact is often with the health centre nurse, and many patients receive all of their care on a given visit from nursing and other non-medical staff. Comparing GP contact rates between these two systems is likely to be misleading.

CODING

In an ideal situation, highly trained coding staff abstract the entire medical record and assign specific codes to each patient's contacts with the services. The records are complete and each item of information is unambiguously recorded.

In reality, the level of information actually recorded is very variable. Medical staff use inconsistent and confusing language. Indeed in many patient contacts no specific diagnosis is reached. This is especially common in primary care where many appropriate attendances are for ill defined conditions, for vague symptoms, or for support and reassurance.

It seems to be the general experience that routinely collected data is of little value for rare conditions, or for conditions where a high level of accuracy in diagnostic coding is required. This is why many countries have established cancer registries and registries of congenital malformations, cerebral palsy and disability.

A strong case can be made for asking people to do routine coding, for example of deaths, patient attendances and admissions to a restricted set of ICD codes. This is probably more important for ICD-10 than for ICD-9. Unfortunately, there are several different sets of abbreviated ICD codes in common use in Europe.

In some countries, notably Sweden and Finland, and in some areas of the information systems in other countries, coding is done by clinical staff at the point of patient contact. This appears to dramatically improve the quality of coding, although clinical staff require adequate support to undertake this role.

AGGREGATION

This refers to data provided not for individuals, or individual encounters with the health services, but rather counts of number of different types of health service encounter. An example would be the number of babies born to residents of each county, in 500g increments of birthweight. For many purposes, aggregated data are all that is required. This has several merits. There is little issue of confidentiality with typical aggregated data (although care is still required). The volume of data is much smaller, and it is typically easier to handle, and easier to understand.

The price however, is a loss of flexibility. It is often very difficult to use aggregated data to answer specific questions. It is typically inconvenient and slow to keep requesting new aggregations of data from the providers. The exact trade-off depends on the skills and needs of the people handling the data.

CONFIDENTIALITY

There are at least two reasons for being very careful about the issue of confidentiality. There are good legal reasons for care. The legal issues are the subject of a separate report commissioned internally within the Department, and we do not propose to address them further here. The other principal reason for being very careful about confidentiality is trust. People will not co-operate with routine data collection if those doing the collection are not trusted. Both the people providing the data, in a health system usually doctors, nurses and other health professionals, and the subjects of the data released, ordinarily patients, mothers, and families, have to trust the process. This is not primarily an issue of legal safeguards, but rather an issue of public perception. Trust must be earned, but can be very easily lost.

We would suggest openness about exactly what data is collected, and precisely what is done with it. Many countries with sophisticated health information systems have equally sophisticated rules governing the release of this information. Typically these include specific ethical review of all proposed uses of the data, and publication of the details of data releases. Many countries also release data with the unique identifiers securely encrypted, so that the recipients of the data cannot make unauthorised use of it, for example by obtaining several datasets and clandestinely linking them on the unique identifier. This is the practice in Finland Sweden and Canada.

Implementation

TIMELINESS

If health data are to be used as the basis for a health information system, they must be made available quickly. This does not prevent the bodies collecting them putting in significant effort to ensure data quality, nor does it prevent them from producing a final report, with definitive results a year or two later. However for purposes of surveillance, monitoring and planning late data are of very limited use.

ANALYSIS

A common failing of health information systems, exemplified very well by the systems in both Ireland and England, is the failure to provide any capacity for analysis of data collected. This has three very undesirable consequences.

First, the people entering the data at the point of service delivery become demotivated. From their perspective they go to a lot of trouble to prepare data, which is then ignored. The result of this is that the data quality deteriorates.

Secondly, the users of health service data realise that for crucial decisions the routinely collected data is unusable. This results in significant expenditure of resources on many small one-off surveys to answer local data requirements[*]. Comparability between areas, so important for the assessment of equity and fairness in resource allocation, becomes impossible.

Finally, policy makers are forced to make decisions and policy, on the basis of incorrect, inadequate and incomplete data. Private sector bodies in this situation go out of business rapidly. The health service continues on.

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[*] Note that this is not to decry the importance of surveys. Many important health questions can only be effectively addressed by survey work. However if routine systems can provide usable information they are usually faster, and considerably cheaper than commissioning surveys.

CODING

PURPOSE OF CODING

Health events are coded to facilitate analysis and payment. The underlying presumption is that, on average, two events allocated to the same code are roughly similar. Some coding systems, for example DRG's are explicitly aimed at resource allocation. Others, for example ICD-9, ICD-10, and Read Codes are intended to capture clinical knowledge.

RELIABILITY OF CODING

This is the probability that the same event would receive the same code if put through the system again. Note that you expect much higher reliability if you test the same coder twice, than if you put the same event through two different coders in the same office. If the coders are in different organisations, say in two different hospitals, reliability will be lower again.

There is little published research on coding reliability. What there is suggests that coders have habits, which they have often learned from previous coders doing the same job. Some of these habits are innocuous, others are very damaging. It is often possible to tell when a new coder starts in a hospital, just by examining their use of individual codes.

PRECISION OF CODING

This is a measure of the correctness of coding. As you might expect coding to coarse groupings, for example the Eurostat list of causes of death, is far more precise (and far more reliable) than coding to fine groupings. How far this matters depend on what you want to do with the coded data.

DATA ITEMS

PERSONAL IDENTIFIERS

There are two kinds of health information system. Those, like the current systems in England, the Netherlands and Ireland, in which there is no unique personal identifier, and those in which there is, for example, Canada, Sweden, Finland and many others.

The advantages of not having unique personal identifiers are twofold. It is not cheap to create and maintain a reliable system for personal identification. A system lacking such identifiers provides better protection for privacy than one which contains them.

There are many advantages of unique personal identifiers. In our view the case for unique identifiers is overwhelming. Without such identifiers it is very difficult for health information systems to respond to health crises. More importantly for routine health planning without such systems it is very hard to link health events together. The Bristol Royal Infirmary provides a good example. The main issue here was mortality post-operatively. Without a system for linking deaths to hospital admissions, the analysis would have been impossible.

GEOCODING

This is the process by which health events are allocated to places. Note that for may health events more than one place could be relevant, and this need to be carefully considered in the design of health information systems. For a typical event there are two relevant locations – the usual place of residence of the person affected, and the location at which care is provided. These are usually unproblematic to define, although coding can be hard.

In certain circumstances more than two locations might be relevant. For injury surveillance it is often essential to know either where, or in what type of place the injury occurred. For example it is often of inestimable value to be able to distinguish farm accidents, construction accidents, sports related accidents and road traffic accidents.

Use of health services by visitors to Ireland might be important. In this case the usual residence would be abroad, and the local address might be quite inappropriate. Health care received by Irish residents abroad is another issue. It might not be appropriate to record these events, but it might be.

QUALITY ASSESSMENT

As we discuss later, the quality of a data system affects two aspects of its use. The first is the ease of use. It is far easier, and far faster to use data known to be of good quality. Poor quality data demands elaborate checking, careful and difficult analyses for the impact of likely coding errors, and meticulous qualification of the results. The second, and perhaps more crucial, is credibility. People will not act on the results from routine information systems, unless they believe them

United Kingdom

THE COUNTRY

There are just over 60 million people living in the UK. The National Health Service covers all four countries. There are only modest differences in the organisation of the health services within the UK. However, health information systems are, by and large, run separately in each of the four component countries – England, Scotland, Wales, and Northern Ireland. For this reason, we will discuss the information systems in each country separately.

HEALTH SYSTEM

DEVELOPMENT

The National Health Service is the great and lasting achievement of the first post-war British Government. It is a comprehensive health service, free to users at the point of delivery for most, though not all services. The cornerstone of the service is the general practitioner system. Almost all of the UK population are registered with a GP, who serves as the primary point of contact for the health services, and in addition has a key role as the gatekeeper for access to hospital services.

ORGANISATIONAL STRUCTURE OF THE HEALTH CARE SYSTEM

The organisation of the NHS in England and Wales has undergone repeated reorganisations since the early 1980's. The Welsh service is now largely independent of the English service, and reports to the National Assembly in Wales. The Scottish service has always been quite separate, and used to report to the Secretary of State for Scotland, and now reports to the Scottish Parliament. The Northern Ireland service was always separate and reported variously to the old Northern Ireland parliament in Stormont, then to the Secretary of State for Northern Ireland, and now to the Assembly in Stormont.

HOSPITAL SERVICES

In most parts of the UK, hospitals, or more commonly, groups of hospitals are independent entities, known as Trusts. They are owned by the relevant Government. Trusts provide health care on a contract basis to various bodies. These include primary care groups, special health authorities, primary care trusts, health authorities, or health and social service boards. The detailed administrative arrangements, especially in England are very complex, and in a state of great flux at the moment. In essence health care is organised (purchased) for a given population (defined in several different ways) by groups of general practitioners, or others.

PRIMARY CARE SERVICES

Primary care and community care services are delivered by general practices, or community trusts respectively. General practices are organised approximately geographically, and community trusts more rigidly so. Community trusts deliver most psychiatric and learning disability services, as well as certain services for the elderly, child health services, and some services for people with physical disabilities.

UK-WIDE HEALTH INFORMATION SYSTEMS

NHS NUMBERS

NHS numbers are unique identifiers issued to everyone registered with an NHS GP. In practice, this is almost all of the population, including almost all residents, immigrants and asylum seekers. The system is being completely revamped at present. All births in the UK are now being allocated an NHS number. These are replacing the previous set of NHS numbers, which originated in the rationing during World War II. All UK residents registered or newly registering with an NHS general practitioner are also being allocated new NHS numbers.

The previous system was scrapped for several reasons :-

First it wasn’t possible to allocate NHS numbers at birth, which made various aspects of providing health care to newborns and newly delivered mothers very difficult.

Secondly the existing registers, maintained at Family Health Service Authority (now, in effect local authority) level were impossible to synchronize. Many people had acquired several NHS numbers over the years, and many people, especially young people did not live anywhere near where the NHS thought they did.

NHS numbers had tended to overstate local population by 3% to 40% depending on the area, and the agegroup under consideration. The principal source of difficulty was people moving between areas, and not re-registering with a GP in their new area. A heroic effort during the mid 1980’s had greatly improved their quality, but few health authorities felt confident in using FHSA registers for planning, and they tended instead to use the Census instead. This imposed significant costs on every health authority, as most had people devoted primarily to working with Census data, and doing population estimates for their area.

NHS numbers were used in most, if not all, general practices, but nowhere else. Hospitals all had their own internal numbering systems, and almost none recorded NHS numbers anywhere.

POSTCODES

Geocoding throughout the UK is done using postcodes. There are several overlapping problems in using postcodes for health administration in the UK.

To understand these it is necessary to review the origin of postcodes. They were introduced by the Royal Mail to facilitate the delivery of mail. Roughly speaking each postcode is one round for a mailman. Postcodes have no particular relation to anything else on the ground, except that they seldom cross district boundaries, and almost never cross county boundaries. However, postcode districts have no relationship to any other administrative boundary.

To make matters worse, UK, and especially English and Welsh health boundaries were defined with little regard either to existing boundaries, or to postcode boundaries. District Health authorities commonly had boundaries containing only parts of certain postcodes. Furthermore these boundaries changed frequently. This caused immense expense to anyone doing work on service planning, service utilisation or disease incidence, as very complex conversions between boundaries were required.

Finally postcodes changed quite frequently. They were redrawn, withdrawn, reissued, and sometimes extensively altered. This made it necessary to keep multiple tables converting between postcodes at various times and different administrative, political and census boundaries at various times. This provided employment for many cartographers and GIS specialists, just to keep administrative and financial systems working. It made, and makes, health surveillance very difficult.

CENSUS

The UK census is only held every 10 years. As a result UK population figures are 10 years out of date. The next set of Census results will be available in early 2003 from the Census held in April 2001. For several reasons the last census (1991) went very badly, and an enormous amount of time effort and money was spent producing reliable population estimates for the UK. These became available in 1995.
http://census.ac.uk/cdu/Datasets/1991_Census_datasets/Area_Stats/Adjusted_data/Undercount_adjusted_census_data/The_missing_millions.htm

HEALTH INFORMATION SYSTEMS

There is a lot of change in the health information systems at present, especially in England and Wales. There are many new organisations, and it has been difficult to get a clear picture of the respective roles of these bodies.

Two recent events have thrown the limits, especially of the English systems into sharp relief. Furthermore, they have given rise to great political pressure for improvement. These are the terrible case of Dr. Shipman, an English general practitioner who murdered a large number of his elderly patients, and the tragic events surrounding cardiac surgery at the Bristol Royal Infirmary. Ironically it is unlikely that even perfect information systems would have detected Dr. Shipman's activities sufficiently early, and while the excess mortality in Bristol was detectable, it could probably only have been identified after it had occurred.

England

England has just over 50 million people, the vast majority of the UK population. It is a very urbanised country, with over 80% of the population living in cities or large towns.

A general comment on English health information systems, made in slightly different terms by several people, was that everything was being collected, but that it was very hard to access information, and even harder to bring it together.

A major issue in England, but not in Wales or Scotland, is that the existing information systems have little credibility amongst health professionals. As a result, indications of problems thrown up by the routine data systems tend to be blamed on errors in data collection, rather than being indications of potentially real health service problems. Clinicians and managers lack confidence in routine systems.

For example, as part of the Bristol inquiry comparisons were done of several sources of routine data on paediatric cardiac surgery. The routine HES data were found to be of better quality than expected. By contrast, the data quality on the National Cardiac Surgery register was poor. This registry had much greater credibility amongst clinicians than HES.

In Egypt, health monitors in villages near Cairo fill in a basic chart on the health of their village each month. Every village has a consistent chart to fill in. These are gathered regionally and extensively used. One of our informants said ‘In England we have never agreed the basic charts’.

PRIMARY CARE DATA

There is no national system for collecting primary care data in England. The Royal College of General Practitioners runs a small sentinel practice system, which has mainly covered infectious diseases. There has been a national survey of GP activity every ten years, most recently in 1992. While most general practices have computers, there are several different, incompatible systems. Furthermore it is very difficult to extract health information from most of these systems.

There are at least two databases of GP data available for analysis, VAMP and the GP Research database. While these are of value for research, their use for health monitoring is very limited. There has been a lot of work on developing tools for obtaining information from practice computer systems, but so far this has not yielded many results.

The Prescription Pricing Authority collects prescriptions dispensed under the NHS, but little analytical work has been done on this system, and it is not of much use at present for health monitoring. It does contain NHS numbers, so, in principle, individual data could be linked.

HOSPITAL DATA

All finished consultant episodes (FCE) are recorded on the HES (Hospital Episode Statistics) system. Typically one hospital admission is one FCE, but cases where care of a patient is transferred from consultant to consultant would give rise to several FCE’s per admission. HES statistics are known to undercount hospital admissions. They are usually grossed up by comparison with KP70 returns – these are returns of hospital bed occupancy.

HES data are coded by coding clerks from hospital notes, and discharge letters. Clerks are trained regionally, and there is a central quality control in the NHS Clinical coding and classification Authority. This is now part of the NHS Information Authority.

PERSONAL IDENTIFIERS

The NHS number is the key identifier in primary care. It has not been used in hospitals, but this is slowly beginning to change. At present the NHS number is not recorded in HES, but this is expected to change shortly.

ORGANISATIONS

OFFICE FOR NATIONAL STATISTICS

http://www.statistics.gov.uk/

This is the UK central statistics office, formerly known as the Office of Population Census and Surveys. It acts as the central repository for death data, birth data, cancer registry data, abortion data, and the national congenital malformations registry.

In general ONS functions well. However, it has very little capacity for the analysis of health data. It does an immense amount of work cleaning and recording vital statistics records. It has not historically been able to exercise much control over the quality of the data received by it. For example the UK cancer registries were notoriously variable in quality, timeliness and completeness. This effectively prevented ONS from producing good quality national figures.

Likewise the national congenital malformation registry is known to be very incomplete, and while ONS have taken a national lead in drawing together regional registries, this process has some way to go. Birth statistics have been particularly badly affected, with maternity data only available for two-thirds of the English population of recent years.

NHSIA

http://www.nhsia.nhs.uk/def/home.asp

The NHSIA is a special health authority with a central role in the infrastructure of NHS information systems. They describe their role as follows –

We want patients to be confident that the NHS professionals caring for them have reliable and rapid access to the information needed to support their care.

We want every NHS professional to have on-line access to the latest local guidance and national evidence on treatment and the information they need to support their professional development.

We want patients and the public to have easy access to information about health and care.

Established in 1999, as a special health authority, our remit is to enable the national infrastructure for an on-line NHS with electronic health records, an electronic library of knowledge, and the convenient services that people expect from a modern NHS.

To support the seamless sharing of information we are also putting in place clinical and data information standards, which will help break down physical and geographical boundaries between organisations and enable a patient-centred approach to care.

WORK PROGRAMME

The work programme includes the following:

- Clinical Information Management Programme
  - Developing health services management tools to match resources with local health care needs.
  - Developing clinical and technical information standards, for use throughout the NHS, which are essential to make integrated information systems a reality.

THE ELECTRONIC HEALTH RECORD

Current work areas are designed to ensure continued promotion and implementation of the Electronic Patient Record throughout the NHS, including primary care, community and secondary care, and the sharing of patient information through the Electronic Health Record across communities.

ACCESS TO KNOWLEDGE

A national electronic library for health – providing on-line knowledge to support evidence based medicine and public access to health information.

NATIONAL INFRASTRUCTURE DEVELOPMENTS

Integrating patient information across the NHS:

NHSnet – the NHS's own private network.

NHS-wide Clearing Service – electronic exchange of data relating to commissioned care episodes.

NHS number – the unique identifier used to build a comprehensive record of a person's health; now being introduced for babies under 6 weeks old.

The Exeter System – core operational software for health authorities that manages GP payments, patient registrations and the national breast and cancer screening programmes.

EDUCATION TRAINING AND DEVELOPMENT

Developing information skills throughout the NHS, through education and learning tailored to suit local needs. Three programme areas will achieve the aim of working together with health information:

- Developing the right information and information management skills for the NHS.
- Finding the right help: support and guidance, problem solving, sharing, and learning across the NHS.
- Getting Education, Training and Development activities right at every level: learning to support local implementation strategies.

NHS CENTRE FOR CODING AND CLASSIFICATION

http://www.coding.nhsia.nhs.uk/

The NHS Centre for coding and Classification is the key authority on coding in the NHS. It is part of the NHSIA. It has responsibility for training and supporting coders, especially those working in the hospital system. It is the main agency doing quality control on the English HES, and provides a great deal of feedback to coders and hospital managers about the results for their own organisations.

PUBLIC HEALTH OBSERVATORIES

http://www.pho.org.uk/

Although there have been public health observatories in parts of England for many years, it is less than a year since a national network of PHO's was established. Initially conceived almost as virtual organisations, they are seen to be under-resourced for their task of monitoring health in specific areas.

They work by forming alliances between public health departments, academic departments, local authorities and others. They have a very broad remit including –

- Monitoring health and disease trends and highlighting areas for action.
- Identifying gaps in health information.
- Advising on methods for health and health inequality assessments.
- Drawing together information from different sources in new ways to improve health.
- Carrying out projects to highlight particular health issues.
- Evaluating progress by local agencies in improving health and cutting inequality.
- Looking ahead to give warning of future public health problems.

A good illustration of the breadth of their work can be seen at http://www.nwpho.org.uk/home.htm which covers the first year of the North-Western PHO.

HEALTH DEVELOPMENT AUTHORITY (HDA)

http://www.hda-online.org.uk/

The Health Development Agency (HDA) is a special health authority, working to improve the health of people and communities in England, in particular, to reduce health inequalities. In partnership with others, it gathers evidence of what works, advises on standards and develops the skills of all those working to improve people's health. It was established in April 2000. It will have a staff of approximately 120 and an estimated annual budget of £10 million.

WHY WE'VE BEEN SET UP

The establishment of the HDA was announced in the White Paper, Saving Lives, Our Healthier Nation in the summer of 1999. The White Paper aims to improve the health of everyone, particularly the worst off, taking into account the social, economic and environmental factors affecting health. The HDA's role in achieving this aim is to:

- gather evidence of what works
- advise on good practice
- support all those working to improve the public's health.

WHAT WE DO

The HDA works with key statutory and non-statutory organisations at national, regional and local level to develop and maintain:

- an accessible evidence base
- guidance on how to translate evidence into practice
- the skills of those working to improve the public's health
- the standards and tools to measure the results
- resources to help those working locally.

During its first year the HDA:

- gave advice and support for developing and implementing the NHS Plan
- developed and launched Evidence Base, the online database of evidence in public health
- released 46 publications of public health evidence and best-practice guidelines
- published and disseminated guidance for supporting the preventive aspects of the National Service Framework for Coronary Heart Disease
- advised and supported the development and implementation of the National Service Framework for older people
- developed and maintained an online public health information service comprising nine websites
- published updated smoking cessation guidelines for health professionals, followed by a series of seminars to publicize them
- continued to roll out the National Healthy School Standard so that 13,000 schools now have access to a locally accredited programme
- supported the Department of Health's sexual health strategy by carrying out consultation with young people
- reviewed Health Improvement Programmes following their first year of operation.

OUR TARGET AUDIENCE

The HDA is in business to improve the public's health, but we will do this by working with a range of organisations and agencies whose remit is health improvement - not just in the NHS but within national and local government, the voluntary and academic sectors and the private sector.

Within the NHS our audience includes directors and officers, policy makers and planners within health authorities and trusts, members of primary care teams and groups, health visitors, school nurses, midwives, health promotion specialists and public health doctors.

Within local authorities we support elected members and staff from a range of functions including health strategy, environmental health, housing, transport, anti-poverty, education, healthy cities, social services, urban regeneration, health promotion and community safety.

Within regional organisations our stakeholders include government offices for the regions, regional development agencies and regional assemblies.

Community organisations we support include community groups, voluntary groups, community development project teams and community health councils.

SAHSU

http://www.ic.ac.uk/

SAHSU was established primarily as a consequence of the Black report, into an excess of leukaemia amongst children around Sellafield. Their remit is to hold national geocoded individual level databases on health events, including births, deaths, cancer incidence and hospital admissions. These are linked with Census data, boundary data, and limited environmental data. Typically the environmental data is restricted to locations of particular types of industrial installations.

Using complex statistical models SAHSU seek evidence for excess numbers of people affected by specified illnesses close to potential sources of environmental pollution.

SAHSU has a core staff of twelve people. They are based at the Department of Epidemiology, St. Mary’s Hospital Medical School, at Imperial College in London[*].

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[*] Note that one of the authors of this report (AS) used to work at SAHSU.

Wales

Wales has a population of about 3 million people, in an area about 1/3 that of Ireland. The Welsh Health Service is organised like the rest of the NHS, but the information systems are different. The Welsh health service is undergoing great changes at present. The systems are described as ‘not yet working reasonably well’, but their usability is expected to improve greatly over the next year.

PRIMARY CARE DATA

At present there is one system covering 30 or 40 practices, about 10 to 15% of the Welsh population. Briefly individual level anonymised and unlinked data is downloaded from each practice computer, and used as a continuous health monitoring system. Data is recorded on consultations, prescriptions and referrals, Read coded, and made available for analysis. In effect this is a rather sophisticated sentinel practice system. Note that it is (deliberately) not possible to link episodes of care for an individual.

HOSPITAL DATA

The Welsh equivalent of the English HES is called the PEDW. At present it records FCE’s for each patient discharged form Welsh hospitals. Unlike the current English HES it is using the new NHS numbers, as these are introduced in Welsh hospitals. Like HES diagnoses are coded to ICD-10 by coding clerks in each hospital.

PEDW doesn’t yet cover A/E or outpatient activity. A/E is partly collected by the AWISS (see below) and PEDW is scheduled to start collecting OPD data next year.

PERSONAL IDENTIFIERS

The introduction of the new NHS numbers is much further advanced in Wales than in England. The NHS Administrative Register hold these. At present these are held for almost everyone in Wales, together with their current GP, whether they are alive or not, and their current address, including a postcode, and previous addresses.

This system makes it easy for hospitals to use the new NHS numbers, as they can readily be obtained for new patients from their name and address. As hospitals introduce new PAS systems the NHS number is coming into widespread use.

Health Solutions Wales has a facility allowing one to match datasets containing NHS numbers in house, and these are made available quickly to researchers and health authorities for their work. The NHS number is removed from the matched datasets, so assuring confidentiality.

ORGANISATIONS

WELSH CENTRE FOR HEALTH

This is a recently established body, with a remit to fulfil the role of a Public Health Observatory. This will include the preparation of regular reports, and the dissemination of health information, as well as health monitoring and surveillance. This agency will work on specific commissioned projects as well as doing routine data analyses. It will report to the National assembly and the Welsh Office.

HEALTH SOLUTIONS WALES

This is the remnant of the old Welsh Common Services Agency. This is an entity which has suffered many re-organisations, and changes in focus. At one time it had a similar remit to ISD in Scotland. At present their main focus is on collecting data. They work closely with the WCH, and the two organisations will shortly be co-located. HSW is primarily a data collection agency. It reports to the Welsh Office.

PHIE GROUP

This group consists of one public health specialist and one information specialist from each Welsh health authority, as well as people from the Cancer registry, Breast Test Wales (who also do cervical cancer screening), Health Solutions Wales and the academic public health departments. It has had as a remit the development of a public health focussed IT strategy for Wales.

WELSH IT STRATEGY

The Welsh IT strategy was published in late 1998. This was a very ambitious strategy to initiate a top-down change in the information structure of the NHS in Wales. The strategy was very focussed on technology, and paid relatively little attention to health information issues. It also paid little attention, at least in its target setting, to getting information into the hands of information providers, like medical and nursing staff. Perhaps for this reason it had little impact.

Scotland

Scotland has long had better health information systems than any other part of the United Kingdom. There seem to be two principal reasons for this. First, Scotland is considerably smaller than England, with a population of just over 5 million at the last census. Secondly the same organisation (ISD) is responsible for most aspects of health information.

Borders are also less of a practical problem in Scotland, as the Census data is available in more flexible output formats than the English and Welsh data.

