National Health Information Strategy

Conference Report

27th November 2000

Royal College of Physicians of Ireland

DEPARTMENT OF HEALTH AND CHILDREN
AN RIONN SLAINTE AGUS LEANA
Shaping a Healthier Future

Faculty of Public Health Medicine for Ireland
National Health Information Strategy

Report on the Workshops held at the Conference

27th November, 2000

Royal College of Physicians of Ireland
# Table of Contents

- **Introduction**

General Question. If you had control of developing a National Health Information Strategy what are the first two things you would do?  

**Question 1.** How can a National Health Information Strategy contribute to service planning and delivery?  

**Question 2.** What health information systems do you find most useful in your work and why?  

**Question 3.** What is effective about existing health information systems and what are the problems?  

**Question 4.** What are the main performance management issues that need to be incorporated into a NHIS?  

**Question 5.** What is the value of an electronic health record?  

**Question 6.** What factors ensure quality information for health.  

**Question 7.** What opportunities for the exploitation of health information are provided by recent developments in ICT?  

**Question 8.** What are the obstacles for the exploitation of ICT for health Information?  

**Question 9.** What legislation is needed to support using information for health?  

**Question 10.** What current legislation hinders using information for health?  

**Hopes for a National Health Information Strategy**
Introduction

In April 2000, the Minister for Health & Children announced the development of a National Health Information Strategy for Ireland. A conference, sponsored jointly by the Department of Health & Children and the Faculty of Public Health Medicine, was held in November 2000 as part of the development process of this strategy.

Key stakeholders and those central to policy development and service provision provided input to the Conference during the afternoon workshop sessions. A wealth of information was generated that is being used to inform and direct the work of the National Health Information Strategy Steering Committee. As was agreed at the time, the proceedings of the Conference would be circulated to participants and subsequently placed on the Department of Health and Children's web site.

The Department of Health and Children and the Faculty of Public Health Medicine would like to record their appreciation for the input of participants. There was intense interest in the initiative, and this was evident in the degree of participation and commitment of participants to remain to the end of proceedings. In general, the publication of the Strategy was being eagerly anticipated. There was great interest in national and international initiatives and a strong support for overcoming any difficulties that may be encountered in developing the Strategy. It was widely appreciated that since the determinants of health lie outside the control of the traditional health services, systems to measure these broader, socio-economic determinants of health must be put in place. A recurring theme in all groups was that of the need for high-quality, patient centred services and an information culture and an infrastructure that would support this.

Overall, the issues to emerge as being considered central to a successful strategy included

- Strong leadership, political will and adequate resources to ensure it comes about;
- A strategy that is realistic with short, medium and long term goals;
- Clear objectives;
- A patient/client centred basis for development.

What follows is a distillation of the issues discussed and prioritised at the Conference. A series of questions was asked of each of the groups and these responses are collated below. There was a series of different themes associated with each question and these are dealt with individually.
Questions

General Question. If you had control of developing a National Health Information Strategy what are the first two things you would do?

This question was addressed to all groups and the following were the principal themes that emerged.

Purpose:
- Define the purpose and scope of a health information strategy. A Statement of Intent would make a powerful public commitment;
- Essential that it should be objective-driven and results-orientated;
- Draw up short, medium and long term strategies;
- Ensure that the proper resources are in place to meet objectives.

Leadership:
- Establish an Information Authority if necessary;
- Ensure strong representative leadership to define the scope of a strategy;
- Agreement of the structure and purpose for the development of the strategy;
- Commitment from DOHC to properly resource the strategy development. Ensure adequate funding – bring in/second the necessary skills to ensure success.

Consultation:
- Identify key stakeholders (statutory, NGO, professional, academic, public, patients, clients, minority groups) and consult widely to ensure consensus and practicality of initiatives;
- Obtain a commitment from stakeholders to ensure the resources necessary for the development and implementation of the strategy;
- Strategy analysis should be on a needs analysis basis.
Audit:

- Identification of current information sources and systems and informational gaps;
- Determine what standards should be set;
- Standardisation of datasets and collection methods;
- Ensurance that standard datasets have minimum data collection and timeliness as core features;
- Continual monitoring of the direction and effectiveness of the implementation of the strategy (tyre-pressure checking);
- Development of a population register;
- A unique patient identifier;
- Electronic patient record.