PRIMARY CARE DATA

ISD produce a GP computer system called GPASS, which is in use in the majority of Scottish general practices. This forms the basis of their system of continuous morbidity recording from primary care. 75 general practices, selected to be representative of the Scottish population and using GPASS are involved in this system. It has been running for 3 years.

HOSPITAL DATA

Hospital discharge data, with linked unique identifiers, is coded by coding clerks, and collected nationally by ISD. Daycase surgery and other procedures are recorded, but outpatient care is not yet routinely collected.

PERSONAL IDENTIFIERS

The NHS number is ubiquitous throughout the Scottish health system, being used by GP's, community care providers and hospitals. This makes it easy to link Scottish health data. Social information is more limited, although postcodes can be used to get area level social data on recorded episodes of health care.

ORGANISATIONS

ISD

http://www.show.scot.nhs.uk/isd/index.htm

ISD, founded in 1965, has several distinct roles besides collecting health information. It is an executive arm of the Scottish Executive, and responsible for all national IT projects management. It has a total of 450 staff including 70 or 80 people working on the GPASS GP computer system. IT has an annual budget of about £IR 13 million.

It is also responsible for population health surveillance, which is done by public health consultants. A new Scottish Public Health Observatory has just been established, which will undertake this role.

ISD describes its role as follows –

Scotland has some of the best health service data in the world. Few other countries have information which combines high quality data, consistency, national coverage and the ability to link data to allow patient based analysis and follow up.

Health service activity, manpower and finance data are collected, validated, interpreted and disseminated by ISD. ISD receives this data from health boards, NHS trusts and general practices. The data are processed securely and in accordance with the requirements of data protection legislation. ISD is part of NHS Scotland.

ISD aims to be :

- an essential support service to NHS Scotland and Scottish Executive Health Department (SEHD)
- responsive to the needs of NHS Scotland as the delivery of health care to patients evolves
- proactive in determining and advising on how information and Information Technology can best be used to ensure efficient and effect delivery of patient care.

QUALITY ASSURANCE

ISD has an elaborate set of systems for quality assurance on its data. There is a Definitions and Quality Issues (DQI) Group within ISD, and they are responsible for:

Data Quality Assurance issues - this includes the direction and steer of the work undertaken, or planned to be undertaken, by ISD's Quality Assurance team. The DQI should advise ISD on particular areas of work, e.g. particular records types, pieces of data, areas of clinical importance, to be prioritised for QA investigation. This remit should extend to monitoring of results from QA projects, and setting quality standards and targets against which QA results can be compared in subsequent projects.

Robustness of data relevant to the purposes for which it is, or may be used. The DQI provides a focal point for data quality issues raised by any of the groups in the health service who are users of national data. Particular areas which may be addressed include, development of national data standards, monitoring and policing of adherence to national data standards, publicity of known anomalies and raising awareness of data quality within the NHSiS.

Definitions advisory process - The DQI provides a forum in which the work of the various Definitions Advisory Groups can be directed, prioritised and in particular co-ordinated with existing information strategy or other areas of national interest.

SHOW SCOTTISH HEALTH ON THE WEB

http://www.show.scot.nhs.uk/

This project, run by ISD, aims to create a health informatics infra-strucutre for Scotland. At present it has three main components – pages for professionals, pages for the general public and pages for NHS organisations.

There is a detailed discussion of the technologies and principles behind show at http://hi-europe.co.uk/files/1998_9/bridges/dev_hcis_scotland.htm . They describe their goals as follows –

As part of the CHIN project an information network is being developed for Scotland which will co-ordinate the efforts of a range of different healthcare providers. This has been given the title

Scottish Health On the Web (SHOW). The overall goal is the creation of a virtual health care library for Scotland that will enable patients to take a more active role in their own health care and provide support for professionals in a variety of ways. The current thrust of activity is aimed at involving all the key health care providers in Scotland and changing their approach to information dissemination to a strategy focused on Web-based tools. After this the content available on the network will expand steadily and become the major source of health care information in Scotland.

Most health care institutions produce a range of paper-based documents aimed at patients. This information may vary from simple patient handbook information to more detailed advice on screening on different medical conditions and their treatment, on particular surgical operations, on support groups, and so on. The problem for a patient is not merely to lay hands on such documents, but to know that they exist and where they can be found. By bringing them all together into a single virtual health care library, one creates a huge source of information that is accessible from any part of the country. Thus all the information which any patient in Scotland may require should be accessible in this information pool. An additional benefit is that institutions can easily learn from each other and are motivated to improve the information sets that they want to target at patients.

From the point of view of medical practitioners this virtual library of healthcare information also includes information aimed primarily at the professional. Hospitals already provide information directed at general practitioners, including information on changes to existing services or the introduction of new ones, laboratory handbooks, etc. Organisations focusing on specific health care problems (e.g. e-coli, cancer, heart disease, etc.) provide information targeted at the professional. Even the Management Executive of the NHS in Scotland needs a rapid channel of communication by which to reach health care professionals.

COMMUNITY HEALTH INDEX

This is the Scottish equivalent of the new NHS number initiative in England and Wales. ISD run the Community Health Index (Northern Ireland uses the same systems). This is a person level community health index. The unique identifying number is issued on registration or birth, and includes the date of birth and sex of the person. These numbers are unique within Britain. ISD are actively encouraging its use, and as NHS organisations adopt new systems it is becoming more widely used. GP’s are using it in correspondence with hospitals.

Northern Ireland

The Department of Health, Social Services and Public Safety (DHSSPS) was established by the Departments (NI) Order 1999. The Department administers Health and Personal Social Services (HPSS), including policy and legislation for hospitals, family practitioner services, community health and personal social services. They have also responsibility for public health, the Fire Authority, food safety and emergency planning.

The Department's mission is to improve the health and social wellbeing of the people of Northern Ireland. It endeavours to do so by ensuring the provision of appropriate health and social care services, both in clinical settings, hospitals and GP practices, through nursing, social work and other professional services. It also supports programmes of health promotion and education. The Department currently employs some 850 staff and the budget of the Department for the year 2000/2001 is provisionally put at £2.1 billion.

ICT STRATEGIES

A consultative document, a "vision statement" about the Information and Communications Strategy for the HPSS was published in June 2001. Briefly, the document identifies the following from the existing service:

- The existing HPSS mechanisms are slow and unwieldy, limited to a small proportion of HPSS data.
- The Unique Patient and Client identifier is an essential pre-requisite to more effective and secure information sharing and must be supported.
- The HPSS is limited in its use of ICT and is poorly resourced to meet the challenges.
- There is great potential for using tools to improve information gathering and sharing, linking services, by the use of e-information, intranets and reliable internet based-information.
- Priority must be given to improving direct care to service users.

This draft document is available in pdf format at:
http://www.dhsspsni.gov.uk/publications/index.html

However a further document, the ICT *plan* for Northern Ireland arising from this consultative draft is due to be published in approximately six weeks time (middle of November 2001). For more information about this document contact the Directorate of Information Systems, 79 Chichester Street, Belfast, BT1 4JR, tel: 048 90 542222.

USE OF HEALTH INFORMATION

THE CENTRAL HEALTH INDEX (CHI)

The Central Health Index is a computerised index of patients, who are issued a number, a system similar to the NHS number in England. The Index is maintained by the Family Practitioner Services of the CSA. In principle, it is thought to be possible to link a patient through various systems, such as the screening services, however apparently in practice this is not done. In the future Northern Ireland hopes to change the system to issue a unique patient identifier to all persons, so that their care can be linked through out the health care system.

THE CENTRAL SERVICES AGENCY (CSA)

The CSA was established in 1973, in the stead of the Northern Ireland Health Services Board, which had been in existence since 1948. The agency is an umbrella organisation and provides a wide range of services to and on behalf of the Northern Ireland Health and Social Services on a regional basis. There are seven different units in the agency:

- Finance
- Human resources
- Family practitioner Services (FPS) (see below)
- Regional Supplies Service
- Nicare
- Research and Development Office
- Legal Services

The agency is staffed by over 200 people. The CSA is one of the major sources of primary health care data for Northern Ireland. The agency does not collect morbidity data, but information is gathered mainly by analysing the reimbursements/payments for primary health care services, which includes GP services, dispensed prescriptions, certain immunisations, etc. This information is mainly collected by the Finance and FPS units. Although it is estimated that 80 – 90% of all GPs have a computer and 60% are fully computerised, most information is still sent to the agency on paper, (apart from dentistry) and the forms are subsequently coded and entered by the CSA. Dentistry is the only service that sends all of its information electronically using the CHI numbers.

Their annual report is available to download in pdf format at http://www.dis.n-i.nhs.uk

The department of General Practice of Queen’s College, Belfast is currently undertaking research in the collection of primary care morbidity data (*no further information on the project at this time).*

FAMILY PRACTITIONER SERVICES (FPS)

Family Practitioner Services is part of the CSA and provides a range of support functions to medical professionals (doctors, dentists, pharmacists) on behalf of the Health Boards. The other main functions of FPS include:

Registration of patients and updating of the Central Health Index (see below)

Processing and payment of Dental and Ophthalmic claim forms

Provision of information to Boards, the professions and the HSS Executive

Payment of doctor's fees and allowances

Processing and payment of prescription items

FPS is also responsible for the Data Preparation Department, which processes information such as pharmacists prescriptions, dental claim forms, and ophthalmic claim forms. The service maintains the Central Health Index.

RESEARCH AND DEVELOPMENT OFFICE

The Research and Development Office was established to promote co-ordinate and support research within the Northern Ireland HPSS. Its remit encompasses the research needs of the Department of Health and Social Services and all sectors of health and social care. The office has a dual role of strategically providing a direction for the HPSS and operationally supporting initiatives from education and training to direct commissioning of projects.

INFORMATION AND ANALYSIS UNIT (IAU)

The IAU is part of the Planning and Resources Group of the DHSSPS. The aim of IAU is to provide a high quality service in support of evidence-based decision making through:

- Administration of Departmental Surveys, Registries and Research Budget
- Objective statistical and economical analyses and interpretation of these and other information
- Provision of relevant, timely and accurate information on the HPSS
- Monitoring of the performance of the HPSS
- Publication/dissemination of reports

There are six areas or branches within the unit:

- Economics
- Information and Research Policy
- Support analysis
- Regional Information (see below)
- Family Practitioners Services Information and Research
- Social Services Analysis

The staff of the IAU is composed of two economists, 19 statisticians and 17 administrative staff.

REGIONAL INFORMATION BRANCH

The Regional Information Branch is part of the IAU and has responsibility for the collection, quality assurance, primary analysis and publication of timely and accurate information derived from a wide range of services supplied by the Health and Personal Social Services (HPSS). The aim of the Branch is to:

"…present information in a meaningful way and give advice on its use to customers in the health and Social Services Committee, Professional Advisory Groups and policy branches within the Department".

The main outputs of this branch are the collation and validation of information from health care facilities within the HPSS. They produce and publish reports annually covering hospital statistics (2000 – 2001 Hospital Statistics Report due out on the 27th September 2001). Data is first sent to the Central Services Agency either by floppy or electronically directly from the hospitals. The hospitals do not use all the same patient registration systems but several similar systems. The information is then analysed by this branch. They also analyse and produce reports on community activities e.g. residential facilities for children and the elderly. They also compile a quarterly waiting list bulletins. A staff of approximately 20 is based in the branch.

THE NORTHERN IRELAND STATISTICS AND RESEARCH AGENCY (NISRA)

The NISRA is Northern Ireland's official statistics organisation with responsibility for the registration of births, marriages and deaths in Northern Ireland. The agency produces the census report and also other reports on economic, social, education and other areas for Northern Ireland. It has recently produced a report on measures of social deprivation.

NORTHERN IRELAND CANCER REGISTRY

The aim of this registry is to provide accurate, timely information on cancers occurring in the population of Northern Ireland to enable research, planning and education so the burden of disease may be reduced. The information gathered is used to facilitate planning of cancer services for prevention, diagnosis, cure and care. The information they collect is used to assist professionals for audits and to promote professional and public education in cancer treatment. The registry is maintained by the Department of Epidemiology and Public Health, in Queen's University of Belfast.

NORTHERN IRELAND CEREBRAL PALSY REGISTER (NICPR)

The registry housed in Queen's University of Belfast. It's overall aim is to collect information in a standard and systemic way within a geographically defined population. The NICPR provides a unique source of information on the population of children with Cerebral Palsy including type, severity and the presence of associated impairments. The core activities of the register are:

- Case ascertainment
- Maintaining and updating the database (including flagging cases)
- Regular/annual reporting on numbers and needs for local use
- Quality control of register data
- Statistical support
- Analysis of birthweight specific trends in cerebral palsy in Northern Ireland (including type and severity)
- Establishing and maintaining links with the Child Health System to ensure
- Mutual exchange of information
- Participating in UK and European based initiatives
- Promotion of the register as a research resource in Northern Ireland

USEFUL WEBSITES

United Kingdom	
Office for National Statistics	http://www.statistics.gov.uk/
NHS Centre for Coding and Classification	http://www.coding.nhsia.nhs.uk/
List of UK electronic health links	http://www.medrecinst.com/resources/forum/europe/uk_ehr.shtml
NHS Information Authority	http://www.nhsia.nhs.uk/def/home.asp
Bristol Royal Infirmary inquiry	http://www.bristol-inquiry.org.uk/
England	
Public Health Observatories	http://www.pho.org.uk/
Health Development Authority	http://www.hda-online.org.uk/
SAHSU	http://www.ic.ac.uk/
Wales	
Welsh National Assembly (Health)	http://www.wales.gov.uk/subihealth/index.htm
NHS Wales	http://www.wales.nhs.uk/
Health Plan on-line	http://www.wales.gov.uk/healthplanonline/
Health Promotion Wales	http://www.hpw.wales.gov.uk/home.htm
Scotland	
Scottish Health on the WEB	http://www.show.scot.nhs.uk
ISD	http://www.show.scot.nhs.uk/isd/index.htm
Health information system for Scotland	http://hi-europe.co.uk/files/1998_9/bridges/dev_hcis_scotland.htm
Northern Ireland	
NISRA	http://www.nisra.gov.uk
DHSSPSNI	http://www.dhsspsni.gov.uk/iau/index.html
Northern Ireland Cancer Registry	http://quis.qub.ac.uk/nicr/nicrpg1a.htm
Central Services Agency	http://www.csa.n-i.nhs.uk/fps/index.shtml

CONTACT NUMBERS

UK

National statistics

http://www.statistics.gov.uk/themes/health_care/default.asp

Health contact number

+44 1633 812973.

Scotland

Information & Statistics Division (ISD)

Common Services Agency for NHS Scotland

Trinity Park House, South Trinity Road. Edinburgh. Scotland. EH5 3SQ

Tel :0131 551 8899 Fax: 0131 551 1392

Northern Ireland

Information and analysis unit, Belfast,

Tel: 048 90 522800

Directorate of Information Systems, Belfast,

048 90 542222

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http://www.csa.n-i.nhs.uk/fps/index.shtml

[Accessed 27th September 2001]

Canada

THE COUNTRY

Occupying the northern half of the North American continent Canada is the second largest country in the world. It has a population of 30.5 million but 60% live in urban areas and three out of four Canadians live within a 150km of its border with the USA. Therefore large tracts of the country are sparsely populated, impacting on the administration of the country, including the health care system.

CANADA'S HEALTH SYSTEM

Canada has a predominantly publicly financed, privately delivered health care system that is best described as an interlocking set of ten provincial and two territorial health insurance plans. Known to Canadians as "Medicare", the system provides access to universal, comprehensive coverage for medically necessary hospital, in-patient and out-patient physician services.

The constitution assigns jurisdiction over most aspects of health care to the provincial governments. The **Canada Health Act** (see http://www.hc-sc.gc.ca/medicare/chaover.htm) stipulates the criteria that provincial health insurance plans must meet in order for a province to qualify for its full federal transfer payments. The following five criteria are known as the "principles" of Canada's national health care system:

- Public administration (of the health insurance plan)
- Comprehensiveness
- Universality
- Accessibility
- Portability

The management and delivery of health services is the responsibility of each province or territory. Health protection, disease prevention, and health promotion are included among federal health functions.

See *Canada's Health Care System*, Health Canada 1999.

(Health Canada, 1999)

PRIVATE SECTOR

In Canada there is a single tier for insured hospital and medical services, meaning that while health care services may be delivered privately, the private sector is excluded as a payer from most health care. The private sector's role as a payer is limited to those services that are not completely covered by provincial health programmes. These include pharmaceuticals, vision care, dental care, and the services of allied health professions such as chiropractors and podiatrists.

(WHO, Europe 1996)

HEALTH INFORMATION STRATEGIES IN CANADA

In 1994 the **National Forum on Health** (NFOH) was launched to engage the public and health stakeholders in a dialogue to chart a course for the future of health and health care in Canada. Its final report ***Canada Health Action: Building on the Legacy*** was submitted to government in 1997. It concluded that a prime objective should be the rapid development of an evidence-based health system in which decisions would be made by health care providers, administrators, policy makers, patients and the public on the basis of appropriate, balanced and high-quality evidence. The NFOH also recommended the creation of a nation-wide population health information system. In response funding was announced for a national strategy for an integrated Canadian Health Information System and the Advisory Council on Health Infostructure was established.

In 1998 the Advisory Council, the Canadian Institute for Health Information (CIHI) and Statistics Canada (see below) brought together some 550 health administrators, researchers, caregivers, government officials, health advocacy groups and consumers to identify Canada's health information needs. The result of these consultations was a national vision and action plan for strengthening Canada's health information system.

Among the priorities identified was the need to

- Better track information on major current and emerging health issues
- Reach consensus on common data and technical standards to enable researchers to more easily share comparable findings and results
- Address problems of fragmented or incomplete data
- Improve the analysis of health information being captured
- More broadly disseminate health information in order to realise its potential for improving the health of Canadians and of their health care system.

In late 1998 this vision for health information was presented to, and endorsed by, the Federal, Provincial and Territorial Conference of Deputy Ministers of Health. To give expression to this vision, which subsequently became known as the **Roadmap Initiative**, the 1999 Budget identified a number of specific priority projects and activities in the health information field and earmarked $95 million over the next four years toward their completion.

The **Roadmap Initiative** comprises projects in five key areas:

- Health Resources Management Projects
- Infostructure and Technical Standards Project
- Integrated Health Services Projects
- Population Health Projects
- Reports and Indicators Project

See *Roadmap Initiative...Launching the Process*

Roadmap Initiative...Launching the Process: 2 Years Later

For more information and publications on the Roadmap Initiative see http://www.cihi.ca/Roadmap/rdindex.shtml

Canada Health Action: Building on the Legacy is available to order from

http://www.hc-sc.gc.ca/english/forum_e.htm for $210.

HEALTH INFORMATION AND COMMUNICATIONS TECHNOLOGY (ICT) STRATEGIES IN CANADA

The Government of Canada has been making financial contributions to the development of a **Canadian Health Infostructure** since the 1997 Budget, following recommendations from the Information Highway Advisory Council (established in 1994 to investigate the development and use of the information highway for the economic, cultural and social advantage of all Canadians), the Canadian Network for the Advancement of Research, Industry and Education (now CANARIE Inc., which published a vision paper describing a Canadian Health "Iway") and the National Forum on Health. The Health Infostructure is a national health information highway utilising the newest information and communications technologies (ICTs) to enhance and strengthen the Canadian health system. Developments have occurred in the context of wider developments in the establishment of a national health information system.

The Advisory Council on Health Infostructure in 1997 laid the foundations for the development of a Canadian vision of a health information system on the information highway and made recommendations regarding mechanisms to achieve this vision. (See Final Report of The Advisory Council on Health Infostructure, ***Canada Health Infoway: Paths to Better Health***).

Also in 1997 Health Canada established the Office of Health and the Information Highway (OHIH) to develop a longer term strategy regarding the Canadian Health Infostructure. It is the federal government's focal point for all infostructure-related activities.

Following on the work of the Advisory Council, the federal, provincial and territorial deputy ministers of health established an Advisory Committee on Health Infostructure to develop national strategies to enhance the utility and use of information, and information and communications technologies, in the health sector.

The Committee's working groups are actively examining issues related to the development and implementation of the Canadian Health Infostructure. The working groups are:

- Strategic Planning
- Protection of Personal Health Information
- Health Surveillance
- Electronic Health Record
- Telehealth

The Strategic Planning Working Group has developed and published a ***Blueprint and Tactical Plan for a pan-Canadian Health Infostructure*** describing the initiatives necessary for a national health technical infostructure.

In 2000, Health Canada sponsored a two and a half day conference, ***"Canada E-Health 2000: From Vision to Action",*** at which almost 400 key health stakeholders came together in Ottawa to discuss progress in developing a national infostructure and the challenges, priorities and directions for the future. Conference abstracts and presentations can be obtained from

http://www.hc-sc.gc.ca/ohih-bsi/available/conference/index_e.html

OHIH maintains an excellent web-site with further information on all of the above developments, on progress on electronic health records and telehealth and on other publications relevant to this topic. Its URL is http://www.hc-sc.gc.ca/ohih-bsi/menu_e.html.

USE OF HEALTH INFORMATION IN CANADA

HEALTH INFORMATION BODIES AT NATIONAL LEVEL

HEALTH CANADA

Health Canada is the federal ministry of health. It maintains an **internet site providing information and resources** on health care in Canada (clinical care, community health, palliative care, home care, pharmacy, health costs, health spending, health-care activities), public health in Canada (healthy living, health promotion programs, health promotion evaluation, groups at risk, health education, emergency services, internet/health infostructure, surveillance), and health factors in Canadians (specific diseases and conditions, disability, health risks, health determinants, health status).

It **provides copies on-line of policy documents and strategies** written by Health Canada **and of Acts of Parliament**, for the administration of which Health Canada is either wholly or partly responsible.

It **provides links to Health Canada's branches and bureaux** including the Population and Public Health Branch and the Information, Analysis and Connectivity Branch, both of which have significant health information responsibilities.

POPULATION AND PUBLIC HEALTH BRANCH (PPHB)

(formerly the Laboratory Centre for Disease Control and the Health Promotion Programs Branch)

PPHB is responsible for directing the implementation of policies, programs and systems relating to prevention, health promotion, **disease surveillance**, community action and disease control. This includes the monitoring and investigation of infectious and non- infectious diseases and injuries, the study of their associated risk factors, and the evaluation of related prevention and control programs.

It has the following bureaux, offices and sections:

- Bureau of Cancer

The Cancer Bureau conducts programs and develops networks for **cancer surveillance** across the life cycle of cancer, ranging from the underlying causes of and risk factors for cancer to palliative care.

Its mandate is

➢ To improve the prevention and control of cancer in Canada by providing strategic information on cancer risks, trends and control strategies.

➢ To provide national and international leadership in cancer surveillance, risk assessment and risk management.

- Bureau of Cardiorespiratory Diseases and Diabetes
- Bureau of HIV/AIDS, STD and TB
- Bureau of Infectious Diseases
- Division of Disease Surveillance

The objectives of this division are

- Maintenance of an aggregate database of reports of notifiable diseases submitted by the provinces and territories together with preparation of monthly provisional reports and the preparation of an annual summary.
- Maintenance and development of a case-by-case database of reports of notifiable diseases submitted by the provinces/territories.
- Analysis of data from aggregate and case-by-case databases and production of reports (done in collaboration with other divisions in the Bureau).
- Maintenance of the mechanism for the active surveillance of specific paediatric diseases/conditions in Canada.

- Bureau of Microbiology
- Office of Global Surveillance and Field Epidemiology
- Bureau of Reproductive & Child Health (includes injury section)
- Reproductive Health Division

This administers the **Canadian Perinatal Surveillance System (CPSS)** which is an ongoing national health surveillance program. The aim of the CPSS is to collect and analyse data on all recognised pregnancies, regardless of their outcome - abortion, ectopic pregnancy, stillbirth or live birth - and on health during the first year of life. Currently, the CPSS uses data from multiple existing sources (mainly administrative) such as national vital statistics and hospitalisation data. These data are analysed collaboratively with perinatal health surveillance partners. For more information see http://www.hc-sc.gc.ca/hpb/lcdc/brch/reprod/about_e.html

- Office of Biosafety

Surveillance activities, either in the epidemiology or laboratory fields, are carried out in collaboration with a wide range of partners from the provincial, territorial and federal levels, the academic community and numerous health related Non-Governmental Organisations (NGOs).

PPHB provides a service called ***Disease Surveillance on-line*** which provides access to the latest statistics for cancer, cardiovascular diseases and infectious diseases. This web-site contains information on methods, standardisation, data sources, limitations and guidance on interpretation of data for cancer and cardiovascular diseases.

For more information on the PPHB and its bureaux see their web-site at

http://www.hc-sc.gc.ca/pphb-dgspsp/new_e.html

(Please note that this site is currently undergoing transition from the web-site of what was the Laboratory Centre for Disease Control)

INFORMATION, ANALYSIS AND CONNECTIVITY BRANCH (IAC)

IAC brings together three key levers of the information spectrum, from the creation of knowledge and information through analytical research to the dissemination of that information through the information highway.

Its mandate is to

- Improve the analytical basis of decision-making at all levels in the department and the health system.
- Develop the long-range strategic framework and policies on the involvement of the federal government in health research policy.
- ***Develop the creative use of the information highway in the health sector***.

- Establish an integrated information management and information technology policy, strategy, plan and infrastructure for Health Canada

(Health Canada, 2001)

OFFICE OF HEALTH AND THE INFORMATION HIGHWAY

The Office of Health and the Information Highway (OHIH) is part of the IAC. It was created in the summer of 1997 as Health Canada's focal point for all matters concerning the use of information and communications technologies (ICTs) in the health sector. OHIH co-ordinates, facilitates and manages health infostructure-related activities, both within Health Canada and with external stakeholders. It promotes the development of policy in the areas of electronic health records, protection of personal health information, telehealth and facilitates the sharing of information about ICTs in health.

OHIH *invests* in the development of health infostructure initiatives through the development of cost-shared funding programs. OHIH has launched two such programs to date:

- **Health Infostructure Support Program (HISP)** (1998-2000)

Established in March 1998 HISP consists of 36 innovative projects developed by communities across Canada. Health Canada, non-governmental groups and major private-sector partners invested $22 million in HISP, which supports pilot projects to test and assess new information technologies and applications in areas such as public health, health surveillance, pharmacare, First Nations health, homecare and telehealth.

For a list of, and information on, the projects involved, see

http://www.hc-sc.gc.ca/ohih-bsi/chi_ics/inv_e.html

- **Canada Health Infostructure Partnerships Program (CHIPP)** (2000-)

CHIPP is a two-year, $80 million, shared-cost incentive program, to support the implementation of innovative applications of ICTs in the health sector. The CHIPP program is designed to encourage the development of innovative ways of improving the delivery of health care to all Canadians, including rural residents. Priority is being given to telehealth and electronic health records applications.

For more information on CHIPP see

http://www.hc-sc.gc.ca/ohih-bsi/chi_ics/inv_e.html

OHIH is *responsible for project leadership* of Health Canada's core infostructure initiatives in the development of a national system of health information in Canada:

- **Canadian Health Network (CHN)**

CHN is a national, bilingual, Internet-based network of health information providers. It provides Canadians with an accessible Internet gateway to information on healthier lifestyles, disease prevention, and self-care from respected Canadian government and non-governmental organisations in a non-commercial format. The CHN has approximately 6000 Web documents focused on 26 major health topics and population groups. A rigorous quality assurance process ensures that the health information included on CHN is:

- ✓ timely,
- ✓ relevant,
- ✓ up-to-date, and
- ✓ accessible.

See http://www.canadian-health-network.ca/customtools/homee.html .

(Canadian Health Network, 2001)

- **National Health Surveillance Infostructure (NHSI)**

NHSI is a series of pilot projects. All projects are based on the secure transfer of, or access to, information using the Internet. They provide concrete steps towards a national health surveillance network which will:

- ✓ improve access to existing databases
- ✓ facilitate the linkage of databases
- ✓ provide affordable tools for analysis and presentation of information
- ✓ provide timely access to information

A list of the pilot projects, with further information is available from

http://www.hc-sc.gc.ca/hpb/transitn/surveile.html

Building on the NHSI a **Surveillance Transition Team** has been tasked to strengthen and expand the PPHB overall surveillance capacity to support an integrated health surveillance network for public health information from the local to the global level. They brought together experiences gained from the pilot projects in the NHSI and the results of consultations held across Canada on the ***Discussion Paper on an Integrated National Health Surveillance Network for Canada*** into a new ***Proposal to Develop a Network for Health Surveillance in Canada.*** The summary document ***A Network for Health Surveillance*** in Canada and the full proposal document are available on the web-site above.

- **First Nations Health Information System (FNHIS).**

FNHIS will provide First Nations and Inuit communities with a basic set of tools for health information management comparable to those available to other jurisdictions.

See http://www.hc-sc.gc.ca/budget/english/factsht6.htm for more information.

Personnel Resources

The OHIH has a staff of 62, including 30 policy analysts and advisors. For more information on OHIH and its activities see the OHIH web-site at

http://www.hc-sc.gc.ca/ohih-bsi/menu_e.html

(OHIH, 2001)

STATISTICS CANADA, HEALTH DIVISION

In Canada, providing statistics is a federal responsibility. As Canada's central statistical agency, Statistics Canada is legislated to serve this function for the whole of Canada and for each of the provinces.

The Health Statistics Division ("HSD"), of Statistics Canada, endeavours to meet the demand for comprehensive, current information on health and health care through two major information programs: **Health & Vital Statistics Data** and **Health & Vital Statistics Studies**.

The Health & Vital Statistics Data covers the social and risk factors that influence health. Information from the census and other surveys is used to investigate how personal behaviour and characteristics such as age, sex and income relate to health. The program maintains birth, marriage, death and stillbirth data plus data on cancer incidence and tuberculosis.

The Health & Vital Statistics Studies analyse & publish analytical studies related to Vital Statistics & other Health studies.

Most of HSD's administrative health status data is, for the most part, supplied by the provinces and is transferred to various databases used in responding to information requests and as a basis for many publications.

Statistics Canada produces ***Health Indicators*** which is a data product in the form of an electronic publication in conjunction with the Canadian Institute for Health Information. This publication provides a set of indicators that measure the health of the Canadian population and the health care system. Health indicators are designed to provide comparable information at the health region and provincial/territorial level, and are based on standard definitions and methods.

It also produces a quarterly journal, ***Health Reports***, providing current and accurate information about topical health themes and vital statistics which is aimed at health professionals. They are based on data collected from more than 15 key health databases and numerous other socio-economic sources maintained by Statistics Canada.

The **Canadian Cancer Registry** is maintained by the Health Statistics Division of Statistics Canada. It is an administrative survey that collects information continuously from all provincial and territorial Canadian Cancer Registries on cancer incidence in Canada.

PRIVACY AND CONFIDENTIALITY

All information given to Statistics Canada through surveys, the census or any other source is confidential. Statistics Canada does not release any information that identifies an individual or group without prior consent. No other government institution has the right to see the answers given in confidence to Statistics Canada. Information is protected by the Statistics Act and the Privacy Act.

(Statistics Canada,2001, Vital Statistics Council 2001)

VITAL STATISTICS COUNCIL OF CANADA

The Vital Statistics Council for Canada is an inter-jurisdictional advisory group composed of the heads of the vital statistics divisions/agencies from all of the provincial and territorial governments and the Health Statistics Division of Statistics Canada. The Council provides a forum for developing common approaches for collecting vital statistics, sharing information with external parties and facilitating problem solving in vital event related issues.

It meets in person once yearly and holds teleconferences in the interim.

For more information see http://www.vscouncil.ca/english.html

(Vital Statistics Council 2001)

CANADIAN INSTITUTE FOR HEALTH INFORMATION (CIHI)

Established in 1994 CIHI is a federally chartered but independent, not-for-profit organisation. It brings programs, functions and activities from what was The Hospital Medical Records Institute, what was The Management Information Systems Group, Health Canada (Health Information Division) and Statistics Canada (Health Statistics Division) together under one roof. It is responsible for developing and maintaining the country's comprehensive health information system.

Institute core functions are:

- identifying health information needs and priorities;
- collecting, processing and maintaining data for a comprehensive and growing number of health databases and registries, covering health human resources, health services and health expenditures;
- setting national standards for financial, statistical and clinical data as well as standards for health informatics/telematics; and

- producing and disseminating value-added analysis.

The **databases** maintained include the following:

- Health Expenditures Databases
  - Annual Hospital Survey
  - OECD Health Database (Canadian Segment)
  - National Health Expenditures Database
- Heath Professionals Databases
  - Health Personnel Database
  - Registered Nurses Database
  - National Physician Database
  - Southam Medical Database
- Health Services Databases
  - Ambulatory Care Database
  - Discharge Abstract Database (DAD)
  - Hospital Mental Health Database
  - Ontario Chronic Care Patient System
  - Therapeutic Abortions Database
  - Hospital Morbidity Database
- Hospital Services Registries
  - Canadian Joint Replacement Registry
  - Canadian Organ Replacement Register
  - National Trauma Registry
  - Ontario Trauma Registry

DISCHARGE ABSTRACT DATABASE

The Discharge Abstract Database was originally developed in 1963 to collect data on hospital discharges in Ontario. Over time, it has expanded to provide national coverage. In addition to data collection and processing for hospital discharges, services include hospital-specific reports and value-added information, and national comparative reporting based on peer groups. Hospitals also use the data to support the evaluation of the use of its resources. The database, in its present form, exists from fiscal year 1979/80 to 2000/01.

For fiscal 2001/02, DAD was redeveloped to

- accommodate the new diagnosis and intervention codes (ICD-10-CA/CCI)
- improve comparability of data through increased interprovinicial standardisation
- improved definitions
- add new data elements
- delete data elements which were no longer relevant.

Data Elements

This database contains demographic, administrative and clinical data for hospital discharges (inpatient acute, chronic, rehabilitation) and day surgeries.

Source

CIHI receives data directly from participating hospitals (about 85% of all hospital inpatient discharges in Canada). This is about 4.3 million records annually. Data files for the remaining hospitals are submitted by the appropriate province or territory.

Restrictions

Data disclosure is determined by ***Privacy and Confidentiality of Health Information at CIHI: Principles and policies for the protection of health information.***

Support Documents

The DAD Abstracting Manual provides detailed abstracting and edit specifications for submitting data on patient discharges.

Timeliness

Fiscal year 2000/2001 data from participating hospitals are available for ad hoc queries, and special custom reports and raw data files in October 2001.

Publications/Outputs

Participating hospitals receive standard and comparative reports. CIHI will respond to research and analysis requests. Information products are made available through a variety of vehicles, such as CIHI Directions, the Internet and Statistics Canada's *The Daily* and *Health Reports*.

HOSPITAL MORBIDITY DATABASE

This database provides a count of cases separated (discharge or death) from a hospital, by primary diagnoses. The collection and publication of national hospital morbidity statistics began in 1960. The Hospital Morbidity Database contains fewer data elements than DAD but it has 100 per cent of acute care discharges for Canada.

Data Elements

It contains the following types of clinical and demographic data:

- ✓ primary diagnosis
- ✓ operation
- ✓ admission date
- ✓ discharge condition
- ✓ total days stay
- ✓ age and gender

Data is received from general and allied special hospitals, including acute care, convalescence and chronic facilities (with the exception of Ontario). Data do not include any outpatient services in any hospital or services in some psychiatric hospitals.

Source

Data are downloaded from the Discharge Abstract Database for those provinces participating 100 per cent in DAD. Data files for the remaining hospitals are submitted by the appropriate provincial or territorial ministry of health.

Restrictions

Data disclosure is determined by *Privacy and Confidentiality of Health Information at CIHI: Principles and policies for the protection of health information.* In some instances, CIHI and Statistics Canada jointly manage the release of information.

Timeliness

Fiscal 1999/2000 data available for general release in September 2001.

Relationships

Beginning with fiscal 1994/95, CIHI is responsible for data collection, processing and editing. Statistics Canada retains the historical series back to 1960.

Publications/Outputs

CIHI will respond to research and analysis requests. Dissemination will be made available through a variety of vehicles, such as CIHI Directions, the Internet and possibly Statistics Canada's *The Daily* and *Health Reports.*

PERSONNEL RESOURCES

CIHI currently employs 250 staff members, split between Toronto, Ottawa and Vancouver:

Senior Management - 12

Analysts - 38

IT staff - 54

Managers - 25

Classifications/health records-related functions - 12

Publications/education/media communications - 20

Human Resources/finance/administration/other support staff - 44

Project consultants - 37

Program/program co-ordinators - 8

For more information on CIHI and its functions see http://www.cihi.ca/eindex.htm

(CIHI, 2001)

CANADIAN COALITION ON CANCER SURVEILLANCE CCOCS)

The CCOCS was established in 1996 to guide the development of a more complete cancer surveillance system. The vision is that it will link existing provincial and national systems, in effect creating a “network of networks”.

A status report of their progress to date is available on the web at

http://www.hc-sc.gc.ca/hpb/lcdc/bc/ccocs/status/index.html

HEALTH INFORMATION BODIES AT REGIONAL LEVEL

There are ten provinces and two territories in Canada, each with its own health information system. Here, rather than exhaustively listing all structures for all provinces and territories, we have concentrated on those of Ontario, the province with the largest population in Canada (11.5 million).

Health Intelligence Units (HIUs)

The Health Intelligence Unit program is an Ontario Ministry of Health and Long-Term Care funded initiative that was established in 1994 to strengthen regional partnerships among District Health

Councils[1], Public Health Units[2] and Academic Health Science Centres, "to support their common and complementary roles in health assessment and planning, and to enhance the capability and capacity of these agencies to analyse, interpret and apply health information in their planning activities. Five HIUs were established, one in each of the following five planning regions in Ontario: south west, central west, central east, east and north. Funding of $2million per year was initially provided for a five-year period.

(Ontario Ministry of Health and Long-Term Care, 2001)

The Ministry has contributed directly to the program by building a data warehouse, which houses a number of administrative databases, and key demographic variables. These files can be linked in a number of ways, and are accessed through a secure government intranet. While the warehouse is a repository for *data* HIUs are expected to create *information* products and tools in various tabulations. The appropriate use of this information to promote Partner objectives is considered *"intelligence*".

All of the units provide a range of services including data access, analytic support, reference documents, software utilities, training, workshops, and conferences.

Individual HIUs have undergone several evaluations, with very positive results. The entire HIU Program has recently been reviewed by the Ontario Ministry of Health and Long-Term Care, revealing strong support from Partners and users of HIU products and services.

See *Interim Review of Central East Information Partnership*, and *Ontario's Health Intelligence Unit Program: Impact Assessment and Recommendations*

Other publications are available on the CEHIP web-site at http://www.cehip.org/.

The Ministry of Health and Long-Term Care web-site is at http://www.gov.on.ca/health/index.html

(CEHIP, 2001)

Central East Health Intelligence Partnership (CEHIP)

One of the five HIUs in Ontario is the **Central East Health Intelligence Partnership (CEHIP)**. It identifies its role as the following:

- contributing to improvement in the quality, relevance and accessibility of the population health data available to District Health Councils, Boards of Health and Universities;
- facilitating the analysis, presentation and use of population health data by District Health Councils, Boards of Health and Universities;
- responding to the needs of District Health Councils, Boards of Health and Universities for health information in planning health services, education and research;
- sharing and enhancing the knowledge and skills of staff and students of District Health Councils, Boards of Health and Universities;
- improving education and training opportunities with a view to improving practices and services of District Health Councils, Boards of Health and Universities;
- doing all such things as are incidental or conclusive to the attainment of the above.

A list of data sets that can be accessed through CEHIP include the following:

Ontario Live Birth Database

Ontario Stillbirth Database

Cancer Incidence

Ontario Mortality Database

Congenital Anomalies

CIHI- Hospital Separation

- Psychiatric Hospitalisation System
- MTO Collision Database
- Ontario Population Estimates & Projections
- Children In Need of Treatment
- National Population Health Survey
- Management Information Systems Data
- Ontario Home Care Administrative
- Canadian Census
- Ontario Dental Health Indices Survey
- Ontario Health Survey - 1990
- Ontario Health Survey - 1996

Personnel Resources

CEHIP employs five full-time and one half-time staff, including the Director, one full-time and one half-time epidemiologists, a health information manager, a health information analyst and an executive secretary.

(Ontario Central East Health Intelligence Partnership, 2001)

Office of the Registrar General

This is the provincial office that collects, codes and collates vital statistics information for the province and forwards it to Statistics Canada on a yearly basis. It is a branch of the Registration Division of the Ontario Ministry of Consumer and Commercial Relations.

Division Registrars' Offices

These are the municipal/local offices to which vital statistics forms are sent, once filled in by the individual or health professional involved. They are then forwarded to the Office of the Registrar General.

Cancer Care Ontario

As the provincial government's principal adviser on cancer issues, Cancer Care Ontario is responsible for long-term planning of the cancer care system. The organisation sets direction and provides leadership in cancer surveillance, prevention, screening, research, treatment and supportive care.

They maintain a web-site (http://www.cancercare.on.ca) with information on prevention and screening, treatment & supportive care programs and statistical information.

Cancer Care Ontario manages the **Ontario Cancer Registry** (http://www.cancercare.on.ca/ocr/ontcancerreg.html) through its Division of Preventive Oncology. This is a computerised database of information on all Ontario residents who have been newly diagnosed with cancer or who have died of cancer. All new cases of cancer are registered, except non-melanoma skin cancer. Currently over one million incident cases have been registered from1964 to the present.

(Cancer Care Ontario, 2001)

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[1] District Health Councils (DHCs) are advisory health planning organisations, they average about 20 members. Membership in each council includes: people who deliver health and health related social services, representatives from local government and people who bring a community perspective.

[2] A Public Health Unit is an official health agency which performs functions similar to those performed by the Departments of Public Health in Ireland. Each health unit is governed by a board of health and is administered by the medical officer of health who reports to the local board of health. The board is largely made up of elected representatives from the local municipal councils.

PROCESSES

VITAL STATISTICS DATA CYCLE

Under a federal-provincial agreement, the registration of births, stillbirths, deaths and marriages is the responsibility of the provinces and territories. The primary function of the provincial and territorial registration systems is to obtain and preserve such documentary evidence as is necessary to protect the legal rights of the individual. While the production of data for statistical analysis is of secondary importance to the provincial and territorial registries of vital statistics, the data are nevertheless used extensively by the research community and other health professionals. At the national level, the primary use of the data is statistical, such as in population estimates and projections, demographic trend analyses, health surveillance and epidemiological research.

Here, the system for all provinces is discussed in general and for Ontario in particular.

COLLECTION

BIRTHS

The **Ontario Live Birth Database** contains records of live births collected, compiled and stored by the Office of the Registrar General.

Live birth data are collected under the Vital Statistics Act, R.S.O. 1990, with the use of two legal documents: Form 1 "Notice of Live Birth or Stillbirth" and Form 2 "Statement of Live Birth". The administration of the Vital Statistics Act is assigned to the Registrar General under the Ministry of Consumer and Commercial Relations.

Form 1 is completed by the medical practitioner or nurse who attended the birth. The original copy of Form 1 must be sent within 48 hours to the Division Registrar of Births.

Form 2 is completed by the parent, and must be sent within 30 days after the date of birth to the Division Registrar of the municipality in which the child was born.

Data contained in Form 1 and Form 2 of the same live birth are merged to create a single statistical record in the Office of the Registrar General. Databases of these records are compiled on a yearly basis and then forwarded to Statistics Canada for editing. Edited files are returned to the Ministry of Health for distribution and analysis.

DEATHS

The **Ontario Mortality Database** contains records of deaths collected, compiled and stored by the Office of the Registrar General.

Mortality data are collected under the Vital Statistics Act R.S.O 1990, Chap. V.4. The death of every person who dies within Ontario is registered in the office of the division registrar within which the death occurs. The form for the registration of a death consists of two parts, personal and medical. An informant, usually a relative of the deceased, supplies personal data. The medical practitioner last in attendance or the coroner, if an inquest or inquiry was held, completes the part of the form comprising the medical certificate of death. The undertaker enters details on burial or other disposition of the body on the death registration form, and is responsible for filing the completed form with the local Registrar, who then issues the burial permit.

Data contained in the two forms are used to create a statistical record in the Office of the Registrar General. Databases of these records are compiled on a yearly basis and then forwarded to Statistics Canada for editing. Edited files are returned to the Ministry of Health for distribution and analysis.

All provinces (except Ontario since 1990) supply microfilm copies of registration forms to Statistics Canada. In addition, New Brunswick, Quebec, Ontario and the western provinces supply machine-readable abstracts of registrations, consisting of the required standard information. For the remaining Atlantic provinces and the territories, the required standard information on microfilm is converted to machine-readable format at Statistics Canada. Subsequent changes to registrations due to errors or omissions are transmitted to Statistics Canada as the information becomes available. However, changes received after a cut-off date are not reflected in published tabulations. Beginning with 1996 data, late-reported events were to be included in the database, but this has not yet been implemented.

Machine-readable files provided by provinces are converted to a standard format at Statistics Canada.

Since 1990, Ontario has used optical imaging technology for storing copies of legal certificates, so microfilm copies are no longer being produced. Statistics Canada is in the process of developing an agreement for the physical transfer of optical images from Ontario to Statistics Canada. To date, however, it has not been possible to completely edit vital statistics data reported by Ontario.

Editing and Error Detection

The provinces that supply data in machine-readable form carry out edits before sending them. Editing varies by province but usually includes checks that data are present, validation of code ranges for coded information and consistency checks between related data items, such as birthweight and period of gestation, cause of death and sex (for sex-specific causes), and marital status and age.

The data from all provinces then undergo more extensive edit routines to ascertain the completeness and quality of the data. Currently, standard edit specifications are being developed by Statistics Canada for inclusion in provincial edit systems. Most errors and omissions detected during processing are corrected by referring to the microfilmed registrations or by consulting with the provinces and territories.

A process has been designed to measure data coding and capture errors. A sample of records is recaptured, recoded and matched against the records on the national database. The data elements under review for births include date, kind (single or multiple), period of gestation, order, sex and weight of child, as well as age, marital status and usual place of residence of the mother. The data elements under review for deaths include date, location, nature and cause of death, and the following characteristics of the deceased: sex, date of birth, age at death, usual place of residence, birthplace, parents' birthplace and marital status. The process has not been implemented yet.

Standard Development

To promote consistency in the manner in which data are collected, Statistics Canada, in collaboration with the provincial and territorial registrars is revising data dictionaries for births, stillbirths, deaths and marriages. Their main purpose is to make available to registrars a standard framework for the description and content of each data element. It is expected that selected provincial registrars will adopt this framework over time.

QUALITY

Statistics Canada provides provinces with training and consultation for cause of death coding and supplies manuals, such as the International Classification of Diseases (ICD) and the Standard Geographical Classification (SGC), to promote data reliability and consistency. Also, CEHIP has undertaken a review of the Ontario Ministry of Health's Public Health Branch's version of the Ontario Live Birth Data File and the Ontario Mortality Data File at the request of its partners to ensure its operation to the highest of standards.

VARIABLE LIST

The following birth variables are reported by all jurisdictions to the national vital statistics registration system:

- date and place of birth
- sex and weight of the new-born
- age, marital status and birthplace of both parents
- place of residence of the mother
- type of birth (single or multiple)
- birth order
- period of gestation.

The following variables are reported by all jurisdictions to the national vital statistics death registration system:

- age and sex of the deceased
- marital status of the deceased
- residence of the deceased
- birthplace of the deceased
- date of death
- underlying cause of death
- place of occurrence of death
- place of accident (for most non-transport accidental deaths)
- autopsy (whether one was held or not, and, if so, whether the results of it were taken into account or not in establishing the cause of death).

Statistics Canada provides definitions for all of the above variables.

Individual provinces and territories have further lists of variables collected, not common to all.

COMPREHENSIVENESS

The vital statistics registration system covers all births occurring in Canada but excludes those of non-Canadian residents. It covers all deaths occurring in Canada. Births and deaths of Canadian residents occurring in the United States are also included, however, no birth or death of Canadian residents occurring in countries other than Canada and the U.S. are reported.

In Ontario the data consists of records describing births to and deaths of residents of Ontario for the years 1981 through to 1997.

COMPLETENESS

The response rate of reporting of core statistical data items varies with the item, the reporting province and the year. For Canada in 1992, it was close to 100% for most variables.

Records received after the "cut-off date" and births and deaths occurring to Canadians in countries other than Canada or the United States are missing. Furthermore, births and deaths of non-permanent residents in Canada may be excluded if the declared usual place of residence of the mother or of the deceased is not Canada.

Also, under-coverage for births might occur when parents of new-borns that die within days of birth do not register the birth. However, in provinces with a Physician Notice of Birth or similar documents, births would still have been reported to the registrar.

There is also thought to be some under-reporting and/or late reporting of births in remote areas.

TIMELINESS

Registration of births and deaths takes approximately four weeks.

AVAILABILITY OF THE DATA

In Ontario the Live Birth and Mortality databases originate with the Office of the Registrar General; access to them can be gained in a number of ways, including purchase of the data from the Registrar General.

The data are available through the Provincial Health Planning Database or Data Warehouse as well as the Ontario Live Birth File and the Ontario Mortality File from the Public Health Branch of the Ministry of Health and Long-Term Care.

PRIVACY

The data consists of pseudonymous (unidentifiable but unique) records.

(CEHIP, 2001, Statistics Canada, 2001)

SECONDARY CARE DATA CYCLE

COLLECTION

Data are collected from the patient's chart at the time of discharge and are recorded on an abstract provided by CIHI. Acute care inpatient abstracts contain three types of clinical and demographic data elements:

- CIHI mandatory elements such as admission and discharge information, most responsible diagnosis, principal procedure, institution transfer
- province-specific mandatory elements, such as health care number, residence code, provincial ancillary data
- optional hospital-specific elements, such as therapies, basic options, special projects.

One abstract is completed for each separation (stillbirth, death, discharge) from the hospital. The abstract must be filled out according to the instructions outlined in the CIHI Abstracting Manual.

A batch of abstracts are submitted from the institution to CIHI electronically (magnetic tapes, diskettes, modem) or by paper and they are entered into the Discharge Abstract Database (DAD).

Editing and Error Detection

Prior to the generation of reports on the data the abstracts are edited for validity and consistency. The editing process identifies erroneous data and prevents the data from being printed or stored on the master file. The data are then stored and updated.

Standard Development

Responsibility for standard development falls to CIHI, which maintains the DAD.

VARIABLE LIST

This includes many patient and hospital data variables for all of which the CIHI abstracting manual provides definitions.

Comprehensiveness

Discharge abstract database (DAD) is one of the most comprehensive national databases of its kind in the world. Over 85 per cent of all Canadians discharged from a Canadian hospital, 4.5 million patient records annually, are submitted to CIHI each year. In addition, through the DAD program, CIHI also processes 1.5 million day procedure episodes annually.

Completeness

The rate of inclusion is not uniform across the provinces. While 100% of 1995/96 discharges were submitted to CIHI from the Yukon and Northwest Territories, British Columbia, Alberta, Saskatchewan, Ontario, New Brunswick, Nova Scotia and Newfoundland, the database includes 34% of discharges in Manitoba, and no discharges from Quebec.

Timeliness

The most recent year of data available is 1998/99 fiscal year (1998 calendar year).

Availability of the Data

In Ontario the data are available through the Provincial Planning Database or Data Warehouse. The most recent year of data available is 1998/99 fiscal year (1998 calendar year).

The web-page for the DAD is at http://www.cihi.ca/wedo/dbdad.shtml

(CIHI, 2001, CEHIP,2001)

PRIMARY CARE DATA CYCLE

Primary health care data are not routinely collected in Ontario. This is because primary care physicians in Canada generally operate on a fee-for-service basis and primary care data systems are designed for billing purposes. There are some groups (e.g. Institute of Clinical and Evaluative Studies), however, working on linking this data with other data, to increase its usefulness in the health sector.

The best primary health care information available is that from the national surveys carried out every two years by Statistics Canada (see below, “Processes to Monitor Health Determinants/Status over Time”). The information is provided down to a population level of approximately 100-150,000.

(Personal Communication with Sten Ardal, Director of CEHIP, 2001)

PERFORMANCE INDICATORS

A Roadmap Initiative project to develop and implement a system of indicators that will support monitoring and ongoing improvement in the quality of primary health care at the local level while allowing regional and national comparisons is ongoing. The intent of the project is to begin the process of developing and testing performance indicators for primary health care. Specific objectives include:

- To obtain agreement on performance indicators for primary health care;
- To identify data needed to support performance indicators using standardised data definitions and elements;
- To test and evaluate recommended performance indicators.

(CIHI, 2001)

POPULATION REGISTER

There is no national population register in Canada but each province registers its citizens. However, there is no effective update mechanism for the register in Ontario and therefore many of the addresses held on the register are incorrect.

Census information, which is considered very reliable, is used for health information purposes, but generally only in aggregate. Occasionally, record level analysis can be carried out on this data but only with specific permission.

(Personal Communication with Sten Ardal, Director of CEHIP, 2001)

PERSONAL IDENTIFIERS

Each person in Ontario has a unique number (see above) which is used for accessing health services and work has been done on “scrambling” this number to create a “pseudo-number”. This protects identity and the pseudo-number can still be used for linkage, if the same scramble is used. However, not a lot of work has been done on linkage in Ontario and other provinces, like British Colombia and Saskatchewan, are ahead in this field.

(Personal Communication with Sten Ardal, Director of CEHIP, 2001)

GEO-CODING

Health data is well geo-coded in Ontario and can be analysed to small area. There is a mail postcode system, and this postcode is collected for most contacts with the health services. People are also assigned a secondary geographical code, a resident’s code, which is the Ministry of Health code. Thirdly, Statistics Canada assigns census division coding. If anything there is considerable redundancy in the geo-coding system. However, this redundancy can be helpful for reviews of the quality of geo-coding.

(Personal Communication with Sten Ardal, Director of CEHIP, 2001)

MONITORING HEALTH STATUS OVER TIME

Toward a Healthy Future: Second Report on the Health of Canadians is a public policy report developed by the Federal, Provincial and Territorial Advisory Committee on Population Health in collaboration with Health Canada, Statistics Canada, CIHI and a project team from the Centre for Health Promotion, University of Toronto. It is the second in a series of reports on the health of Canadians and is intended as a monitoring tool by offering benchmarks for gauging progress in the future. A copy of the report is available at

http://www.hc-sc.gc.ca/hppb/phdd/report/toward/eng/index.html

LESSONS FROM THE ONTARIO/CANADIAN EXPERIENCE

The feeling is that there is a lot of good health information available in Ontario and in Canada but that more ways need to be found of using that information effectively, to feed into planning and policy areas.

The main problem seems to be that the information systems were originally designed for purposes other than those for which they are now being used. The problem is in linking scattered databases, designed for different purposes. The use and interpretation of administrative data is a challenge, and it is thought that many of those using this data are not aware of the issues involved in using it.

Sten Ardal (Director, CEHIP) feels that a strategic approach to health information systems is required. At present there are some attempts to provide leadership at Federal level but as yet there is no Health Information Strategy in Ontario.

(Personal Communication with Sten Ardal, Director of CEHIP, 2001)

USEFUL WEB-SITES

Health Canada	http://www.hc-sc.gc.ca
PPHB, Health Canada	http://www.hc-sc.gc.ca/pphb-dgspsp/new_e.html
Canadian Institute of Health Information	http://www.cihi.ca/eindex.htm
Statistics Canada	http://www.statcan.ca/
Health Statistics Division, Statistics Canada	http://www.statcan.ca/english/freepub/82-573-GIE/guide.htm
Office of Health and the Information Highway	http://www.hc-sc.gc.ca/ohih-bsi/menu_e.html
Canadian Health Network	http://www.canadian-health-network.ca/customtools/homee.html
Vital Statistics Council	http://www.vscouncil.ca/english.html
Canadian Coalition on Cancer Surveillance	http://www.hc-sc.gc.ca/hpb/lcdc/bc/ccocs/status/index.html
Ontario Ministry of Health and Long-Term Care	http://www.gov.on.ca/health/index.html
Central East Health Intelligence Partnership	http://www.cehip.org/menujs.html
Cancer Care Ontario	http://www.cancercare.on.ca
Ontario Cancer Registry	http://www.cancercare.on.ca/ocr/ontcancerreg.html
European Observatory on Health Care Systems	http://www.observatory.dk/index.htm
CANARIE Inc.	http://www.canarie.ca/about/about.html

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Australia

THE COUNTRY

Australia has a land mass roughly the same size as Western Europe or the USA. It comprises six States and two territories, each of which has a parliament. There is also a Commonwealth (federal) Government. There is a population of 18.7 million, about 80% of which lives in cities.

AUSTRALIA'S HEALTH SYSTEM

The two levels of government have overlapping responsibilities in the field of health; the Commonwealth has a leadership role in policy making and particularly in national issues like public health, research and national information management; the States and Territories are primarily responsible for the delivery and management of public health services and for maintaining direct relationships with most health care providers, including the regulation of health professionals.

NATIONAL HEALTH STRATEGY

The ***National Health Strategy*** was a major Commonwealth project that commenced in 1990. It was primarily concerned with acute care services, although there was also consideration given to public health and health promotion activities.

The Strategy involved the publication of twelve background papers, nine issues papers and two research papers, addressing a variety of topics ranging from delivery of hospital services, health financing and health research, to rural health, health promotion and the effect of income and environment on health status. It should be noted that none of the papers produced under the Strategy was formally adopted or endorsed as policy.

See *National Health Strategy* documents at
http://www.health.gov.au/publth/strateg/nhs/index.htm

PRIVATE SECTOR

The Commonwealth Government considers that strong private sector involvement in health services provision and financing is essential to the viability of the Australian health system. For this reason the Commonwealth provides a 30 per cent subsidy to individuals who acquire private health insurance and has introduced additional arrangements to foster lifelong participation in private health insurance.

(Commonwealth Department of Health and Aged Care, 2000)

HEALTH INFORMATION STRATEGIES IN

AUSTRALIA

The **National Health Information Agreement (NHIA)** came into effect in 1993, initially to run until 1998 but was subsequently extended to 2003. The Agreement, signed by Commonwealth, State and Territory health and statistical authorities is the cornerstone of national health information development in Australia.

It aims to ensure that the collection, compilation and interpretation of nationally relevant health information is appropriate and carried out efficiently. This requires agreement on definitions, standards and rules of collection of information and on guidelines for the co-ordination of access, interpretation and publication of national health information.

The Agreement aims also to improve access to uniform health information by community groups, health professionals, and government and non-government organisations. Its implementation is the responsibility of the National Health Data Committee of the Australian Institute of Health and Welfare (see below).

The machinery of development comprises a National Health Information Development Plan and associated National Health Information Work Program.

(Australian Institute of Health and Welfare, 2000)

For recent approaches to developing and implementing health information strategies at regional level see the ***Program for Enhanced Population Health Infostructure (PEPHI)*** and the ***Strategy for Population Health Surveillance in NSW***.

DEVELOPING/IMPLEMENTING HEALTH ICT STRATEGIES

In 1998 the Commonwealth Government released its strategy document *A Strategic Framework for the Information Economy – Identifying Priorities for action*, which set a national direction for Australia for the information economy. As part of this overall strategy specific action plans were to be developed for ten priority areas, including health.

In April 1999 **The National Health Information Management Advisory Council (NHIMAC)*** was established by Australian Health Ministers as the peak body for progressing key issues regarding the use of information in the health sector.

The Council's role is to:

- advise Health Ministers on options to promote a nationally uniform approach to more effective information management within the health sector;
- promote the efficient and effective use of information technology in health;
- develop a partnership with the private health and information technology sectors;
- encourage the development of a market for Australian health information technology and services;
- protect the public interest – particularly in relation to privacy.

HEALTH ONLINE

Health Online: A Health Information Action Plan for Australia was developed by the NHIMAC, in collaboration with commonwealth, state and territory agencies as a blueprint for progressing the health information management/information technology agenda nationally over the following five years. It was published in 1999 but is a living document that is updated and monitored over time under the direction of the council.

The second edition was released in September 2001. It reports on the progress made in many of the key activity areas described in the first edition, and incorporates new strategies and projects that are planned for the next five years.

The main focus of the Health Online document is the action plans it contains. These were developed within a strategic framework that was designed to achieve the overall objectives. This framework was essentially to:

- build the national co-ordination mechanisms and partnerships as a first priority;
- get the building blocks (data protection, standards, infrastructure etc) established;
- design and deliver important national initiatives (information and health services) that would address the needs of key interest groups.

* The membership of the council draws from Commonwealth and state governments, clinical practice, the information and technology industry, the private health sector and consumer interests. The Federal Privacy Commissioner is also a member of the council.

This framework is represented by the following key areas of work:

- achieving national collaboration;
- laying sound foundations;
- empowering consumers and communities for better health;
- supporting clinical care;
- using information to build a more efficient and effective health care system;
- export of Australian "online" health services.

Some Health Online projects include the following:

HEALTHINSITE

Health*Insite* is an Commonwealth Government of Australia initiative which is aimed at providing Australians with a single entry point to access quality information from leading health information providers, including peak health organisations, government agencies and educational and research institutions.

Content is provided through information partnerships established between Health*Insite* and selected organisations that provide quality information on their web-sites. Organisations and web-sites whose content has been proposed for access through Health*Insite* must go through the process for the "Assessment of Content for Health*Insite*" and be approved by a highly qualified editorial board.

As the information on the site is further developed, it is hoped that Health*Insite* will also become a resource for health professionals, service providers and researchers for both their own use and for patient referral.

Health*Insite* is at http://www.healthinsite.gov.au/

HEALTHCONNECT

The **National Electronic Health Records Taskforce** was established in November 1999 under the auspices of the NHIMAC, to recommend a way ahead to Australian Health Ministers on a national approach to electronic health records. Its report ***A Health Information Network for Australia*** was subsequently endorsed by Australian Health Ministers in 2000.

The Taskforce has proposed the concept of a national health information network (Health*Connect*) that would allow personal health information to be collected, safely stored and exchanged - but only with the individual health consumer's permission.

Under Health*Connect*, health-related information about an individual would be collected in a standard, electronic format at the point of care (such as at a hospital or a general practitioner's clinic). This information would take the form of event summaries, not all the notes that a health care provider may choose to keep about a consultation.

With the consumer's consent, these summaries would then be able to be retrieved at any time they were needed and exchanged via a secure network with those health care providers authorised by consumers to access this information.

For more information and for a copy of the Taskforce report see http://www.health.gov.au/healthonline/ehr_rep.htm

BETTER MEDICATION MANAGEMENT SYSTEM (BMSS)

The BMSS is a Health Online initiative to improve provider and consumer access to medicines information through personal electronic medication records, a centralised database and a communication network. Participation is to be voluntary. A consultation process in setting up the legislative and administrative arrangements for BMMS is currently ongoing.

For more information on this project see http://www.bmms.gov.au/

DEVELOPMENT OF HEALTH INFORMATION STANDARDS

Following on from *Health Online: A Health Information Action Plan for Australia* and *A Health Information Network for Australia* developments in this area include establishment of the National Information Standards Advisory Committee under the auspices of the NHIMAC and the publication this year of ***Setting the Standards: A National Health Information Standards Plan for Australia****.* The plan is a key strategic tool that formalises the importance of national standards and standards organisations in achieving an integrated approach to information management and information technology in Australia.

A copy of this publication is available at http://www.health.gov.au/healthonline/sp/index.htm.

For more information on Health Online, its development, its projects and related publications see the Health Online web-site at http://www.health.gov.au/healthonline/.

NATIONAL OFFICE FOR THE INFORMATION ECONOMY (NOIE)

NOIE has also been active in the area of developing and implementing health ICT strategies. Its early work in this area focused on telemedicine and in 1998 the Government released its report

The Telemedicine Industry in Australia : From Fragmentation to Integration. In response to the consultations with industry, government and consumers triggered by that report, it became clear that a new paradigm was emerging that goes beyond just telemedicine, and takes the issues into the broader area of e-health.

A second report which discusses the relationship between, and transition from, Telemedicine to Electronic Health ***From Telehealth to E-Health: The Unstoppable Rise of E-Health*** was commissioned by NOIE in 1999.

Both these publications and more information on the work of NOIE in this area is available from the NOIE web-site at http://www.noie.gov.au/projects/ecommerce/ehealth/index.htm

USE OF HEALTH INFORMATION

HEALTH INFORMATION BODIES AT NATIONAL LEVEL

COMMONWEALTH DEPARTMENT OF HEALTH AND AGED CARE

The Commonwealth Department of Health and Aged Care maintains an **internet site providing information** on its functions, programs, initiatives and publications, as well as access to Health*Insite,* its gateway to quality health information on the web.

POPULATION HEALTH DIVISION

This is the division that is responsible for national leadership in public health matters, such as communicable diseases, immunisation, cancer, smoking, diabetes and drug abuse.

NATIONAL CENTRE FOR DISEASE CONTROL (NCDC)

The National Centre for Disease Control (NCDC) holds key roles as a co-ordinator of national action in response to communicable disease outbreaks, and as a leader in the development of best practice guidelines and national public health policy. It is also the Commonwealth's **primary data collection centre for many communicable diseases**, and **surveillance data is disseminated** through the monthly publication ***Communicable Diseases Intelligence***.

The Surveillance and Management Section of the NCDC provides direction and support to the Communicable Diseases Network Australia New Zealand and to the Public Health Laboratory Network (see below).

COMMUNICABLE DISEASES NETWORK AUSTRALIA NEW ZEALAND (CDNANZ)

CDNANZ was established in October 1989 as a joint initiative of the National Health and Medical Research Council and the Australian Health Ministers Advisory Council to enhance the national capacity for communicable disease surveillance and control. It meets fortnightly by teleconference and oversees the co-ordination of national communicable disease surveillance and communicable disease outbreak control where a national response is required.

The CDNANZ is currently implementing the ***National Communicable Disease Surveillance Strategy***. For more information and to see a copy of the strategy see http://www.health.gov.au/pubhlth/strateg/communic/index.htm

PUBLIC HEALTH LABORATORY NETWORK (PHLN)

The Public Health Laboratory Network was established through the CDNANZ in 1996. It is a collaborative group of laboratories, nominated by State and Territory health departments, which have expertise in public health microbiology and are major providers of public health laboratory services. The aim of the PHLN is to enhance the national capacity for the laboratory based surveillance of communicable diseases in Australia.

HEALTHWIZ

HealthWIZ is the National Social Health Database, developed by Prometheus Information Pty Ltd* for the Commonwealth Department of Health and Aged Care as part of its commitment to providing easy public access to Australia's key health and welfare information. It is an expanding library of integrated social health data that is accessible though easy-to-use software.

Data Collection Types include

- ✓ Population Censuses
- ✓ Medicare Claims
- ✓ Medicare Cancer Screening
- ✓ Immunisation status
- ✓ Deaths
- ✓ Hospital Use
- ✓ Department of Social Security data
- ✓ Veterans Affairs
- ✓ Aged Care
- ✓ Child Care
- ✓ National Cancer
- ✓ State Cancer
- ✓ Dementia
- ✓ Hospital Capacity (Establishments)

- ✓ Social Health Atlas
- ✓ Standardisation data

Data provided comes from the major Australian health agencies.

HealthWIZ has been recognised as a Community Service Obligation Product by the Department and is distributed free of charge to individuals and organisations in the health sector. The total cost to users outside the health sector is $1,263.90.

*Prometheus Information is a company specialising in health information, statistical data and information technology. It develops statistical software and acts as a clearing house for one of the largest publicly available collections of disparate statistical health data in Australia.

At present a web version of HealthWIZ which will deliver the full statistical functionality of the HealthWIZ CD-ROM product is being developed.

Prometheus Information has also developed two **Online Resource Centres (ORCs)**:

- Australian Drug Information Network (See http://www.adin.com.au/)
- Healthy Ageing Quality Ageing (See http://www.healthyageing.com.au/)

Each ORC is built around a major health theme and delivers ordered and filtered information from selected ranked quality-assured web sites.

The company has also developed, and maintains **databases of** projects, publications, **information and resources** on the following:

- Health Education and Promotion (See http://www.prometheus.com.au/heaps/heaps.html)
- Adolescent Health Promotion (See http://www.prometheus.com.au/teen/teen.html)
- Community-based Falls Intervention (See http://www.healthyageing.com.au/falls/falls.html)

Healthwiz is at http://www.prometheus.com.au/healthwiz/hwizf.htm

AUSTRALIAN INSTITUTE OF HEALTH AND WELFARE (AIHW)

The AIHW, established under the Australian Institute of Health and Welfare Act 1987, is a statutory authority in the Health and Aged Care portfolio. It is Australia's national agency for health and welfare statistics and information. As an independent agency, it works with many government and non-government bodies across the nation.

It has three divisions Health, Welfare, and Economics and Business Services. The Health Division comprises the following units

- Cardiovascular Disease and Diabetes Monitoring Unit

This unit aims to set standards and develop and co-ordinate data to monitor cardiovascular disease and diabetes, risk factors and outcomes of public health interventions and treatment strategies.

- Health Monitoring and Development Unit

This unit undertakes surveillance and monitoring of non-communicable, chronic diseases in Australia.

- Health Registers and Cancer Monitoring Unit

The main functions of this unit are to monitor, investigate and report on mortality, disease incidence and survival, and population-based cancer-screening indicators.

- Hospitals and Mental Health Services Unit

This unit's main functions are compilation and maintenance of the **National Hospital Morbidity Database (NHMD)** and routine statistical reporting from the NHMD in ***Australian Hospital Statistics.***

- Population Health Unit

The main functions of this unit are to develop and provide information on the health of the Australian population and various sub-populations to inform community discussion and policy development.

- Population Health Data and Information Services Unit

This unit aims to provide information and data management services about public health to the Population Health Division of the Commonwealth Department of Health and Aged Care.

AIHW publishes many reports and discussion papers, drawing on a wide range of data collections - the two flagship publications being ***Australia's Health*** and ***Australia's Welfare***. It also develops and **publishes standards and classifications** for health and welfare statistics.

In line with the Prime Minister's 1997 policy statement *Investing for Growth* which outlined the Commonwealth Government's commitment to delivering all appropriate services online AIHW is committed to exploiting the opportunities offered by the Internet to support its mission and to enhance the delivery of its services.

In conjunction with AIHW there are five Collaborating Units that carry out selected AIHW functions under the AIHW Act, on the basis of their unique expertise. These include the National Perinatal Statistics Unit and the General Practice Statistics and Classification Unit.

NATIONAL PERINATAL STATISTICS UNIT

The National Perinatal Statistics Unit aims to contribute to the health and wellbeing of mothers and babies in Australia through the collection, analysis and reporting of national reproductive and perinatal information. The Unit collaborates with State and territory perinatal data groups and other professional and consumer groups in developing national reproductive and perinatal health statistics and information systems.

For more information see the web-site at http://www.aihw.gov.au/npsu/

GENERAL PRACTICE STATISTICS AND CLASSIFICATION UNIT, UNIVERSITY OF SYDNEY

The General Practice Statistics and Classification Unit operates within the University of Sydney's Family Medicine Research Centre. It conducts national surveys of general practice activity and maintains and develops the classifications needed for this purpose.

For more information see the web-site at http://www.fmrc.org.au/gpscu.htm

NATIONAL HEALTH INFORMATION MANAGEMENT GROUP (NHIMG)

The NHIMG comprises a representative from each of the signatory organisations of the National Health Information Agreement (see above). It directs the implementation of the NHIA and is supported by the AIHW through membership and by its providing the Secretariat.

THE KNOWLEDGEBASE

The Knowledgebase is an electronic storage site for Australian health, community services, housing and related data definitions and standards. It can be used to look in the contents of national Health, Community Services and related Data Dictionaries. The Health Data Dictionary is the authoritative source of national health data definitions and contains definitions of data elements that have been described according to a standard set of rules, and endorsed by the NHIMG as the national standard to apply whenever this information is collected in the health field.

The Knowledgebase also contains the national information development products.

See http://www.aihw.gov.au/knowledgebase/aboutkb.html

AUSTRALIAN BUREAU OF STATISTICS

The Australian Bureau of Statistics is Australia's official statistical organisation. In the health field it produces statistics on health status (mortality, health and well-being), the national health priority areas (cardiovascular health, cancer, injury prevention and control, diabetes mellitus, mental health and asthma), health lifestyles and risk factors (diet and nutrition, physical activity, drug use, children’s immunisation) indigenous health, hospitals and private health insurance.

NATIONAL CENTRE FOR CLASSIFICATION IN HEALTH (NCCH)

NCCH was formed as a result of a joint venture agreement in 1997 between the National Coding Centre at the University of Sydney and the National Reference Centre for Classification in Health situated at Queensland University of Technology.

Its role is "to create an Australian centre of expertise in classifications for morbidity, mortality and health interventions and to develop Australian standards for the application of such classifications”.

NCCH (Sydney) is funded by the Commonwealth Department of Health & Aged Care. NCCH (Brisbane) is funded by the Australian Institute of Health & Welfare, the Australian Bureau of Statistics and the Queensland University of Technology.

See http://www.cchs.usyd.edu.au/ncch/ for more information.

AUSTRALIAN INDIGENOUS HEALTH*INFONET*

This internet site (http://www.healthinfonet.ecu.edu.au/) is a dynamic, evolving resource which makes published, unpublished and specially-developed material about Indigenous health freely accessible to policy makers, service providers, researchers, students and the general community.

The work of the Australian Indigenous HealthInfoNet is undertaken currently by a small part-time team at Edith Cowan University in Perth, supported by funds from a variety of sources, including the Commonwealth Department of Health and Aged Care's Office for Aboriginal and Torres Strait Islander Health,

HEALTH INSURANCE COMMISSION (HIC)

The HIC is an organisation which is responsible for administering payments and information for programs such as Medicare, the Pharmaceutical Benefits Scheme, the Australian Childhood Immunisation Register, the Practice Incentives Program and the General Practice Immunisation Incentives scheme. It also maintains the Australian Childhood Immunisation Register and the Australian Organ Donor Register.

For more information see http://www.hic.gov.au/

HEALTH INFORMATION BODIES AT REGIONAL LEVEL

For the purposes of this report we have concentrated on the health information systems of New South Wales, which is the state in the south-eastern corner of Australia. It has a population of 5.6 million, 3.7 million of which lives in Sydney.

NEW SOUTH WALES HEALTH

This is the New South Wales Ministry of Health. It maintains a **web-site with information and resources** on its Divisions and Branches, health, health status and health services.

PUBLIC HEALTH DIVISION

The **Epidemiology & Surveillance Branch** of the Public Health Division has a key role in monitoring health in NSW, identifying adverse trends and evaluating the impact of health services.

The Branch is divided into five units, with core functions as follows:

POPULATION HEALTH INFORMATION UNIT

The Population Health Information Unit is responsible for developing epidemiological information systems, and analytic and reporting tools, for use throughout NSW Health and the Area Health Services.

The unit operates the **Health Outcomes Statistical Toolkit (HOIST)** system, which is a SAS-based population health data access and analysis facility comprising epidemiological datasets in a standardised format, plus a range of standard analytic programs.

The **datasets** include NSW Health Department data collections covering

- notifiable diseases
- cancer
- births
- birth defects
- dental health
- hospital inpatient statistics
- emergency department presentations
- population-based survey data

as well as data sourced from the Australian Bureau of Statistics (census, population, mortality and survey data) and other organisations. Historical as well as current data is available for most data collections on HOIST.

The system helps to ensure that consistent epidemiological data and methods are used throughout the health system and facilitates local analysis and needs assessment at Area Health Service level, where epidemiological resources are very limited.

The Population Health Information Unit is also responsible for the ***Program for Enhanced Population Health Infostructure (PEPHI).*** PEPHI comprises a series of projects to improve access to, and analysis and reporting of, population health information in NSW. Many of the improvements build on the existing ***Strategy for Population Health Surveillance in NSW***.

A discussion paper on PEPHI and a copy of the Strategy for Population Health Surveillance in NSW are available from http://www.health.nsw.gov.au/public-health/epi/pubs.html.

POPULATION HEALTH INDICATORS UNIT

The Population Health Indicators Unit is responsible for developing and validating outcome, risk, process and capacity indicators of population health status in NSW and systems for measuring, reporting and promoting the use of these indicators.

The Unit is responsible for co-ordinating the production of the biannual ***Report of the Chief Health Officer on the Health of the People of NSW*****,** which is a regular report on the health status of the population of NSW. The Unit is also responsible for producing annual ***Area Health Service Health Status Profiles****,* which are used as a basis for the development of Area Health Service performance contracts, and as a reference document during annual Area Health Service performance reviews.

NSW HEALTH SURVEY PROGRAM UNIT

The NSW Health Survey Program Unit operates the **NSW Health Survey Program**, and has its own Computer-Assisted Telephone Interview (CATI) facility, which employs around 35 FTE survey interviewers.

The NSW Health Survey Program comprises yearly telephone surveys of around 17,000 NSW residents (1,000 per Health Area). The Survey Program is NSW Health's main mechanism for monitoring health-related behaviours, health risk factors, prevalence of health conditions and overall satisfaction with health services in NSW. This information is used to inform and support planning and policy development in the 17 NSW Area Health Services and across the state.

The Unit also runs a range of ad-hoc and commissioned surveys, including investigations of acute infectious disease outbreaks.

SURVEILLANCE METHODS UNIT

The Surveillance Methods Unit is responsible for developing and validating epidemiological methods for health surveillance, to inform and support health planning and monitor health system performance. The Unit is responsible for developing novel methods to "add value" to existing health data sets (e.g. probabilistic data linkage) and, in collaboration with other branches, for developing new surveillance systems (e.g. for surveillance of morbidity and mortality associated with illicit drug use).

The Unit manages the operation of the **NSW Birth Defects Register** and **NSW Sudden Infant Death Syndrome (SIDS) Register**, which are used to monitor perinatal outcomes in NSW.

The Unit also produces the annual ***Health of NSW Mothers and Babies*** report, which is widely used by Area Health Service staff, health professionals and members of the public as a source of reference information about maternal and perinatal service delivery and outcomes.

PUBLIC HEALTH TRAINING & DEVELOPMENT UNIT

The Public Health Training & Development Unit supports the development of the public health workforce in NSW through training and development. One of its functions is production and distribution of the ***NSW Public Health Bulletin***.

For more information on the Public Health Division see http://www.health.nsw.gov.au/public-health/

INFORMATION MANAGEMENT AND CLINICAL SYSTEMS BRANCH

PATIENT DATA MANAGEMENT UNIT

The Patient Data Management Unit of the Information Management and Clinical Systems Branch is responsible for managing the development, processing and supporting documentation for the following data collections:

- Inpatient Statistics Collection (see below, under Secondary Care Data Cycle)
- Waiting List Collection
- Midwives Data Collection

The New South Wales Midwives Data Collection (MDC) is a population-based surveillance system covering all births in NSW public and private hospitals, as well as home births. It is a collection of information about pregnancy care, services and pregnancy outcomes.

The data collection has operated continuously since mid-1986 and encompasses all live-births and still-births of at least 20 weeks gestation or at least 400 grams birth-weight. For every birth in NSW the attending midwife or medical practitioner completes a form (or its electronic equivalent) giving demographic, medical and obstetric information on the mother, and information on the labour, delivery and condition of the infant. The information is sent to the NSW Health Department where it is checked and compiled into one statewide dataset. It provides **perinatal statistics** compatible for national and international comparison.

PERSONNEL RESOURCES

The Patient Data Management Unit has seven staff

- ✓ Manager
- ✓ Senior Project Officer - Inpatient Statistics Collection
- ✓ Project Officer - Inpatient Statistics Collection
- ✓ Assistant Project Officer - Inpatient Statistics Collection
- ✓ Project Officer - Waiting Times Data Collection
- ✓ Clinical Nurse Consultant - Midwives Data Collection
- ✓ Clerical Officer

For more information on the Patient Data Management Unit http://www.health.nsw.gov.au/iasd/dm/pdmu/

MANAGEMENT INFORMATION SYSTEMS UNIT

The Management Information Systems Unit is responsible for the following data collections:

Department of Health Reporting System

Un-audited Annual Returns Data Collection

Audited Annual Returns Data Collection

Hospital Utilisation and Costs Study

Visiting Medical Officer's Data Collection

Brain Injury Rehabilitation Program Data Collection

Emergency Department Data Collection

Sexual Assault Data Collection

Complaints Data Collection

Physical Abuse and Neglect of Children Data Collection

STRUCTURAL AND FUNDING POLICY BRANCH

The Structural and Funding Policy Branch is responsible for the Sub and Non-acute Data Collection.

CANCER COUNCIL

The Cancer Council was established in 1955 by an Act of the NSW Parliament. It engages in many activities, including provision of information and services, sponsoring research, advocacy and fund-raising. The **NSW Central Cancer Registry** was established by the NSW Health Department in 1971 but has been administered by the NSW Cancer Council under contract since 1986.

For more information on the NSW Central Cancer Registry see http://www.nswcc.org.au/cncrinfo/research/index.htm ,

and the Cancer Council home page at http://www.nswcc.org.au/

CLINICAL INFORMATION ACCESS PROGRAM (CIAP)

The Clinical Information Access Program (CIAP) web-site is a NSW Health – backed project supporting evidence-based practice at the point of care. The web-site is available to nurses, doctors, allied health professionals, community health, ancillary and library staff working in the NSW Health public health system. A User ID and password are required to access the knowledge resources (MIMS, Journals, Cochrane etc).

PROCESSES

VITAL STATISTICS DATA CYCLE

Since Federation in 1900, all deaths for which a coroner's inquiry is not required must be certified as to cause and date by a registered medical practitioner, and the certificate registered by the Registrar of Births, Deaths and Marriages in each State or Territory.

Deaths registered since 1999 have been classified by the Australian Bureau of Statistics according to ICD-9.

ABS mortality data for deaths of NSW residents registered anywhere in Australia are accessed via the Health Outcomes Information and Statistical Toolkit (HOIST).

Important issues affecting the reliability and interpretation of mortality data that have been identified include:

- the accuracy of the diagnosis recorded on the death certificate. If multiple conditions are present at the time of death, the decision about what the underlying cause of death was may be equivocal;
- misinterpretation of the guidelines for determining the underlying cause of death by the attending physician completing the death certificate
- errors in transcription and coding of death certificates.

Secondary Care Data Cycle

In-patient Statistics Collection

The Inpatient Statistics Collection is a census of all admitted patient services provided by New South Wales Public Hospitals, Public Psychiatric Hospitals, Public Multi-Purpose Serivces, Private Hospitals, and Private Day Procedures Centres.

Collection

All data for the Inpatient Statistics Collection must be reported via patient administration systems direct to the Area Health Service Health Information Exchange (HIE), and then forwarded by the HIE Co-ordinator to the NSW Health Department. Inpatient records are sent via a broad range of media (paper, disk, tape, and electronically). The fastest and most efficient method of data submission is direct submission via **Inpatient Statistics Collection On-line System (ISCOS**). This is a tool for collecting, editing and reporting inpatient activity in public, private and psychiatric hospitals in NSW and is gradually being adopted by sites across the state.

The system has three modules:

Module 1. Data Submission

Module 2. On-line Input Editing

Module 3. Output

If the record passes all input edits (see below) it is then passed through grouping processes through which ANDRG (Australian National Diagnostic Related Groups) and Statistical Local Area variable codes (see below, “Geo-coding”) are assigned. It is then released into the “release database” which is available to general users.

For more information on ISCOS see http://www.health.nsw.gov.au/iasd/dm/isc/iscos/index.html

Editing and Error Detection

Once loaded into ISCOS the data is held in batches (groups of records) in the “input database”. Access to this is restricted to Central Office data processing staff who pass these batches through the input edit checking procedure in ISCOS. If a record does not pass this process it is returned to the source for correction. If the data supplier has connected to ISCOS On-line Editing, records can be corrected on the screen and immediately resubmitted.

A number of sources of error have been identified which include:

- non-response (failure to collect all relevant data);
- errors in transcribing patient data from medical records to the collection media;
- coding errors;
- clerical and editing errors.

Unit of Measurement

Until 1993 the ISC enumerated periods of stay in hospital. A period of stay in hospital ended with a discharge, transfer or death of a patient. If a patient was admitted to hospital five times in a year, at least five separate records were included in the ISC. Since 1993, the ISC has enumerated episodes of care. An episode of care ends by either the patient ending a period of stay in hospital (i.e. by discharge, transfer or death) or by the patient becoming a different type of patient within the same period of stay in hospital.

Quality

Training is regularly conducted by NSW Health at both NSW Health Department and at local sites throughout the state.

Variable List

The information reported includes the patient demographics, source of referral to the service, service referred to on separation, diagnoses, procedures, and external causes. For public sector sites the information also includes admitted patient events such as changes in ward, treating doctor, legal status, financial class and leave.

Comprehensiveness

The Inpatient Statistics Collection covers all inpatient separations (discharges, transfers and deaths) from all Public (including Psychiatric), Private, and Repatriation Hospitals, Private Day Procedures Centres and Public Nursing Homes in NSW. Patient separations from Developmental Disability Institutions and Private Nursing Homes are not included.

The collection also includes data relating to NSW residents hospitalised interstate and in Commonwealth Department of Veteran’s Affairs facilities.

Completeness

The Patient Data Management Unit monitors completeness of the collection on a monthly basis. Compliance reports are sent to each hospital and Health Service.

On average, the public sector is 90% complete by the due date. The outstanding 10% is mostly attributable to sites that are migrating to new patient administration systems. The private sector's compliance lags considerably and has recently been targeted in this regard.

Timeliness

The date for 100% clean data is the final working day of the second month after the month of separation.

Data Usage

The ISC is widely used within the Health sector. It plays a key role in monitoring health trends, monitoring hospital utilisation, and calculations for the distribution of funding. The information is also used to allow the comparison of public hospitals against benchmarks and peer hospitals. The information is used at the local area, State and national levels.

Availability

Information about inpatient activity can be obtained from the responsible Area Health Service. For Statewide information, or requests where the Area Health Service is unable to assist, information is available from the NSW Health Department Information Analysis and Dissemination Unit.

Users employed by Area Health Services and Public Health Units have full access to the data of their own residents, whether they attended hospital in their Area or not. Access to personal identifying information, and information identifying private hospitals, is not provided for residents of other Areas.

Users employed by Hospitals, have full access to their own hospital's data. Access is not provided for the patients of other hospitals (public or private).

Users employed by the Central Office of the New South Wales Health Department have access to every Area Health Service's information. Access to personal identifying information (Medical Record Number and Patient Address) and Private Hospital codes are granted on a need-to-know basis.

For more information on the Secondary Care Data Cycle see the Patient Data Management Unit web-site at http://www.health.nsw.gov.au/iasd/dm/pdmu/

NATIONAL HOSPITAL MORBIDITY DATABASE

The National Hospital Morbidity Database (NHMD) is compiled by the AIHW from data supplied by the State and Territory health authorities. It is a collection of electronic confidential summary records for admitted patients separated in public and private hospitals in Australia. Data is held from the year 1993-94.

Almost all hospitals in Australia are included: public acute, public psychiatric hospitals, private acute and psychiatric hospitals, and private free standing day hospital facilities. The total number of records for 1998-99 was 5.7 million.

Main data elements included in the NHMD include

- ✓ Establishment data
- ✓ Demographic data
- ✓ Administrative data
- ✓ Length of stay data
- ✓ Clinical and related data

For more details see http://www.aihw.gov.au/hospitaldata/morbidity.html

PRIMARY CARE DATA CYCLE

Primary Care Data is collected at the national level by the Health Insurance Commission. However this information is largely for administrative and financial purposes.

There are some Sentinel Practice Networks operating to collect clinical Primary Care Data.

PERSONAL IDENTIFIERS

Unique personal identifiers are not yet used in New South Wales, but the possibility is currently being explored.

See Health*Connect*, above, for information on national plans to introduce a web-based, voluntary system for electronic health records.

GEO-CODING

The Australian Standards Geographical Classification is a hierarchical classification system consisting of six interrelated classification structures. In practice, statistical units such as households and businesses are first classified or assigned to a geographical area in one of the six ASGC structures. Data collected from these statistical units are then compiled into ASGC defined geographic aggregations which, subject to confidentiality restrictions, are then available for publication.

Statistical Local Area is a component of the Australian Standards Geographical Classification. This classification is maintained by the Australian Bureau of Statistics. The ABS also maintains the National Locality Index which is an index of suburb, localities, post codes, streets and street numbers, mapped to Statistical Local Areas.

NSW Health has a batch program which utilises the National Locality Index to assign the Statistical Local Area to residential addresses. This program sits on the Health Information Exchange at each Area Health Service and at NSW Health and so Statistical Local Area variable codes are assigned to data as it passes through the HIE.

In the NSW Health System, Area Health Service borders usually run along Statistical Local Area boundaries.

Post-codes do not map neatly into Health Service boundaries – some map to five different Area Health Services. For this reason, the Data Management Unit discourages data users from attempting to use Post Code, on its own, to assign Area Health Service. A better way of assigning Statistical Local Area is through a combination of Suburb/Locality and Post Code. 95% of these unique combinations map neatly into one Area Health Service. The remaining 5% are split at the street level.

(Australian Bureau of Statistics, 2001)

MONITORING HEALTH STATUS/DETERMINANTS

Australia's Health 2000 is the seventh biennial health report of the Australian Institute of Health and Welfare. It is the nation's authoritative source of information on patterns of health and illness, determinants of health, the supply and use of health services, and health services costs and performance.

At the regional level the biannual *Report of the NSW Chief Health Officer* on the health of the people of New South Wales provides a detailed account of available measures of health for the population. It includes more than 200 health indicators. Also, the NSW Health Survey Program (see above) is a program to monitor health-related behaviours, health risk factors, prevalence of health conditions and overall satisfaction with health services in NSW on a yearly basis.

See http://www.health.nsw.gov.au/public-health/chorep/chorep.html for a copy of the *Report of the NSW Chief Health Officer* (302 pages).

Australia's Health 2000 can be obtained from http://www.aihw.gov.au/inet/publications/health/ah00/index.html

USEFUL WEB-SITES

Commonwealth Dept. of Health and Aged Care	http://www.health.gov.au/
Australian Institute of Health and Welfare	http://www.aihw.gov.au
The Knowledgebase (at AIHW)	http://www.aihw.gov.au/knowledgebase/aboutkb.html
Health Online	http://www.health.gov.au/healthonline/
Australian Bureau of Statistics	http://www.abs.gov.au
National Perinatal Statistics Unit	http://www.aihw.gov.au/npsu/
General Practice Statistics and Classification Unit	http://www.fmrc.org.au/gpscu.htm
National Centre for Classification in Health	http://www.cchs.usyd.edu.au/ncch/ for more information.
National Office of the Information Economy	http://www.noie.gov.au/projects/ecommerce/ehealth/index.htm
Better Medication Management System	http://www.bmms.gov.au/
Health Wiz	http://www.prometheus.com.au/healthwiz/hwizf.htm
New South Wales Health	http://www.health.nsw.gov.au/
Public Health Division, NSW Health	http://www.health.nsw.gov.au/public-health/
Patient Data Management Unit, NSW Health	http://www.health.nsw.gov.au/iasd/dm/pdmu/
NSW Inpatient Data Collection On-line	http://www.health.nsw.gov.au/iasd/dm/isc/iscos/index.html
National Hospital Morbidity Database	http://www.aihw.gov.au/hospitaldata/morbidity.html
Cancer Council New South Wales	http://www.nswcc.org.au/
NSW Central Cancer Registry	http://www.nswcc.org.au/cncrinfo/research/index.htm

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Commonwealth Department of Health and Aged Care (2001) *Health Online: A Health Information Action Plan for Australia,* Second Edition Canberra, Commonwealth Department of Health and Aged Care

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New Zealand

THE COUNTRY

Formerly a British colony, New Zealand became an independent dominion in 1907. The population of 3.8 million consists of 75% Zealand Europeans, 10% Maori, 4% Pacific Islanders and 11% others.

NEW ZEALAND'S HEALTH SYSTEM

The two islands are broken down into 93 counties, nine districts and three town districts of administrational purposes, covered by 22 district health boards (DHBs). There is mixture of public and private care, with the DHBs funded by the government to run all public hospitals and health care services. There is some fixed payment for services, such as GP visits and prescriptions.

The Health Funding Authority (HFA) develops and reviews health information standards and National Data Policy Group (NDPG) oversees changes to national data reporting requirements.

Recent Approaches in Developing and Implementing Health Information Strategies in New Zealand

Health Information Strategy

Currently the Ministry of Health is preparing a new health information strategy, due for publication at the end of this month (September 2001). The previous strategy was launched in 1996 for the year 2000.[*] The aim of that strategy was:

"Timely, accurate and robust information appropriate to their roles and needs will be available to all individuals and agencies involved in the provision of health and disability support services, and to consumers, with the knowledge, agreement and confidence of everyone, which will facilitate the ongoing, continuous improvement in the health and disability status of all New Zealand people."

Two central tenets of the strategy are:

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[*] Electronic version not available, hard copy only

- That the right information is available at the right place at the right time
- Information is captured once at the place of origination and shared across the sector between all parties that need it within the bounds of privacy.

The current health information strategy is based around the WAVE Project (Working to Add Value through E-information). This project was commissioned by the Ministry of Health to review how health and disability information is managed in the country. Representatives from the Ministry and those involved in health information are involved in looking at eight topics, each one a specific project in itself. Submissions were invited from any other interested parties. The eight topics/projects are:

- Knowledge
- Electronic Health Records
- Data Standards
- Privacy
- Systems Architecture
- Sector Investment
- Organisation Design
- Strategy

Each project was charged with producing a set of recommendations and an action plan for implementation. A draft summary of these projects is now available on the website. Briefly, it was recommended that a common portal or interface be developed to access electronic information sources. The data architecture recommended is HL7 RIM and 128 bit SSL (or equivalent) encryptions to be set as minimum standards for secure exchange of electronic data. It was recommended that two new government organisations should be set up to manage health information in the future, Shared Services Organisation (SSO) and Health Information Standards Organisation (NZHISO). The draft document is available at: http://www.moh.govt.nz/moh.nsf/23

8fd5fb4fd051844c256669006aed57/06385799538200b9cc256ac40015b760?OpenDocument (*also available with other NZ hard copy documents).*

USE OF HEALTH INFORMATION IN NEW

ZEALAND

STATISTICS NEW ZEALAND (TE TARI TATAU)

This agency compiles demographic data on births, deaths and marriages, along with financial, educational, social and economic data. It publishes reports on a frequent basis, many of which are available in pdf format on the web.

THE NEW ZEALAND HEALTH INFORMATION SERVICE (NZHIS)

This NZHIS is part of the Ministry of Health and has the main responsibility for the collection and dissemination of health-related information in the country.

The NZHIS has responsibility for:

- Collection, processing, maintenance, and dissemination of health data, health statistics and health information
- Continuing maintenance and development of the national health and disability information systems
- Provision of appropriate databases, systems and information products
- Development and provision of health and disability information standards and quality-audit programmes for data
- Co-ordination of ongoing national health and disability information collections and proposals for their development
- Analysis of health information and advice on the use of information obtained from NZHIS.

The NZHIS currently manages four major health information systems, the Health Index (NHI), the Medical Warnings System (MWS), the National Minimum Dataset (NMDS) and the Mental Health Information National Collection (MHINC). Data is also collected by this organisation on the workforce in the health sector.

THE NATIONAL HEALTH INDEX (NHI)

There is no compulsory register or health identifier for New Zealanders, however many are registered on the NHI. This is a population-based register of all patients in New Zealand. Each patient is assigned a unique identifier the Index stores their name, date of birth and address, no clinical information is contained in the register. It enables an individual to be uniquely identified while maintaining privacy and anonymity. Its purpose is to ensure that when health information is sent between hospitals easily recognisable identifying details can be removed and access is restricted to authorised users only. The information is sent as soon as possible via HL7 messages to NZHIS.

For more information on NHI please access the following New Zealand Government website: http://www.nzhis.govt.nz/publications/NHI-MWS.html

The Medical Warnings System (MWS)

This system is closely linked with the NHI is designed to alert healthcare professionals of any serious or life threatening condition of the patient that may influence their clinical decisions, for example allergies, sensitivities, past medical history. It is coded in ICD-9 and data is sent immediately with HL7. For more information on MWS please access the following New Zealand Government website: http://www.nzhis.govt.nz/publications/NHI-MWS.html

Patient Throughput Statistics (PTS) National Booking Reporting System (NBRS)

These databases record in and outpatient hospital information. The PTS collects details of patient who receive assessments of priority for a medical or surgical service and are accepted for *publicly* funded treatment. The NBRS collects details of first time admissions for those over 65 years of age, along with outpatient specialities.

The National Minimum Dataset (NMDS)

The NMDS is a single integrated collection of data from all hospitals. It was developed to provide information at a national level for:

- Policy formulation
- Monitoring and evaluation of policy implementation
- Performance monitoring and evaluation
- Health status measurement
- Meeting international requirements

The Dataset amalgamates information from several sources:

- Inpatients and daypatients in public and private hospitals. The information is sent directly to the NMDS from hospital based computers. Data collected includes demographic details, diagnosis and procedures (based on DRGs and ICD-9 codes). Data has to be sent to NZHIS in the correct format 21 days post discharge.
- The New Zealand Cancer Registry (*see below)*
- Mental Health Information National Collection (MHINC)
- Birth data
- Mortality data
- Injuries
- Health sector workforce information from the Health Workforce Data Collection, which actually is 13 separate registries from all types of health professional, including doctors, nurses, dentists, dentist, technicians, physiotherapists and dietitians.

All data is anonymous. A guide to the data available from the NMDS is available from the this website

http://www.nzhis.govt.nz/publications/gdr/Guide_contents.html

MENTAL HEALTH INFORMATION NATIONAL COLLECTION (MHINC)

Since 1974 this national register has compiled the details of all psychiatric patients currently in hospitals together. Admissions, discharges, transfers and any change of legal status are recorded from all hospital and community mental health facilities including all alcohol and drug treatment centres.

THE HEALTH INTRANET

The Health Intranet arose out of the 1996 health information strategy and has been developed as a "whole of health" network. It is designed to assist the delivery of integrated healthcare by connecting, for example, general practice and secondary care clinicians, and enabling access to administrative systems such as the above mention NHI and NMDS. One the underlying principles of the Intranet is that:

"…eligible parties in the health sector should be able to access and exchange health information with other eligible parties, based on pre-agreed rights to access health information.

Security of the information is provided by several methods. A user password and a digital certificate (called a *HealthCert*) provide user authentication. The data is also encrypted and send by secure private networks ensures that information is exchanged safely. After an initial pilot phase in 1998, the Intranet went online on 15th November 1999, and in March 2001 nine District Health Boards agreed to use to the Health Intranet for access to information. GPs involved can now link into their local hospital's system to make theatre bookings and to examine referral and discharge information. Several more District Health Boards are joining in the near future.

NEW ZEALAND CANCER REGISTRY

The NZ Cancer Register has been in existence since 1948 and is a population-based tumour register of all primary malignant disease. Demographic information is collected as well as tumour details. It is maintained by the NZHIS.

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[Accessed 19th September 2001].

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Ministry of Health, Wellington (+12 hrs)

00 64 4 49620000

NZHIS, Wellington (+12 hrs)

00 64 4 9221800

USEFUL WEBSITES

New Zealand Health Information Service	http://www.nzhis.govt.nz
Statistics New Zealand	http://www.stats.govt.nz
Ministry of Health	http://www.moh.govt.nz

Finland

THE COUNTRY

Finland has a population of 5.2 million spread out over 300,000 square miles. Most people live in cities and towns, and the landscape is dominated by over 60,000 lakes. The country is divided into 11 provinces, and about 450 municipalities. Municipalities are the key mechanism for delivering most public services to citizens, including health care. Municipalities have considerable freedom in deciding what services to purchase, and in tailoring service provision to local needs.

HEALTH SYSTEM

DEVELOPMENT

An excellent introduction to the Finnish Heath system is available at http://www.observatory.dk/index-2.htm. as part of the Health Care Systems in Transition series from the European Observatory on Health Care Systems. The following is abstracted from that source.

In Finland, the organisation and financing of health care has long been considered a public responsibility, a tax-financed health care system has developed gradually.

The Finnish Municipalities have long been the basic units to arrange health care for their citizens. In the time before the Second World War Municipalities concentrated mainly on the treatment of tuberculosis, other communicable diseases and mental diseases. Municipalities began to organise health services by employing General Practitioners and public health nurses. Municipalities usually provided these General Practitioners with facilities and personnel but a considerable part of General Practitioners' income came from direct payments by patients. As the overall number of doctors and nurses was small, they had to handle a wide variety of health problems.

In the 1940s maternity and child care centres began to be built throughout the country. The right to maternal and child health care was fixed by law to every mother and child irrespective of residence and financial situation.

The provision of hospital care was fairly modest in the first half of this century. Treatment for tuberculosis was provided at specific tuberculosis hospitals. In the 1940s Municipalities formed federations, so called Tuberculosis Districts, which were responsible for the treatment and prevention of tuberculosis.

The development of the hospital system was given a push in the 1950s. A new law stated that secondary care was to be provided by about 20 central hospitals which were built in larger towns with separate psychiatric hospitals. The bulk of state owned hospitals were passed into the possession of Municipalities. Later in the 1960s, regional hospitals were built in smaller towns.

A State Sickness Insurance scheme was therefore introduced in the 1960s. Part of the costs for medical care, drugs and some other services were reimbursed through this scheme.

In the beginning of the 1970s, there were still striking differences in the availability of health services. Most of the services were concentrated in urban areas. There was also an imbalance between primary and secondary health care. A network of specialised hospitals with high standard existed, but the supply of outpatient services and primary health care was insufficient. Also almost 90% of total health care expenditure was spent on hospital care and only 10% on primary care.

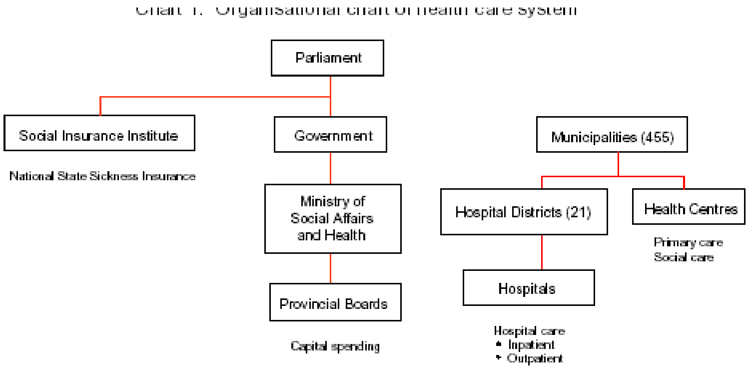
These issues were the reasons for the introduction of the Primary Health Care Act in 1972. A national plan for primary health care was also introduced then. The 1972 Primary Health Care Act obliged Municipalities to provide primary and public health care to their inhabitants. This care was to be provided in health centres. All primary and public health care which had until then been provided in a fragmented way, were brought together under the administration of health centres. This meant that the health centres began to provide primary medical care, various kinds of preventive services, home nursing, occupational health care and many other services. As health centres did not exist before the introduction of the law, the 1970s saw a comprehensive build-up of health centres in the country.

Other cornerstones in the history of Finnish health care are the inclusion of hospital care in the national planning in 1974 and the introduction of the Occupational Health Act in 1979. The latter obliges employers to provide occupational health services to their employees. In 1984, new legislation brought social services, (for example, children's day care and homes for the elderly) into the same planning and financing system as health care. Since then, the collaboration of social and health care has been stressed both on local and national level. A marked feature of the 1980s was the continuous decrease in the regulation by the state.

ORGANISATIONAL STRUCTURE OF THE HEALTH CARE SYSTEM

CENTRAL AND LOCAL GOVERNMENT IN FINLAND

Organisational Chart for the Finnish health care system



http://www.vn.fi/stm/english/

The Ministry of social affairs and health has responsibility for health policy making, for environmental health, for health promotion and for setting standards in health care. () Most health service delivery is the responsibility of the municipalities, the fundamental unit of local government in Finland. Infectious disease notification is the responsibility of the Ministry, but is delivered by the National Public Health institute and the Hospital boards.

Municipalities

http://www.intermin.fi/eng/municipal/index.html

In Finland, Municipalities have by law the main responsibility for arranging basic services like schooling, social and health services, to their populations. At the moment there are 455 Municipalities. The range of population varies from less than 1 000 inhabitants to about 500 000, the average size being about 11 000 inhabitants. Municipalities have the right to levy taxes. They also receive a subsidy from the state to enable them to arrange the services they are obliged to provide. In addition to the state subsidy for health care, Municipalities receive subsidies for social services and schooling.

A key feature of the Municipality system in Finland is the possibility of inter-municipal co-operation. Much of the Finnish Health service is provided by this mechanism.

Hospital services

Hospital services are delivered, overwhelmingly by public hospitals, organised into 21 Hospital Districts, established in 1991. These do not correspond to the eleven provinces.The Hospital Districts are responsible for providing hospital services and co-ordinating public hospital care within a defined area. Each Municipality must be member of a Hospital District. One Hospital District usually comprises 1-3 acute (non-psychiatric) hospitals and 1-2 psychiatric hospitals. Both in-patient and out-patient care is provided in these hospitals.

Purchasing of services

Municipalities usually purchase services from hospitals within the Hospital District they belong to, although they may purchase services from outside their own district or from a private provider.

The reasons for Municipalities not purchasing from outside their own district may be geographical (distance) or it may be that the service prices are higher for members of another Hospital District. As prices and services are defined in very different ways it is impossible to compare different producers and choose the most cost-effective one.

There is a sophisticated equalisation system. This covers very costly procedures. Essentially costs over an agreed threshold for care to an individual are shared amongst all of the municipalities in a given hospital district. As a small municipality might have only 2000 inhabitants, such a system is clearly essential.

Private health care

Private hospitals have a very limited role in the provision of health care in Finland. Most private care is ambulatory care provided by specialists with positions in the public sector. However about 7% of all Finnish doctors work exclusively in private practice, and around one in three have some private practice.

Primary care services

The original role of the municipalities in providing health care was the organisation of family doctor and community nurse services. However occupationally provided health care is also important, and a significant proportion of the health care budget comes from employers through the National State Sickness Insurance fund. This partly accounts for the large size of the Finnish Institute of Occupational Health.

Primary care is mainly provided through 250 health centres. These may, and in cities often do, occupy more than one site. They are well equipped, often having laboratory and radiology facilities. Services provided include nursing services, general practitioner services, mother and child heath services, immunisation, and a limited supply of in-patient beds. These are mainly occupied by elderly patients. There are national guidelines for quality of service provision.

Health centres also provide some of the occupational health care. Most of this care is provided in on-site health centres established by employers.

HEALTH INFORMATION SYSTEMS

POPULATION REGISTERS

http://www.vaestorekisterikeskus.fi/prc.htm

Like the other Nordic countries Finland has a comprehensive set of population registers. These are controlled by the Ministry of the Interior. The most important of these is the master population index, which contains a single record for each person living in Finland, with a unique identifier. This identifier is the key link in most of the health statistics systems in Finland. It is allocated at birth registration. There is also a residence index, which allows the allocation of individuals to areas of usual residence with great reliability.

It is important to emphasise that these identifiers are used for everything. There are registers of education, of taxation, of residence, and many other non-health registers. These identifiers and registers are far more than health service numbers.

In Finland, the authorities have been collecting population information since the 16th century. The population registration entered the computer era at the beginning of the 1970s, shortly after the nationwide central population register was established. The Population Register Centre was founded in 1969 and it operates under the Ministry of Interior. Data on buildings and residences has been collected since the beginning of the 1980s. The present population information system is one of the most sophisticated on earth.

Population information is used for various purposes. The population information system contains the official information for the whole country on

- Finnish citizens and aliens residing permanently in Finland
- Buildings and residences and their holders.
- Real estate units and office and business premises.

The population information system provides data to the administrative authorities and courts of law as well as for statistical and research purposes. Business enterprises and private citizens may obtain for example address information.

DATA SERVICE

Considerable savings in costs are achieved in society when basic information on people, buildings and real estate are obtained centrally from the population information system. For instance in administration avoiding the handling of numerous certificates and extracts and thus serves the private citizens better. For private companies and other organisations the population information system is a cost-efficient information source for example for the maintenance of customer databases.

Their services include

Direct computer connections

- direct-access inquiries to the population information system
- application connections and message data transfer

Up-dating of customer registers

- continuous or one-time-only updating
- service on changes in the data

Random samples

- samples, for example addresses in various forms

Telephone data service

- address-information telephone
- the Population Information Telephone for authorities

Document services

- extracts from the population information system

The mass distribution of population information is based on the Act on Population Information (1993/507) and always requires a data permit from the party maintaining the register and giving out information from it. This procedure ensures that data protection principles are observed.

A person may forbid the giving out of his personal and address information for direct marketing, address service, personal registers or genealogy by notifying the Population Register Centre or the local register office.

REGISTRATION OF A FOREIGNER IN FINLAND

Basic information on people residing in Finland are recorded in the Population Information System. Such information to be registered include e.g. name, date of birth, nationality, family relationships and address. The information that is registered is used for example for the purposes of elections, taxation, health care, judicial administration and statistical purposes.

WHAT IS A PERSONAL IDENTITY NUMBER

The personal identity number is a series of numbers, consisting of the persons date of birth, individual number and a control sign. The individual number differentiates people born on the same day. The individual number is uneven for men and even for women. The control sign is either a number or a letter.

EXAMPLE: personal identity number 131052-308T

1 31052 = date of birth (date/month/year)

308 = individual number

T = control sign

The personal identity number is used for identification purposes, for example banks, hospitals and the registers of different authorities.

LOCAL REGISTER OFFICES

Local register offices (maistraatti in Finnish) function as local authorities within the area of one or several judicial districts. Local register offices and their service units are responsible for the registration of data and they serve customers by issuing certificates and extracts as well as by providing local information services.

THE POPULATION REGISTER CENTRE

The Population Register Centre develops and controls the registration, maintenance and delivery of population information together with the local register offices. It is responsible for the national information services and permit decisions relating thereto. Information services are developed and tailored to meet the needs of the customers. It plays a key role in Vital Statistics as it collates and provides the weekly vital statistics notifications to Statistics Finland.

A recent development is the electronic ID card, more information on which is available here. http://www.fineid.fi/default.asp?todo=setlang&lang=uk This provides ready access to the personal identifier for citizens. It also provides for electronic signatures, serves as a personal identifier, and can be used as a travel document within Europe.

HOSPITAL EPISODE DATA

Discharges from hospitals are recorded in the hospital, coded locally to ICD-10 by medical staff and collated by STAKES. More details are given below.

PRIMARY CARE DATA

There is no central collation of primary care data in Finland, although pilot projects are under way. There are several functioning sentinel practice systems, for example in Turku. Many Finnish health centres have sophisticated computerised systems for data handling, and electronic patient records are in fairly common use. We anticipate that a Finnish primary care information system could be established fairly easily in the next few years.

STAKES

http://www.stakes.fi/english/

STAKES, or the National Research and Development Centre for Welfare and Health, is the other key organisation. It has two distinct roles. It is the major data collection agency for Finnish health information. It is responsible for data collection from hospitals, and for the maintenance of most of the Finnish disease registers. The NPHI (KTL) develop their own registers from data supplied by

STAKES. It promotes and provides related training and makes the proposals and initiatives needed to develop social welfare and health care. Its goals focus on prevention, services, information sources and information services.

It is also a research unit with two specific functions. It monitors and prepares regular reports on the health and social status of the Finnish population, and makes this information available to decision makers. STAKES monitors and evaluates the operation and development of the social welfare and health care systems and carries out research and development in the field of social and health care services. It produces and acquires Finnish and foreign information and know-how, and passes this on to field workers, workplaces and decision-makers in the sector.

It reports to the Ministry of Social Affairs and Health. It is smaller, with 200 staff, and an annual turnover of £25 million. Compared with KTL, STAKES has a less medical orientation. Although STAKES itself is only a decade old, it has a long history. STAKES originated in the merging of the research arms of the Board of Health and the Board of Social Welfare. It also acquired the research arm of the state Alcohol Corporation.

STAKES collects information from all Finnish hospitals, public and private and form nursing homes. It covers all admissions including day surgery. Outpatient data is not yet collected but a pilot project is underway. There are no plans at present to collect A/E data. Data are coded by doctors or nurses. This used to be dome manually, using short lists of common codes on paper, but is now done with the help of computerised systems in many places. This system is the basis for the registries.

STAKES provides much of its information over the Web. This has two goal, one is to reduce the amount of their time taken up providing simple reports for other, and the second is to speed access to current health information for users, planners, citizens and others.

STAKES is also responsible for providing benchmarking information to Finnish hospitals. Until recently there was relatively little feedback from STAKES to those collecting the data. An exception was the perinatal data system. One of our informants felt that this adversely affected the quality of some of the other registers.

There are about twenty specific disease registers in Finland, These are mostly held by STAKES or KTL. They are of variable, but generally very high quality. Specific difficulties have been noted with disability registers.

NATIONAL PUBLIC HEALTH INSTITUTE (KTL)

http://www.ktl.fi/en/nphi.en.html

The Finnish National Public Health Institute (KTL) is a large research and information analysis organisation. They currently employ 850 people, 320 of whom are researchers, and have a budget of approximately £35 million pounds.

Founded in 1911 as the state serum institute the KTL is now an independent agency, forming part of the Ministry of Social Affairs and Health. It has a diverse set of functions, partly reflecting its historical origins. These include

- research to promote the health of the population
- monitoring issues affecting the health of the population
- performing a range of public health service functions (e.g. vaccination, maternity clinic, monitoring of infectious diseases, some research in forensic medicine)
- developing, assessing and performs some laboratory research
- participating in further and professional education in its own field

- participating in the dissemination of health information and health education

Their research programme covers three main areas, the health impact of smoking, alcohol and drug use; environmental health, including food safety; genetics and health. One of their key roles is as the principal surveillance agency in Finland. They are responsible for infectious disease surveillance, vaccination surveillance, monitoring of chronic diseases (but not occupationally induced diseases), monitoring health behaviour and monitoring dietary patterns. They prepare regular national disease audits.

An interesting component of their monitoring activity is the Health 2000 survey, a comprehensive national sample survey on population health, similar in intent to the Irish Slan survey. They have several disease registers, derived from linkages between the Hospital Discharge register, the population register and the death register. They have an important role in reporting on the health of the Finnish population and health service activity in Finland. These include the Cancer registry, registers of congenital malformations, cardiovascular disease and others.

FINNISH INSTITUTE OF OCCUPATIONAL HEALTH (TTL)

http://www.occuphealth.fi/e/

The Finnish Institute of Occupational Health (TTL) is a research and advisory institute whose main tasks are research, training of occupational health and safety professionals, provision of advisory services, and dissemination of information. Altogether 10 disciplines related to occupational health and safety are covered by the Institute. The Institute has a total of 850 employees. The Central Institute and six Regional Institutes provide services for the whole country.

TTL has several different functions, all related to the Work environment. It monitors occupational disease, and is responsible for occupational health and safety, including training and exposure monitoring. It also studies working patterns, and has a substantial programme of work on white collar and retail workers, in addition to the more traditional work on industrial workers, construction workers and workers in the timber industry (very important in Finland).

It has many departments including epidemiology, physics, psychology, occupational health, occupational safety, industrial hygiene and toxicology, and occupational monitoring, including a sophisticated laboratory service.

It maintains a national register of occupational diseases, which produces annual reports. The 1999 report was produced early in 2001. Data comes from employers and occupational physicians, through the insurance systems, and directly from doctors, through the labour inspection system. The report is available from here –

http://www.occuphealth.fi/e/infoserv.htm

Training, in occupational health and safety, is another major role for TTL. The training of the Institute consists mostly of courses which are open to everybody working in the field of occupational health and safety; of tailored courses ordered by companies and organisations, and distance education courses, which are becoming increasingly popular. The main target groups (customers) consist of occupational health care personnel (physicians, nurses, physiotherapists, etc.).

TTL also runs an open-access information services centre at http://www.occuphealth.fi/e/dept/tpk/overview.htm There are library facilities, and many electronic resources.

STATISTICS FINLAND

http://www.stat.fi/index_en.html

Statistics Finland provides a range of reports on Vital Statistics and population data. The annual report "Population Structure" publishes detailed data on the structure of the population, 7 months after the end of the reference year.

The annual "Vital Statistics" publishes detailed data on the vital statistics of the population, 11 months after the end of the reference year. This publication includes time series data for 10 series. The quarterly "Vital Statistics Bulletin" disseminates data covering the whole year.

The annual "Statistical News: Vital Statistics" publishes more detailed data on the vital statistics of the population, 9 months after the end of the reference year.

The Statistics Finland SuomiCD (CD Finland), a regional CD-ROM database, contains a wide variety of information on consumers and households by postal code areas and municipalities. SuomiCD consists of a database and a software program, which enables users to search for target groups and to manipulate, sort and print out the data, as well as create areas and compile tables to their individual specifications.

The Geographic Information Service Unit of Statistics Finland provides geographic information on population in the form of data and boundaries, databases, map printouts or regional analysis by: (1) grid square; (2) block; (3) town quarter; (4) postal code area: (5) localities; (6) municipality; (7) economic, work or other area; and (7) a regional division specified by the client.

USEFUL WEB ADDRESSES

Statistics Finland	Http://www.stat.fi/index_en.html
Institute of Occupational Health (TTL)	Http://www.occuphealth.fi/e/
National Public Health Institute (KTL)	Http://www.ktl.fi/en/nphi.en.html
STAKES	Http://www.stakes.fi/english/
Population registry	Http://www.vaestorekisterikeskus.fi/prc.htm
Ministry of the Interior (Municipalities)	Http://www.intermin.fi/eng/municipal/index.html
Ministry of Social Affairs and Health	Http://www.vn.fi/stm/english/

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APPENDIX 1

This report seems to us to be of special interest. It is available at http://www.vn.fi/stm/english/health/it_health.htm

THE UTILISATION OF ICT IN FINNISH HEALTH CARE

– a Report for the EU Working Group on Health Telematics

1. Health care and social welfare in Finland

The Finnish social protection system is built on the Nordic welfare model. The central features of the Nordic welfare state are the principle of universality, a strong public sector, tax funding and equal treatment. The State plays a relatively strong role with regard to steering it by setting core principles and monitoring the implementation of these. The Ministry of Social Affairs and Health sets forth the operating principles and directs and guides the development of services. Together with the Parliament it defines national policy guidelines, prepares key reforms and guides their implementation.

However, the responsibility for organising and financing health care and social welfare services is mainly vested at the local level, in municipalities (448 municipalities in total). Services are financed primarily out of the taxes collected by the State and municipal government. Municipalities produce services independently, through their own functions. Some services are provided jointly by several municipalities or by purchasing services from another municipality, from non-governmental organisations or from the private sector.

The municipality bears the main responsibility for financing health care and social services. Municipalities receive every year a block grant from the government for all local operational costs.

Municipalities are responsible for organising the provision of health care. Hospital care is provided by a hierarchy of hospitals comprising university hospitals, central hospitals and health centres with sick wards. Nearly all hospitals are owned by a municipality or by a joint municipal board.

Municipal health centres also provide the needed out-patient care. Health centres are also responsible for arranging home nursing within their respective areas. Private medical care supplements the services provided by the public sector, in particular in large towns. Private occupational health care covers all citizens of working age.

2. The strategy for utilising of ICT in social welfare and heath care and its implementation

During the first years of the 1990's it was clear that information and communication technology would be the leading technology. The government published a national strategy "Finland's Way to the Information Society" in 1995.

The National Committee for the Strategy for Utilising of ICT in Social Welfare and Heath Care (The Ministry of Social Affairs and Health 1996) proposed a new citizen centred care model, seamless services where the client will be an active partner and where the present organisational and information barriers are made invisible. Because seamless services also need seamless information access it is necessary to use the possibilities of information and communication technology to make this possible.

The implementation phase of these principles is realised by:

- Disseminating best practise rules from pilot projects and formulating national guidelines
- Financial participation of the Ministry of Social Affairs and Health in major local and regional ICT projects
- New provisional legislation for pilot projects
- High industrial participation in the local development projects
- Utilisation of new technology like smart cards, secure web and virtual patient records
- Technology programmes for developing innovative products to improve health care processes through ICT solutions

A central part of the implementation process was the establishment of national committees for seamless care and services, citizen smart card and security (1998). The Ministry of Social Welfare and Health currently funds several local and regional ICT-projects. The largest of them is the Satakunta Macro Pilot.

3. Information systems

3.1 Legacy systems

All Finnish hospitals are using some kind of digital information systems (e.g. some form of HIS). Those legacy systems typically include functions such as patient administration, clinical laboratory services, workstations for departments and emergency units. Picture archiving systems are typically separate subsystems having a limited number of workstations for emergency units and departments.

Most Finnish hospital information systems are 10-15 years old and based on local (non-commercial) design. Therefore they have limited EPR functionality. There are two parallel re-engineering processes running at the moment. During the next 3-5 years many hospitals will change their old legacy system to a new commercial EPR system. At the same time the rest of the hospitals are updating their old text based terminals to workstations with browser-interface to patient records.

From the roughly 200 primary health care centres only the smallest have a manual patient administrations system. PHC software is commercial and nearly 60% of health care centres have a full scale EHCR system in daily use. The trend is to install a commercial EHCR system and connect it to the nearby located hospital.

Private occupational health care is using EPR systems tuned to this purpose. There are nearly 20 separate commercial software systems on the market for occupational health care.

3.2 Regional and national infrastructure

There is a strong trend towards moving from isolated hospital information systems to networked regional systems. The first phase was to connect all Finnish hospitals together using broad band connection (via ATM network). This has been done during the last 5 years of the 1990's. At the same time hospitals and health care centres will be networked inside a hospital district. The result is an open (and commercial) national health information highway – a target set by the previously mentioned national ICT strategy for health care.

In Finland both the industry and health care providers have selected a message based integration architecture for regional and national communication. We are using HL7 message standards and in the future more and more XML messages for transferring patient information between health providers and professionals.

The national PKI architecture for e-health applications is now under development. This architecture includes also security and e-consent features and is supported by the Finnish social security smart card.

On the other side some specialities such as imaging and clinical laboratories are building their own regional systems. There are 4-5 regional projects under way (e.g. HUS- PACS project and TEL-Lappi tele-consultation project). Another widely used regional application is the electrical referral-care report system, which is quite close to being a de-facto standard in Finland.

The Social Insurance Institution (KELA) - a body subordinate to Parliament - is responsible for providing social security to everyone living in Finland. One of the schemes administrated by the Social Insurance Institution is National Health Insurance financed via State taxation. The Social Insurance Institution is servicing citizens via a nation wide ATM network with about 200 distributed workstations. The Social Insurance Institution is also the distributor of the Finnish social security card and therefore a partner in the national PKI system.

3.3 Systems for seamless care

The regional ICT system supporting seamless care and services is the major development line in health care domain. A reference architecture is developed by the Satakunta Macro Pilot project for this purpose. This architecture both links the information systems of regional service providers (private and public) and at the same time gives web-based services for health professionals and citizens. The two major projects for seamless care are the Satakunta Macro Pilot and HUS Regional system (Hospital District of Helsinki and Uusimaa), but also other hospital districts will install similar systems supporting seamless care.

The purpose of the Macro Pilot is to implement seamless welfare and health care services.

It uses several ICT applications (e.g. regional virtual patient records, social security card, identification and encryption, e-signature, secure web for consultation and yellow pages) to support the seamless service principle. The Ministry of Social Affairs and Health has also prepared a pilot act for the Macro Pilot. This legislation includes necessary rules for the social security card, service chain "managers" and security principles for virtually networked patient records. The implementation of the needed regional information system is realised by a large industrial consortium.

4. ICT and medical devices

Hospitals and health care centres use widely computerised medical devices for many kinds of services (e.g. EEG and ECG analyses). The mobile use of clinical analysers is also common. In the mobile case measured signals will be transferred via GSM network to the specialist or to the hospital. Ambulances, home hospitals and home care services are the primary users of mobile analysers.

There will also be a growing number of clinical analysers used at home by patients themselves. Self-measured results can be sent via Internet or GSM links to the patient's family doctor. This kind of applications (applications supporting independent living) are typically targeted to patients having asthma, diabetes or high blood pressure.

5. The access to Internet based services

5.1 E-mail

About 50% of Finnish hospitals and health care centres are providing Internet services for professionals (1999). Internal e-mail is widely used but some old legacy systems have still limited possibility to support e-mail or Internet services directly from clinical workstations. All service providers have plans to give e-mail facilities to their health professionals.

5.2. Tele-consultation

Tele-consultation is widely used between hospitals and health care centres. There are more than 40 pilots/applications in use (e.g. tele-radiology, tele-psychiatry, tele-dermatology, teleophthalmology). A new application is the consultative and interactive referral between GP and the specialist. The e-mail consultation via the secure web is becoming a daily practise.

5.3 Citizen access

Until now the citizen access has been limited to the external web-services (e.g. Yellow pages) of hospitals. New regional systems like the Satakunta Macro Pilot will also support the possibility to access patient's own health information using secure web-services. Some private medical centres have also introduced a system of Internet-based bookings.

5.4 Access to knowledge- bases

Most hospitals have enabled access to knowledge bases located outside the hospital Intranet, but for security reasons there are limitations regarding where you open the connection. All medical doctors can buy and use the CD-based "GP's Handbook" in their daily practice.

The Finnish Medical Science Association (Duodecim http://www.duodecim.fi/english/) has a new portal for health professionals. This portal makes it possible for health professionals to access both national and international knowledge bases. Most hospitals and many health care stations will also provide access to this portal in the near future.

Health-related information for citizens over the Internet is provided by a wide range of actors. These include public bodies, private enterprises as well as non-governmental organisations.

Sweden

THE COUNTRY

Sweden is situated in the eastern part of the Scandinavian peninsula. It covers an area of 400,000 square miles, with forests covering 58% of the land area. The capital is Stockholm, which is also the largest city. The country is unevenly populated, with a high concentration of inhabitants in the coastal regions and the south. 84% of the population live in urban areas. The population is about 9 million (1995).

Swedes are the predominant ethnic group, constituting roughly 90% of the population. Other residents include people from Finland, South America, the Middle East, Asia and the Balkans. The main language is Swedish. 90% of the population belong to the Lutheran church. The educational system reaches the entire population resulting in a literacy rate of 99%. Living standards are among the highest in the world. Life expectancy is high, and infant mortality rates are among the lowest in the world.

There are great similarities between the administrative systems in Finland and Sweden. This partly reflects history. Finland was ruled by Sweden for many years, before it fell under Russian domination. The comparison between the two systems is of great interest.

HEALTH SYSTEM

DEVELOPMENT

Much of the following material is derived from the excellent introduction to the Finnish Heath system at http://www.observatory.dk/index-2.htm as part of the Health Care Systems in Transition series from the European Observatory on Health Care Systems. The following is abstracted from that source.

In 1862, county council administrative units were established, as a secondary level of local government and were given the power to levy taxes on their residents. Health care become one of their principal duties. This marked the beginning of the present structure of the Swedish health care system, which is characterised by a strong degree of decentralization. However, health care responsibilities were transferred from central government to the county councils over nearly 120 years.

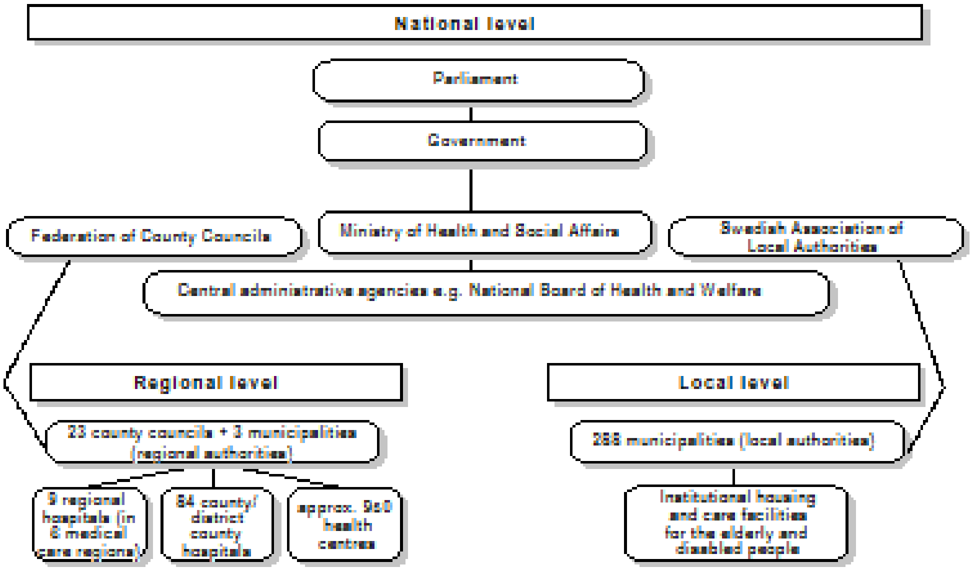
A considerable expansion of the health sector took place following the second world war and continued throughout the 1960s and 1970s. In particular, this involved the hospital sector and at the time the Swedish health care delivery system became more hospital-based. At this time there was also further transfer of responsibilities to the county councils.

In 1970, as part of the "seven crown reform", out-patient services in public hospitals were taken over by the county councils. Patients were asked to pay seven crowns to the county council for each out-patient consultation and the county council was compensated directly by the health insurance authority for the remainder of the cost.

The considerably reduced fee incurred by the patient made health care more accessible to low-income groups. The reform also meant that physicians in hospital outpatient departments became salaried employees of the county councils. At the same time hospital physicians were no longer allowed to treat private out-patients in county council facilities.

ORGANISATION OF THE HEALTH CARE SYSTEM

Figure 1 shows the current organisational structure of the Swedish health care system.



At present responsibility for the health service is divided in a rather complex way, between county councils, municipalities and central government. In contrast to Finland where the roles of municipality and central government are very distinct in Sweden the organisation is less clear.

The county councils were fully responsible for the financing and provision of health care between 1983 and 1992. In 1992, a major change was introduced through the ÄDEL-reform, whereby the responsibility for long term inpatient health care and social welfare services to disabled individuals and to the elderly became the responsibility of local municipalities.

As a result of this reform, one fifth of total county council health care expenditure was transferred to the municipalities. The central government also made it possible for the municipalities, subject to agreement with their corresponding county councils, to temporarily (for five years) assume county council responsibilities for primary care on an experimental basis. In 1995, municipalities became responsible for the care of those suffering from long-term mental illnesses (the "psychiatric" reform).

CENTRAL AND LOCAL GOVERNMENT IN SWEDEN

The principal responsibility of the central government of Sweden is to ensure that the health care system runs efficiently and according to its fundamental objectives. This is the responsibility of the Ministry of Health and Social Affairs. It prepares Cabinet business and deals with policy matters and legislation in health care, social welfare services and health insurance. It allocates financial assistance and acts as a supervisor of the activities in the county councils. The government may legislate on temporary ceilings on county council and local municipality tax rates.

HEALTH CARE PRINCIPLES

The main objectives of health care are good health and care on equal terms for the entire population.

One priority is that medical care should be easily accessible for anyone not feeling well or having a disease. Everyone who needs medical attention should be able to receive it. At the same time, the responsibilities of health care are limited to care which demands the clinical personnel's special skills. In the event of sickness or injury, patients are guaranteed medical attention by the appropriate medical institutions with the competence and resources to deal with the problem.

In 1995, an official report on health care priorities suggested three major principles as guidelines:

- The principle of **human rights**: all humans have equal value and equal rights irrespective of their personal qualities and positions in society.
- The principle of **need or solidarity**: resources expended should focus on the human being or the sector that is in greatest need.
- The principle of **cost-effectiveness**: when choosing among different sectors or actions, a reasonable relationship between costs and effects, should be obtained – measured in improved health and higher quality of life.

The above three principles are ranked, so that the principle of human rights takes precedence over the principle of need and solidarity. The principle of cost-effectiveness is subordinated to the other two.

Guidelines are distributed by the National Board of Health and Welfare, but it is up to the county councils to establish their own priorities. There are five levels of priorities to be followed according to the guidelines.

Table 1. Priorities for political/administrative prioritzation

Priority description of care needed

1. Care of life-threatening acute diseases and diseases which without treatment will lead to a longer invalidity or too early death. Care of serious chronic diseases. Palliative care in the final phase of life. Care of people with reduced autonomy.
2. Prevention with documented benefit. Rehabilitation etc. according to the definition in the Health Care Act.
3. Care of less serious acute and chronic diseases
4. Borderline cases
5. Care for other reasons than disease or injury

ORGANISATIONS

COUNTY COUNCILS

The tier under the central Government is the ‘county council’. These correspond to the Finnish provinces, but unlike these they have considerable powers and resources. There are 23 of these, and three municipalities, Gotland, Gothenburg and Malmoe. These three municipalities have decided not belong to any county council. Originally, the counties were the main providers of health care, however a significant proportion of their responsibilities now lie with the municipalities.

In January 1984, the 23 county councils and three municipalities were grouped into six medical care regions: the Stockholm Region, the South Eastern Region, the Southern Region, the Western Region, the Uppsala-Örebro Region and the Northern Region.

The rationale for establishing these regions was to facilitate co-operation between the county councils and the three municipalities in highly specialized treatment (tertiary care). Top clinical hospitals are, by agreement, organised at the level of the six regions and run individually by the county councils.

Each of the regions serves a population averaging more than a million. There is no large administrative structure associated with the six regions. Instead, small regional offices have been established to deal with matters related to the financing and production of tertiary care. In these six regions there are a total of nine regional hospitals which are highly specialized. With the exception of Örebro, they are also affiliated to medical schools and function as research and teaching hospitals. The regional hospitals provide secondary care to the population in their respective county councils, in addition to highly specialized tertiary care.

Private health care is quite limited, with only about 8% of physicians working full time in private practice. It is mainly in the larger cities that private practices are common.

MUNICIPALITIES

Physically under the county councils, but not in any real sense directly subordinated to them, are the municipalities. There are 288 of these, varying greatly in size. By comparison note that there are nearly twice as many Finnish municpalities.

Like the county councils, the municipalities are governed by local councils elected every fourth year and also have the right to levy taxes on their population.

The Municipal Executive Board leads and co-ordinates all the Municipality’s business and acts as a supervisor for the committees. The municipalities are responsible for social welfare services, child care, care of elderly, disabled persons and long term psychiatric patients, care of environmental hygiene and for school health services.

In 1992, municipalities took over the responsibilities of the care of elderly and disabled from the county councils (the ÄDEL-reform). As a result they now operate public nursing homes and home care. In a similar way on 1 January 1995 they also took over responsibility for the care of those suffering from long-term mental illnesses including their living conditions, employment and support.

PRIMARY CARE SERVICES

Primary health care is mainly publicly provided. Primary care services deliver both first-level curative as well as preventive care through public primary care centres. Sweden has approximately 950 health centres, each of which provides services to 20 000–50 000 inhabitants. These are administered by the county councils, not by the municipalities.

GP’s provide treatment, advice and prevention. Primary care services also include clinics for children, vaccinations, maternity controls, health checks and consultations as well as certain types of treatment. Others directly employed at this level are nurses, midwives, physiotherapists, paediatricians and gynaecologists, all of whom are part of the health centres.

District nurses have a special role as many first contacts with the health care system are their responsibility. They often see the patients first, and if necessary send them on the GP or refer them to the hospital. They also make home visits, especially to the elderly.

The GP is not necessarily the first contact for patients with health problems, nor does she or he have a role as gatekeeper to other levels of care. Despite this, the GP often provides first contact services especially for the adult and elderly populations with mainly physical health problems.

Within this general system, there are many different models of care. Each county council has to decide on how to provide primary care for their own population. Care of the elderly has been moved from the county councils to the municipalities in recent years. This is also the case for psychiatric treatment and care for the mentally disabled.

Quality

In 1994, the National Board of Health and Welfare produced a new regulation, according to which regular, systematic and documented work to ensure quality shall take place in the health services. Health care workers are obliged to integrate continuous and methodical quality assurance activities into their daily routines. The patient's needs are often the decisive factor when the objectives for these programmes are established.

Several county councils have established quality committees or assigned a special quality assurance manager to support the hospital and the health centres in developing systems for quality assurance and continuous quality improvement. Some county councils also have a special budget for quality improvement activities. In hospitals, quality committees at management levels are becoming common. Health care staff meet in order to continuously observe their performance and seek possibilities for improvement.

Freedom of choice

Freedom of choice gives the patient the right to choose a primary health centre or hospital within the same level of care. However, patients cannot always make choices about care on higher levels of referral. In the majority of the county councils it is possible to choose which hospital the patient wishes to use.

One method available to the county councils to influence the decisions of patients is to differentiate the fees patients have to pay for the services. If a patient wishes to receive medical care at a hospital outside the county council in which he or she resides, a referral may be required. In inpatient care, the patient has the right to choose a department for treatment or surgery outside or inside the county councils. Certain special rules apply when a patient chooses a hospital outside the county council boundaries.

Private health care

The private sector has a limited, but growing role in Swedish health care. Most private care is in large cities. There are several private health insurance companies, which compete with each other.

ENVIRONMENTAL HEALTH

Environmental protection is becoming increasingly important both locally and on a national level. The local authorities, municipalities, bear the responsibility for the major part of local environmental policy. This includes disease prevention, food quality, animal protection, nature management and conservation, water management, drinking water quality, sewerage policy, garbage disposal, supervision of environmentally hazardous activities, and chemical controls.

Environmental safeguards in the form of natural resource management and structural planning are also becoming increasingly important, not least in the light of efforts to ensure local implementation of Agenda 21, signed at the Rio summit on the world environment in 1992. Municipalities also work on new forms of environmental auditing and accounting as well as on new environmental tariffs to improve protection, food quality and animal welfare.

NATIONAL SOCIAL INSURANCE BOARD

The National Social Insurance Board handles national social health insurance, and acts as a supervisor for the local insurance offices. The Board administers the social insurance system and sees that it runs efficiently. The national public drug system and health insurance system are strongly linked to health care, prescription of drugs and prescription of sick-leave.

SBU

The Swedish Council on Technology Assessment in Health Care (SBU), is a body associated with the NBHW, whose principal objective is to promote the use of cost effective health care technologies. It reviews and evaluates the impact of both new and existing technology from medical, social and ethical perspectives. Information on results is disseminated to central and local government officials and medical staff to provide basic data for decision making purposes.

SPRI

http://www.spri.se/english/default.htm

SPRI (The Swedish Institute for Development of Health Services),works on planning and efficiency measures. It is an independent research and development institute committed to advancing healthcare delivery in Sweden. They promote quality improvement in health care, develop methods for efficient resource utilization, and create opportunities for information exchange. Spri engages several thousand healthcare professionals in a wide range of projects. he Institute works with health statistics, health quality and health economics. SPRI is jointly owned by the central government and the county councils. It ahs a staff of about 100, and an annual budget of 90 million Kroner (about £IR 7 million)

PHARMACEUTICAL REGULATION

The National Corporation of Swedish Pharmacies is a state monopoly which owns all pharmacies and thereby maintains a countrywide distribution system. It operates community pharmacies and hospital pharmacies under one year contracts with the county councils. Besides this, the National Corporation of Swedish Pharmacies is responsible for providing fact sheets and other information about drugs to the public and to physicians. The Medical Products Agency is a central government agency whose principle task is to control pharmaceutical preparations. All drugs sold in Sweden must be approved and registered by the Agency.

HEALTH INFORMATION SYSTEMS

NATIONAL BOARD OF HEALTH AND WELFARE (SOS)

http://www.sos.se/sosmenye.htm

The National Board of Health and Welfare (SOS) is the key agency for national health information in Sweden. It combines most of the roles of STAKES and KTL in Finland in part of one very large organization. The SOS is responsible for official statistics on social services, public health, health care and medical services, and causes of death. It covers inpatient registers, essentially hospital discharge registers, the national cancer registry and the birth register.

The SOS is regarded as being approachable, science-oriented and easy to work with. There is a rigorous framework for ethical approval of proposed uses of SOS data, but once this has been complied with data is usually available quickly and easily.

The key omission from SOS is social and demographic data. These come from Statistics Sweden, and are quite expensive to obtain.

The most important tasks of the National Board are :-

- supervision of medical care and social services as to quality, safety, and the rights of the individual
- evaluation and follow-up studies of social policy
- mediation of expertise
- development and training
- coordination of social services statistics
- epidemiologic surveying

INFORMATION SYSTEMS

The systems are very similar to the Finnish system, in particular extensive use is made of the National Identification Number for data linkage in all of these systems. Another similarity is the paucity of primary care data.

HOSPITAL DATA

As in Finland hospital discharges are coded, with ICD-10 by doctors or nurses. Birth registry data is largely provided by the attending midwife. OPD data is not routinely recorded, but this is beginning to change.

PRIMARY CARE DATA

This is not collated nationally. Swedish primary care systems are also highly computerised, so it seems as if this should be possible. There is a sentinel practice system in operation.

LINKAGE

These registers are linked to the National Death register, using the unique personal identifier. This allows for ready analysis of mortality.

QUALITY CONTROL

This is a function of SOS. They cross-check data carefully with Statistics Sweden, and they provide data validation.

ADMINISTRATIVE FUNCTIONS

The SOS has a supervisory function over the county councils as it acts as the government's central advisory and supervisory agency for health and social services. The Board supervises implementation of public policy matters and legislation in health care and social welfare services. Its role includes supervising, monitoring and evaluating developments in all areas of social policy. Its most important duty is to follow-up and evaluate the services provided to see if they correspond to the goals laid down by the central government.

All health care personnel come under the supervision of the Board of Health and Welfare. The function of supervision of personnel within the county councils is based on The Supervision of Health and Medical Personnel Act of 1980. The Ministry of Health and the National Medical Disciplinary Board decide on disciplinary measures in the event of complaints or possible malpractice. If responsibility for misconduct lies with health care personnel, the matter is handled by the National Medical Disciplinary Board. The Board acts on reports from The National Board of Health and Welfare, the patient, or relatives of the patient. The Board may limit or withdraw the right of practice of a health care professional.

The Board is making more of its health data available on the Web (in Swedish at http://192.137.163.37/EpCFS/index.asp . It is hard to compare with STAKES, for linguistic reasons, but it appears to be less comprehensive than the Finnish system.

STATISTICS SWEDEN

http://www.scb.se/eng/

Statistics Sweden ahs its origins in the population registration of 1749, and the organisation was established in 1858. Its role has enlarged and shrunk many times since then, but since 1994 it has had two main roles, as described at http://www.scb.se/eng/omscb/organisation/uppgift.asp

PRODUCE AND COORDINATE OFFICIAL STATISTICS

The mission at Statistics Sweden is to produce and make available official statistics relating to different areas of society, which can serve as a basis for decisions, public debate and research. These statistics are to be objective, reliable, comparable, up-to-date and easily accessible.

They have particular responsibility for official statistics in certain broad social fields, e.g.

- the labour market

- the economy, trade and industry, prices
- population and welfare
- housing and construction.

In several other areas they have co-operation agreements with various other public authorities that have statistical responsibilities and produce the official statistics in these areas on their behalf. One of these is the SOS.

REGULATION OF NATIONAL STATISTICS

Statistics Sweden also bears overall responsibility for co-ordinating and supervising official statistics and elaborating statistical nomenclatures and classifications. In addition, we are responsible for co-ordinating the international reporting of statistics and take an active part in international co-operation.

Statistics Sweden also provide internet access to many of their statistics at http://www.svenskstatistik.net/eng/index.htm .

COUNTY COUNCILS

Every county council has a public health department. These vary greatly in size and capacity. The largest is that in Stockholm, which has a staff of about 50. http://www.sll.se/ (in Swedish) These are responsible for local health research, health services research, and making information available to health planners.

PERSONNUMMER

The Swedish peronal identity number system is very similar to the Finnish system. Again the system is used for a very wide range of purposes both inside and outside the Government. For research purposes SOS prepares merged datasets in house, and strips the identity number before making these available to outsiders.

USEFUL WEB ADDRESSES

SOS (National Board of Health and Welfare)	http://www.sos.se/sosmenye.htm
SPRI (Institute for the development of Health Services)	http://www.spri.se/english/default.htm
Swedish health data on the Web (SOS)	http://192.137.163.37/EpCFS/index.asp
Statistics Sweden	http://www.scb.se/eng/
Statistics Sweden Web Information Delivery	http://www.svenskstatistik.net/eng/index.htm
SLL (Stockholm County Council)	http://www.sll.se/

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Norway

THE COUNTRY

Norway has a population of 4.5 million, but its geographic location and size mean that climate and population density vary greatly from the sparsely populated north to the capital Oslo in the south. Norway has a constitutional Monarchy since it gained independence from Sweden in 1905.

NORWAY'S HEALTH CARE SYSTEM

Norway's health care system is mainly public and integrated. General taxation and a national insurance scheme cover over 80% of health care costs, with the remaining costs borne by the patient, which include user fees for primary health and emergency care.

The main responsibility for the provision of health care services lies with the 19 counties and 435 municipalities. IN 1974 five health regions were created (comprising of 3 to 5 counties), each with a regional teaching hospital, however so far this division has had limited impact. At the national level the Ministry of Health and Social Affairs is the executive body with special responsibility for:

- Legislation
- Capacity expansion
- Budgeting and planning
- Information management
- Policy design

Regulation and supervision of the services are the responsibility of the national authorities.

The Norwegian Board of Health is an independent professional body which, in collaboration with the nineteen county medical officers, is responsible for promoting safeguards within the Norwegian health sector. The operational framework of the Board of Health and the county medical officers is based on four strategic areas: quality improvement; legal clarity and consistency; collection and analysis of data; and dissemination of experience. The Board of Health has 150 staff while there are approximately 300 county medical officers.

USE OF HEALTH INFORMATION

PERSONAL IDENTIFICATION NUMBER

All persons born in Norway or registering in Norway are issued with a personal identification number, although this is not used for all personal data registries.

NORWEGIAN PATIENT REGISTRY (NPR)

The Norwegian Patient Registry gathers information on all patients admitted to hospitals or who attended hospital outpatient clinics. It is thought the data set for the whole country is complete from 1990 onwards. The registry was not designed for health monitoring or collection, but to describe hospital use and for financial reasons. Patients do not use a PIN, but are given a hospital number unique to that particular facility, and coded based on diagnosis related group (DRGs). This means that patients cannot be tracked through the system, either for re-admission or from hospital to hospital. It is also not possible to link the system to the Registry of Cause of Death.

Until 1998, information on secondary diagnoses was extremely limited.

SAMDATA

The SAMDATA registry collects data from psychiatric hospitals and is managed by The Foundation for Scientific and Industrial Research at the Norwegian Institute of Technology (SINTEF NIS) an independent contract research company. However reports exists for four years since that time and the data sets are of variable quality, with a lot of missing information. There are plans to implement a new Minimum Basis Data Set for psychiatry (*further information on this as yet unavailable*).

PRIMARY HEALTH DATA

There is no collection of primary health data in Norway at this moment, although there is research project in process (Anne Sundvoll, Statistics Norway, 00 47 21094545)

THE CANCER REGISTRY OF NORWAY

This registry has been in existence since 1953 and has used ICD-10 coding since 1996. The personal identity numbers are used so it can be linked to the Register of Causes of Death. The registry regularly publishes data on cancer incidence, by type and by county and municipality.

STATISTICS NORWAY

Produces extensive statistical reports on overall health indications, but also all relevant subject matter/indices, including demographics from the Medical Birth Registry and the Registry of Cause of Death, economics, employment, education, social and environment. The agency offers publications, data sets and has an extensive English translation on the web. They also manage the vital statistics data registers. They manage the Registry of cause of Death, but not the Medical Birth Register. The Department of Health Statistics is responsible for compiling health data from all sources, and works with a staff of around 25.

MEDICAL BIRTH REGISTER (MEDISINSK FØDSEKSREGISTER)

Births have been registered in the country since 1967 and will include cause of death at birth and congenital deformities.

REGISTRY OF CAUSE OF DEATH

Commenced in 1966, deaths are registered using a personal identification number, which is issued to every resident of Norway, with the coding of caused of death changing from ICD-9 to ICD-10 in 1996.

THE NATIONAL HEALTH INDICATOR SYSTEM (NHIS)

On January 1st 2000, Norgeshelsa (lit. "the Norwegian Health") was established as a fixed health monitoring programme, commissioned by the Department of Health and Social Affairs. The aim of the programme is to offer a comprehensive overview of all medical data collected in the country, accessible to all interested parties. The targets for Norgeshelsa are:

- Obtain relevant data and information on health and health related conditions, including important risk and protective factors on the Norwegian population
- Make the data available to relevant users. Data about health services are not (important) in this context.
- Give a common presentation of the most important data about society. This implies that a system that is as simple, accessible and well arranged as possible is of the greatest importance.
- Contribute to improve the foundation for prioritising target groups, priority areas and strategies.
- Describe inequalities between different population groups, according to geographical divisions and the development over time.

The programme is run by the National Institute of Public Health (Statens Insitutt for folkehelse) in Oslo and comprises of a common data base and presentation programme. Data is sent in txt-files or Excel-files from all the agencies listed above and aggregated, with about 70% of the information emanating from Statistics Norway. Health and demographic data is not the only data incorporated but also data about accidents and injuries, nutrition and diet, tobacco, drug and alcohol and other such information. Data dates back to 1970 and the data set is updated four times per year. The NHIS is staffed by six staff members from the Institute, which has an annual budget of almost €250,500 (£200,000 Irish Punts).

The data and interactive presentation programme are free to download to all users from the website and the data is also regularly updated. This programme which allows the user to manipulate and extract the information they require, down to municipality level. It is available at http://www.folkehelsa.no/fag/nhis/english.html

The Institute wishes to update the system to make it more interactive, and are currently waiting for the new update of the WHO system “Health for All”.

USEFUL WEBSITES

Norwegian Government website	http://odin.dep.no	Some English pages
Statistics Norway	http://www.ssb.no	Several English pages & pdf files
National Institute of Public Health	http://www.folkehelsa.no/	Several English pages & pdf files
The Cancer Registry of Norway	http://www.kreftregisteret.no	Some English pages
Norwegian Board of Health	http://www.helsetilsynet.no/	No English pages
Department of Health and Social Affairs	http://www.dep.no/shd/	No English pages
Medical Birth Register	http://www.uib.no/	No English pages

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The Netherlands

THE COUNTRY

The Netherlands was formed in 1815 and has a constitutional monarchy. It was one of the founders of the European Union and NATO. The population currently stands 15.9 million.

THE DUTCH HEALTH CARE SYSTEM

The health care system is based on public and private insurance schemes. Every resident in The Netherlands is covered by a national insurance scheme for chronic illness and catastrophic health expenditure. For other "acute" services i.e. GP, dental care, maternity services, there is an annual income level calculated yearly and the national insurance scheme covers those who earn less than this calculated amount (approximately 60% of the population). The remainder of the population take out a private insurance for these services. As part of all insurance schemes, every person must register with a GP.

There are 12 provinces and 646 municipalities in the country, with each province having its own elected governing body, the Provincial State. It is these decentralised governing bodies that have most responsibility for the running of the health care services in the country. The government retains responsibility of the financial control of the health care system thorough The Central Agency for Health Care Tariffs.

NATIONAL HEALTH INFORMATION STRATEGY

There is a national policy in regard to health information and for the provision of ICT. (Documents in Dutch only, awaiting translation and/or summary from Dutch Ministry of Health). PcW consultants have recently completed a review of ICT systems in health care in ten countries. We have secured a copy of this.

USE OF HEALTH INFORMATION IN THE NETHERLANDS

STATISTICS NETHERLANDS (CENTRAAL BUREAU VOOR DE STATISTIEK)

This institution is responsible for collating all the vital statistics data and also all economic and social data. The agency manages the death registry, however there is no perinatal register as such and births are recorded at provincial level. Statistics Netherlands produces annual reports and numerous other publications. The agency provide free online access to STATLINE, an interactive electronic data base which provides graphs and tables of most of their information. There is an English version however that does not contain (as yet) as much data as the Dutch version, available at http://statline.cbs.nl/statweb/index_ENG.stm

Personal identity number

There is no system of personal identifiers in The Netherlands. Numbers of issued for medical insurance, however these may not remain the same over time. Geocoding is possible using zipcodes. However, the Dutch are also investigating the possibility of using unique personal identifiers (no further information as yet).

The Netherlands Institute for Health Services Research (Nivel)

Nivel has operated as an independent research centre for primary care and general practice for the Dutch government and all other interested health care professionals for over 30 years. Its remit is to conduct research, but also to manage several primary care registration systems. Its annual budget is €2,000,000, of which one quarter is from the government, the rest of their funding comes from other private research work. It manages the three primary care registers:

Netherlands Information Network in General Practice (NIP GP) *see below*

Sentinel Station Network (for rapid monitoring of influenza)

Paramedical registers for physiotherapists (just started, to be expanded to cover occupational therapists, dieticians etc in the future)

Netherlands Information Network in General Practice (NIP GP)

The aim of NIP GP is to collect representative data on primary care delivered by GPs on a national scale. The project originally started as a pilot in 1994 and has progressed since that time, as it is now the only national primary care register in the country. One hundred and twenty three practices are involved, representing approximately 450,000 patients. There are no plans to substantially increase the numbers involved as it is felt that the current numbers are adequately representative of the population.

GP practices that were computerised were recruited into the database, although it is estimated that 95% of all practices in the country have a computer. GP information systems (eight different systems in total) in use in the practices were minimally adapted, in co-operation with the manufacturers, to standardise programmes and to ensure all GPs were recording the same standardised information. Monthly these electronic records are copied to floppy disk and sent to Nivel where they are entered into an extraction programme. All data is anonymous, in regard to demographics of patients, number and type of consultations, prescriptions (using ATC classification) and referrals. In the beginning of the Network only referrals, prescriptions and number of consultations were recorded, along with primary diagnosis. Very recently they have begun to collect more detailed morbidity data, classified using the International Classification of Primary Care (ICPC).

DUTCH MEDICAL REGISTRATION (LMR)

This national registry of hospital data is managed by Prismant, a private commercial company. The registry contains three parts, hospital inpatients, outpatients /day patients and survey information about patient utilisation and financial issues. Every hospital in the Netherlands sends data to the registry and pays for the service. Data is sent to the company either on a programme especially developed by them for the registry or the hospitals can send it to them in their own format, providing it contains all the relevant data. There are three full time staff working on the registry with a majority of the coding and cleaning of data done at hospital level, which adds to the quality control of the information.

As there are no unique patient identifiers it is not possible to identify individual patients from the data or track the patient through the system for re-admission. Prismant compile quarterly reports for the hospitals, which can be individualised for the hospitals own specific queries. The data is also sent back to them in a format that can be used in the application, POWERPLAY, so the hospitals can use and manipulate their own data if they so desire.

The database is now ten years old and the company wishes to expand and update the registry in line with changes in the Dutch health care system, in regard to financial and legal aspects as well as the changing status of the European Union.

USEFUL WEB-SITES

Central Bureau of Statistics	Http://www.cbs.nl/en	Several English pages & pdf files
Ministry of Health, Welfare & Sport	Http://www.minvws.nl	Some English pages
NIVEL	Http://www.nivel.nl	Several English pages
Council for Public Health and Healthcare	Http://www.rvz.net	Some English pages
Prismant	Http://www.prismant.nl	No English pages

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France

THE COUNTRY

The French Republic is one of the largest countries in Europe, has a constitutional democracy and a population of 59.3 million.

FRANCE'S HEALTH CARE SYSTEM

The health services are a mix of public and private services. Approximately three quarters of the health service is publicly funded by a compulsory national health insurance scheme, while 10% is paid for by supplementary insurance and the remainder privately. Around 80% of the population are also covered by supplementary insurance.

The country is divided into 22 regions, comprising of 100 *départements*, which have responsibility of administering health care in their areas. There are four other départements overseas, the islands of Guadeloupe, Guyana, Martinique and Reunion. The Ministère de l'Emploi et de la Solidarité (employment and solidarity) currently holds responsibility for health.

HEALTH INFORMATION STRATEGIES IN FRANCE

A health information policy was developed by the department of health four years ago (hard copy not available in French or English at this time). Two of the aims of the strategy were to provide access at all levels to all health information in France and also to develop a national set of health indicators. The information database, SCORE-santé has since arisen as a direct result of this policy.

USE OF HEALTH INFORMATION IN FRANCE

PERSONAL IDENTITY NUMBER

Every French person is given a unique identifier as part of the social security system, although the number is not used universally throughout the health services. A new system has emerged where all persons registered with social security (95% of the population) are issued with a "smart card", the *Sesame-Vitale*, on which their number is recorded. The primary aim of this card is to record health expenditure for that patient e.g. doctors visits, prescriptions and allow rapid reimbursement. The aim of the card is also to monitor health expenditure in the country. There are plans (but no time scale for the project) to produce *Sesame-Vitale* #2, which would link through a secured computer network each individual patient with all health care providers and record morbidity details as well.

INSITUT NATIONAL DE AL STATISIQUE ET DES ÉTUDES ÉCONOMIQUES (INSEE)

INSEE is the national institution responsible for collecting and analysing data on vital (civil) statistics, economics, education, agriculture and the environment. It also collates and amalgamates information from other organisations about those topics. It produces frequent reports and publications on these various topics.

INSEE maintains the vital statistic registries, but only information on actual births and deaths (*not* cause of death, which is collected and analysed by INSERM). The agency also conducts the decennial countrywide health survey, on a sample of 20,000 adults (next survey due to start in 2002) in partnership with the organisations DREES and CREDES (see below). The survey collects information on health expenditure and morbidity and as such is one of the major sources of information on primary health care.

DIRECTION DE LA RECHERCHE, DES ÉTUDES, DE L'ÉVALUATION ET DES STATISTIQUES/THE DIRECTORATE FOR RESEARCH, ANALYSIS, ASSESSMENT, AND STATISTICS (DREES)

This research agency has been in existence since the 1980’s, but was re-named DREES in 1998 and is part of the Ministry of Employment and Solidarity (who have responsibility for health). The remit of DREES is to be responsible for collecting, analysing, and disseminating statistics for healthcare, welfare and social protection. Part of their responsibilities is also to manage the hospital data collection registry PMIS (see below).

DREES prepares studies and socio-demographic, economic, and financial projections. It compiles summary documents, in particular about the health-sector and social-protection accounts in the national-accounting framework. There is no website for DREES however copies (in French only) of DREES publications can be found in pdf format at the Ministry of Employment and Solidarity website:

http://www.sante.gouv.fr/htm/publication/index.htm.

PROGRAMME DE MÉDICALISATION DES SYSTÈMES D’INFORMATIONS (PMSI)

This database was developed to follow hospital activity, but also gathers medical and epidemiology data about patients and medical procedures. The database is jointly managed by DREES and Direction de l’Hospitalisation et de l’Organisation des Soins (DHOS). The programme uses ICD – 10 for coding purposes and is DRG based. Every patient who is admitted is entered into the system at hospital level. It is apparently possible, but extremely difficult to follow a patient through the system or link it with other registers. The information from this registry is used extensively by many institutions.

THE FRENCH INSTITUTION OF HEALTH AND MEDICAL RESEARCH (INSERM)

The institute was established in 1964 and functions under the auspices of the Ministries of Research and Health. The aim and objectives of INSERM are:

- To promote health
- Improve understanding of human diseases
- Ensure patients, the medical community national and international partners benefit rapidly from the latest research findings

INSERM is a huge institution, employing 10,000 research professionals in 300 different laboratories through out France with an annual budget of 3 billion francs. The scope of INSERM is also very wide both in France and on an international stage, ranging from genetic and molecular science, to epidemiology, to perinatal mortality. INSERM collects data on cause of death, for both perinatal and all other ages in France. It also runs national peri-natal surveys to monitor indicators of perinatal health, medical practice and risk factors.

CANCER REGISTRY

There is no national cancer registry in France, however there are 13 regional registers, data from which are analysed by InVS and INSERM. There is also a network of these registries, FRANCIM, run by INSERM. There is no website for this at present.

INSTITUT DE VEILLE SANITAIRE/THE NATIONAL INSTITUTE FOR PUBLIC HEALTH SURVEILLANCE (INVS)

InVS has been recently created for public health surveillance for the whole of France. The aims and objectives of the institute include:

- Monitor health of the population and its evolution. Using epidemiological surveillance, risk evaluation and observation of health.
- Detect all threats for the public health and to alert the Minister of Health of such threats
- Collect, analyse and disseminate information health problems, their trends and determinants
- Contribute to the training of public health professionals in the methods of epidemiological surveillance
- Facilitate the interface between research and field epidemiology.

InVS is primarily interested in five general areas: Infectious diseases, environmental health, chronic diseases (and injuries), information systems and communication and European Programmes. The annual budget is 100 millions French Francs (15 million Euros) and it employs approximately 100 people, mainly epidemiologists.

PRIMARY HEALTH CARE DATA

Routine data for primary health care is collected only through health insurance companies, both public and private, as every French national is obliged by law to have insurance (public or private). Most of the information is based on financial expenditure and very little morbidity data is actually collected. The are three main insurance companies in France, CNAMTS, CANAM and MSA, which cover the majority of the population. Despite legislation being passed in the 90's obliging doctors to send morbidity data to health insurance companies about their patients, this has never been enforced, as there is no system for collecting or analysing such data. Data collected by the insurers is collated and analysed by other research bodies.

CENTRE DE RECHERCHE D' ETUDE ET DE DOCUMENTATION EN ECONOMIE DE LA SANTÉ/RESEARCH AND INFORMATION CENTRE FOR HEALTH ECONOMICS (CREDES)

CREDES's mission is to provide a basis for the understanding of the future of the health care. The centre monitors and analyses trends in the behaviour of consumers and health care professionals from a medical, economic, geographic and sociological perspective. The Centre compiles and analyses topics from many sources:

- Health status and illnesses
- Prevalence and incidence
- Disability
- Health care utilisation - geographic, economic and socio-cultural variations.
- Health insurance: statistical profiles of the population covered
- Physicians' health care practices: socio-demographic characteristics of physicians and their patients, diagnosed morbidity, prescription practices, activity and income profiles.
- Public and private hospitals: socio-demographic characteristics of inpatients; morbidity; use of resources and care provided.
- The elderly: trends in health status, utilisation of health care, home care and nursing homes.
- Economically disadvantaged populations: socio-demographic characteristics and biographical information; health status, access to care, health care utilisation
- Geographical analysis: variations in health care supply and demand, allocation of resources.
- International comparisons: health care systems and policies; level, structure and funding of health care expenditure.

As part its work, CREDES conducts surveys on health care at a national level, often in partnership with other national bodies, which provides some of the only morbidity data on a primary health care level. One of the most important surveys they are involved with is the decennial survey on health and medical care, conducted in collaboration with INSEE since 1960, which aims to highlight underlying societal changes in relation to health insurance, self-assessed morbidity, medical expenditures and utilisation.

Every year CREDES also produces the health care and health insurance survey which provides a run-down on the determinants of medical consumption (socio-economic characteristics, private health insurance, morbidity) from a panel of sickness funds members of the three main insurers, CNAMTS, CANAM and MSA.

LA FÉDÉRATION NATIONALE DES OBSERVATOIRES RÉGIONAUX DE LA SANTÉ/ THE NATIONAL FEDERATION OF REGIONAL HEALTH OBSERVATORIES (FNORS)

In the 1980's 26 Regional Health Observatories (ORS) were created, for each region in France including the four overseas territories (Guadeloupe, Guyana, Martinique, and Reunion). The objective of the ORSs is to improve information on health status and health needs of the population in the regions, in order to assist decision-making. This is achieved by identifying, validating and subsequently analysing routinely available data (from health insures, PMSI, INSEE, etc) from each region, as well as carrying out surveys. Reports are disseminated to all interested parties.

In 1998, the 26 observatories employed a total of 240 permanent staff and had a budget of 61 million French Francs. The Federation of all the Observatories came into being in 1989 and has helped to strengthen links and co-operation between the regions. The objective of the Federation is not to undertake work at a national level, but is however to compile the work of all the regions.

One of their major achievements so far has been to compile and publish a report on health indicators by region. The outcome was also the design of standardised data analysis protocols, and a common presentation format, in order to provide a comprehensive picture of health status in the French regions. The reports contain tables and graphs and are accompanied by interpretation and comments. The subjects covered include: Supply and use of health services, mother and child, elderly, disabled people, poverty, disease specific topics, risk factors, health and the environment. In order to determine the indicators, data were provided from the institutions listed above as well as other national and local institutions e.g. INSEE, INSERM, DREES, InVS, CANAM and the Regional councils. Arising from this continuous work on regional health indicators, a web-based database, The Health and Social Indicators Database, was created to allow online access to the information (see SCORE-santé). The information is provided free of charge and themes and sub-themes by region can be chosen. Data tables are available in English at either of these sites:

http://www.fnors.org/Base/Cgi-bin/asp/Menu_bdd_ang.asp
http://www.fnors.org/Base/Indic/Index/Index_ang.htm

SCORE- SANTÉ

This initiative arose from the French national health information policy and grew out of the FNORS Health and Social Indicators Database. The objective of the database is similar to that of the FNORS, to allow access to reliable, valid and comparable regional health data to all interested parties. Score-santé was set up last year, however the data is only limited to the amount of health information that exists in France today. The aim is to update the database constantly.

There are currently two levels accessible on the database, level 1 gives tabular information on regional indicators of health, concerning nine topics or themes. At level 2, data can be downloaded in EXCEL format to allow more complicated manipulated of the data by those interested parties. The database is available free of charge at the following website: http://www.fnors.org/Score/Index1.htm

USEFUL WEBSITES

Government Health	http://www.sante.gouv.fr/index.htm	No English pages

Dept		
INSEE	http://www.insee.fr/en/carte/accueil_carte.htm	English pages of website
INSERM	http://www.inserm.fr/servcom/servcom.nsf/(Web+Startup+Page)?OpenForm&english	English pages of website
InVS	http://www.invs.sante.fr/	One English page
FNORS	http://www.fnors.org/Anglais/default.htm	Several English pages
SCORE-sante	http://score-sante.atrium.rss.fr/	No English pages
CREDES	http://www.credes.fr/english/home.htm	English pages of website

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European Union

EU HEALTH STRATEGY

Note that the EU has competencies in public health, not in health care delivery. In May 2000, the European Commission published a Communication on the health strategy of the European Community, together with a Proposal for a Decision of the European Parliament and of the Council for a new programme of Community action in the field of public health (2001-2006).

The Commission therefore announced that it intended to set up a **European Health Forum** as an important element of the health strategy. This would be an information and consultation mechanism to ensure that the aims of the Community's health strategy and how they are being pursued are made clear to the public and respond to their concerns. It will also allow representative organisations of patients, health professionals and other stakeholders, such as health service providers, to have an opportunity to make contributions to health policy development and implementation and the setting of priorities for action. In addition, the intention is to provide an opportunity to organise consultations, to exchange views and experience on a wide range of topics and to assist in implementation and follow-up of specific initiatives.

HEALTH INFORMATION STRATEGIES IN THE EU

PROGRAMME OF COMMUNITY ACTION ON HEALTH MONITORING

The present overall picture of European health monitoring has developed gradually. Various organisations have contributed to the development on the basis of their own specific policies. Development has been brought forward by many different agendas and the various initiatives have not always been co-ordinated in any major way.

The consequences of this situation are :

- Member States are reporting data to a number of bodies which implies multiple reporting;
- There is unnecessary duplication of effort;
- The data and information are often of limited comparability among countries and sometimes of medium or poor quality;.
- There are significant gaps in the data available on a number of important diseases.

Against this background Decision No. 1400/97/EC of the European Parliament and of the Council adopted a programme of Community action on health monitoring within the framework for action in the field of public health in 1997. The objective of this programme is to contribute to the establishment of a Community health monitoring system which makes it possible to :

- ✓ Measure health status, trends and determinants throughout the Community;
- ✓ Facilitate the planning, monitoring and evaluation of Community programmes and action;
- ✓ Provide Member States with appropriate health information to make comparisons and support their national health policies.

The idea is that the programme would work through making use of the expertise built up in the Member States and act as a co-ordinating force between them. It has been mainly structured into three pillars :

- Pillar A deals with the establishment of Community health indicators;
- Pillar B deals with the development of a community-wide network for sharing health data;
- Pillar C deals with the development of methods and tools necessary for analysis and reporting.

For more information see Decision No.1400/97/EC of the European Parliament and of the Council, the Draft Work Programme 1998-1999, and Work Programmes 2000 and 2001 for the Programme of Community Action on Health Monitoring.

See also the Health Monitoring web-page of the Public Health Division of the Health and Consumer Protection Directorate-General of the EU at http://europa.eu.int/comm/health/ph/programmes/monitor/index_en.htm

(Public Health Division of the Health and Consumer Protection Directorate-General of the EU, 2001)

HEALTH INFORMATION AND COMMUNICATION (ICT) STRATEGIES IN THE EU

INFORMATION SOCIETY TECHNOLOGIES PROGRAMME (IST)

A major theme of research and technological development within the European Union's Fifth RTD Framework Programme (1998-2002), IST is a single, integrated research programme that builds on the convergence of information processing, communications and media technologies. It has an indicative budget of 3,600 million Euros, and is managed by the Information Society Directorate General of the European Commission.

The IST Programme (http://www.cordis.lu/ist) contains four inter-related **key actions**, which define the research priorities:

1. Systems and services for the citizen
2. New methods of work and electronic commerce
3. Multimedia content and tools
4. Essential technologies and infrastructures

For Key Action 1, work includes RTD in the following fields: **health**: special needs, including ageing and disability; administrations, environment; and transport and tourism.

The work programme for health 2001 includes the following:

1. "Intelligent environment for citizen centred health management"

To allow all citizens to respond to risk factors (such as high blood pressure, diabetes or high cholesterol levels) whether at home, work, or school, through new generation systems, for example information and decision support systems, which take advantage of advances in ambient intelligence.

2. "Intelligent collaborative environments supporting continuity of care"

To enable patients and health professionals to collaborate and share patient and other health related data for continuity of care. This will help patients who are not confined to hospital to participate actively, in close collaboration with their health care provider, in their ongoing care.

3. "Best practice and trials in e-Health"

To promote the uptake of health telematics applications at healthcare provider and healthcare authority/administration level in order to support e-Health initiatives adopted in Member and Associated States. Such initiatives include: online medical advice and information for citizens; assessment of health telematics applications; collaborative healthcare provision environments supporting inter alia second medical opinions; applications for evidence based medicine; and systems supporting continuing education.

For more information on any of these work programmes see http://www.cordis.lu/ist/ka1/home.html

TEN-Telecom (Trans-European Telecommunications Networks)

TEN-Telecom is a European Commission action supporting the trans-European deployment of e-society applications and services. It promotes the use of global telecommunications networks in areas of high socio-economic value, by aiding new trans-European multimedia applications. TEN-Telecom does not provide support for the deployment of physical infrastructures.

Trans-European Telecommunications Networks for Health

For the purposes of the TEN-Telecom work programme three mainstream activities have been identified for health:

- Public health information services

Information services for authorities, health care institutions, professionals and citizens are to be deployed, in order to increase access and quality of data for prevention, diagnosis, and therapy of diseases (eg internet-based health portals).

- Continuity of care and health care management

By developing applications and integrated networks for complementary health centres shared access to transparent patient-related information will be promoted.

- Telemedicine

This involves teleconsultation and telediagnosis, including diagnosis and supervision of patients and citizens with special needs at home or in small, remote and isolated communities.

MELIC

MELIC, "Multimedia Health Information for Citizens", is an example of a TEN-Telecom initiative in the health area. It is a trans-European project that aims to provide, through telematics, high quality information and education resources to help European citizens make better choices and the right decisions about their health.

It plans to establish pan-European telematics channels to develop, test and distribute health information and educational content in common hardware and software platforms, and to make the resulting materials available to the citizens through easy-to-use systems. Several scenarios will be considered to implement these services: health care centres, community pharmacies, libraries, schools and public locations, insurance companies and also at home.

MELIC has been directly supported and partially funded by the European Union.

For more information on TEN-Telecom see http://www.ten-telecom.org/

USE OF HEALTH INFORMATION IN THE EU

EUROSTAT

Eurostat is the Statistical Office of the European Communities, situated in Luxembourg. Its task is to provide the European Union with statistics at European level that enable comparisons between countries and regions.

Eurostat was established in 1953 to meet the requirements of the Coal and Steel Community. Over the years its task has broadened and when the European Community was founded in 1958 it became a Directorate-General (DG) of the European Commission. Eurostat's key role is to supply statistics to other DG's and to supply the Commission and other European Institutions with data so they can define, implement and analyse Community policies.

Eurostat does not collect data. This is done in Member States by their statistical authorities. They verify and analyse national data and send them to Eurostat. Eurostat's role is to consolidate the data and ensure they are comparable, using harmonised methodology.

In 1997 three major acts were adopted giving Community statistics a solid legal basis:

- In June 1997 Article 285 was inserted in the Amsterdam Treaty, providing Community statistics with a constitutional basis for the first time.
- The Council of the European Union adopted what is known as the Statistical Law in February 1997. This Regulation defines the division of responsibility between national and Community statistical authorities. It also defines the basic conditions, procedures and general provisions governing official statistics at EU level.
- A Commission Decision later in 1997 clarified the role of the Community Statistical Authority (Eurostat). Secondly, it reaffirmed the need for those involved in Community statistics to follow fundamental principles in ensuring that statistics are scientifically independent, transparent, impartial, reliable, pertinent and cost-effective.

Much of the emphasis in Eurostat is on financial and economic statistics but in the framework of the domain **Health and Safety** it presents a systematic and, as far as possible, harmonised set of regular and official statistics which are directly relevant to Community actions in the field of health. The domain is divided into two main items: Public Health and Health and Safety at work.

The Public Health collection is divided into four chapters: life styles (includes anthropometric characteristics, smoking, drinking, etc), health status (includes disabilities and some specific diseases such as AIDS and cancer), health care (includes human resources on health, hospitals beds and treatments) and causes of death.

The tables compiled for the Public Health collection are the product of data provided mainly by the National Statistical Institutes and the Ministries of Health, by other international organisations (OECD, WHO, International Agency of Cancer, AIDS Surveillance Centre and others). The data are also the result of various epidemiological or concerted actions, some of which are financed by the European Commission. The emphasis is on basic data and well-known common measures, e.g. rates and ratios.

The collection Health and Safety at work is also divided into four chapters: accidents at work, commuting accidents, occupational diseases and work-related health problems and accidental injuries.

THE EUROPEAN STATISTICAL SYSTEM

Since the early days of the Community it was realised that decisions on, and planning and implementation of, Community policies must be based on reliable and comparable statistics. As a result the European Statistical System (ESS) was built up gradually with the objective of providing comparable statistics at EU level.

The ESS comprises Eurostat and the statistical offices, ministries, agencies and central banks that collect official statistics in EU Member States, Iceland, Norway and Liechtenstein. Member States collect data and compile statistics for national and EU purposes. The ESS functions as a network in which Eurostat’s role is to lead the way in the harmonisation of statistics. ESS work concentrates mainly on EU policy areas but, with the extension of EU policies, harmonisation has been extended to nearly all statistical fields.

STATISTICAL PROGRAMME COMMITTEE

At the heart of the ESS is the Statistical Programme Committee (SPC) which is chaired by Eurostat and brings together the heads of Member States’ national statistical offices. SPC discusses the most important joint actions and programmes to be carried out to meet EU information requirements. It agrees a five-year programme, which is implemented by the national authorities and monitored by Eurostat.

SPC co-ordinates the following activities:

- development of common classifications, methodology and definitions for application in Member States
- implementation of common statistical surveys based on harmonised methods, and
- collection, analysis and dissemination of statistical data for the EU, including comparisons between countries and regions.

STAFF AND BUDGET

In 1999 around 730 people worked in Eurostat. Of these, 560 were officials, 70 were experts sent from Member States and another 100 had other types of contracts. Eurostat had a total budget of around 154 million Euro in 1998.

For more information see the Eurostat web-site at http://europa.eu.int/comm/eurostat/Public/datashop/print-catalogue/EN?catalogue=Eurostat

EUROPEAN HEALTH AND TELEMATICS OBSERVATORY (EHTO)

EHTO is the first European Web solution, now extending worldwide, for tackling the problem of an over-fragmented health telematics information and decision structure in Europe. It aims to collect and disseminate valuable information on relevant issues relating to health telematics, including European standards, regulatory and ethical issues. Moreover, it offers a space for displaying interactive news and a space for on-line virtual electronic demonstrations, available to users, industry and service providers.

Started as an "Accompanying Measure" to the European Commission's 4th Framework Programme for raising awareness of the health community to the potential of telematics, EHTO has rapidly become a successful product recognised by the market and has achieved independence of EU funding since July 1999. EHTO has created an interactive "Electronic Central Market Place" where European health industry and services can meet influential users and decision makers, discuss their needs and make them aware of the solutions they offer.

For more see the EHTO web-site at http://www.ehto.org/

EUROPEAN COMMISSION DIRECTORATE-GENERAL FOR THE INFORMATION SOCIETY

The objective of the Directorate-General for the Information Society is to implement the Commission's policy with regard to the Information Society. Its main tasks are as follows:

- To assist the College and the Members of the Commission with special responsibility for the Information Society with the formulation of a policy concerning the Information Society in the European Union.
- To implement Community policy with regard to the Information Society in accordance with the guidelines set by the College and instructions given by the Members of the Commission with special responsibility for the Information Society.

The development of the information society in **health care** is one of the many topic areas covered in the remit of the Information Society Directorate-General. Two relevant programmes include the Information Society Technologies Programme and TEN-Telecom (see above).

The web-site of the European Commission Information Society Directorate-General is at http://europa.eu.int/comm/dgs/information_society/index_en.htm

WHO, EUROPE

WHO, Europe maintains the Health For All Database (HFA-DB). It contains Health for All indicators which have been submitted by European Member States to the WHO Regional Office for Europe or collected from other international organisations or other sources. HFA indicators cover health status of populations (mortality, morbidity, disability), it's determinants (life-styles, environment, health care) and some background demographic and socio-economic indicators. Early versions of the HFA-DB have been available since 1987 and an updated issue for distribution is produced and placed on the Internet twice per year, in January and June. .

HFA indicators have been developed to monitor the progress in European countries towards the targets of the European common health policy (*Targets for Health for All,* WHO, 1985, *Health 21: The health for all policy framework for the European Region,* WHO, 1998).

The HFA-DB covers the period starting in 1970 up to the latest available information. However, data availability varies between indicators and countries. Time-series for mortality indicators start for most countries from 1970. Data for other indicators are generally available from more recent years. Data comparability may be limited for some countries.

The HFA indicators for which data is available fall into the following categories:

- Basic demographic and socio-economic indicators
- Mortality based indicators
- Morbidity, disability and hospital discharges
- Life-styles
- Environment
- Health care resources
- Health care utilisation and costs
- Maternal and Child health

The WHO Europe web-site is at http://www.who.dk/

This site also maintains the “Highlights on Health” series, which provides overviews of the health situation in the countries of the WHO European Region.

EUROPEAN COMMITTEE FOR STANDARDISATION

CEN is the European Committee for Standardisation for medical informatics. Its Members are the national standardisation organisations of the eighteen EU and EFTA (European Free Trade Association) countries.

CEN only deals with precise and limited subjects for which standardisation is clearly and urgently needed and which are approved for inclusion in its programme of work. If the subject is already being studied in the ISO (International Standards Organisation) in an appropriate way, any CEN work will be directed to implementing and, if necessary, complementing the ISO work.

CEN works through procedures which guarantee respect for the following principles:

- ✓ openness and transparency: all interested concerns take part in the work;
- ✓ consensus: European Standards are developed on the basis of voluntary agreement between the interested parties;
- ✓ national commitment: formal adoption of European Standards is decided by a majority vote of all CEN National Members and is binding on all of them;
- ✓ technical coherence at the European and national level: standards form a collection, which ensures its own continuity for the benefit of users, both at European and national level through compulsory national implementation of European Standards and withdrawal of conflicting national standards.

Members of CEN are also Members of ISO.

For more information on CEN and its four working groups see European Commission Information Society Directorate-General

PROCESSES TO MONITOR HEALTH STATUS/DETERMINANTS OVER TIME

A series of reports on the state of health in the European Union drawn up by the European Commission provides the Member States, policy makers, analysts and researchers with a comparative overview on the health status of the general population, or of selected sub-groups, across the European Union. Reports published include: *The State of Health in the European Community*, Luxembourg 1996; *The State of Women's Health in the European Community*, Luxembourg 1997; *Report on the State of Young People's Health in the European Union* Luxembourg 2000; *The Health Status of Migrants in the EU*, Luxembourg 2001.

See *Report on the State of Young People's Health in the European Union* Luxembourg 2000 as an example.

WHO, Europe also publish a series of reports on health in Europe, the general objective being to describe the most significant health trends in the region and to evaluate them from the perspective of European policy and targets for Health for All. The latest in the series is *Health in Europe 1997: Report on the third evaluation of progress towards health for all in the European Region of WHO (1996-1997).*

These are available on the WHO web-site at http://www.who.dk/policy/hie97/hie97.htm

USEFUL WEB-SITES

Eurostat	http://europa.eu.int/comm/eurostat/Public/datashop/print-catalogue/EN?catalogue=Eurostat
European Observatory on Health Care Systems	http://www.observatory.dk/index-3.htm
WHO, Europe	http://www.who.dk
Health Monitoring Web-page	http://europa.eu.int/comm/health/ph/programmes/monitor/index_en.htm
Information Society Technologies Programme	http://www.cordis.lu/ist
TEN-Telecom	http://www.ten-telecom.org/
CEN(European Committee for Standardisation	European Commission Information Society Directorate-General

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