Implementation Infrastructure

- Establish a group with a clear task, targets and timeframe;
- National Technical Infrastructure (IT, informational, library).

Legal Issues

- Ensure the legal framework for easy, safe transfer of information is in place;
- Co-operate to ensure that data protection and FOI are not an impediment to health information;
- Ensure confidentiality.
Question 1. How can a National Health Information Strategy contribute to service planning and delivery?

This question was addressed to two groups that included representatives from a wide cross-section of the health services and associated organisations. The principal ways in which the NHIS can contribute to health service planning and delivery were identified as follows:

Client-centred Service - The availability of information on health for clients will empower them to have a more active role in their healthcare and promote self-care. It will inform clients of access to and the quality of the health services, which they use. The groups emphasised the importance of user-friendly information couched in language that is understood by clients.

Provision of standardised health information, which supports and ensures:

- Comprehensive health needs assessments;
- Identification of need;
- Targeting interventions;
- Preventive strategies for population health;
- Efficient use of resources;
- Informed public debate in relation to resource allocation;
- Effective monitoring and evaluation;
- Integration of service planning across agencies;
- Standardisation of service delivery;
- Inter-regional comparisons across health boards in relation to service planning, monitoring and evaluation.

Improved quality of services - Integrated, quality health information will facilitate clinical audit and clinical governance. Development of performance indicators in order to ensure the provision of a quality health service. This will lead to standardisation of practice however, organisational issues in terms of cultural change to implement quality initiatives will have to be addressed in conjunction with this.
Question 2. What health information systems do you find most useful in your work and why?

This question was posed to a single group that was intended to represent as many sectors of the health system as possible. The group identified the following information systems as most valuable to their daily work:

**Public Health Information System (PHIS)**

**Strengths:**
- A strength of the system is the comprehensive range of data and standardised regional data on mortality and morbidity (HIPE);

**Weaknesses:**
- Absence of some available data sets e.g. disability, drug prescribing patterns, mental health, determinants of health and primary care;
- Limited scope for analysis including geo-coding.

**HIPE**

**Strengths:**
- Generic open structure;
- Provides a national standard.

**Weaknesses:**
- Restricted access to data;
- Limited use for accreditation and performance assessment.

**Mortality Data**

**Strengths:**
- Completeness and reliability of data.

**Weaknesses:**
- Limited area coding;
- Large number of cases with "unknown" social class information;
- Coding of SEG for females (based on husband's occupation);
• Problems with death certification procedures.

Internet/E-mail:
• Access to literature and information on work;
• Facilitate professional communication.

Gaps in available health information systems were identified as poor data on:
• Health inequalities;
• Morbidity;
• Health status of the population;
• Primary care;
• Health services research database.
Question 3. What is effective about existing health information systems and what are the problems?

This question was addressed to a single group that was representative of many sectors of the health system. The group identified the following effective elements and problems of existing health information systems:

**Effective:**
- An increasing trend towards better access to data;
- Lots of data sources are being used;
- More computerisation of systems;
- PHIS is an example of a computer based system that works well by combining data from many sources;
- More systems are improving access to information, particularly administrative.

**Problems:**
- Lack of integration between different HIS;
- Inflexible systems;
- Lack of standardisation of data — unable to compare like with like;
- No standard definitions;
- Lack of unique patient identifier;
- Unable to identify particular groups e.g. disease groups, ethnic groups;
- Not always user-friendly;
- Systems not Window compatible (DOS-based);
- Insufficient manpower to keep systems up-to-date;
- Inadequate data on community health and health services;
- Poor infrastructure leading to inadequate hardware.
Question 4. What are the main performance management issues that need to be incorporated into a NHIS?

This question was posed to a group that had representatives from many sectors. The group identified the following performance management issues as essential to a National Health Information Strategy:

- Standardisation of Data – on national, regional and local levels;
- Development of Performance Indicators;
  - Closely linked to health outcome measures;
  - Linked to patient identifier;
  - Multidimensional to address issues in relation to equity, effectiveness, efficiency and responsiveness to patients;
  - Compare performance at national, regional and local levels;
  - Differentiate between measuring activity and effectiveness;
  - Measure client satisfaction with services;
  - Measure access and responsiveness of health services;
  - Base on client groups e.g. children, older people.
- Access to performance indicator data;
  - Professionals only;
  - Mechanism to permit public publication of performance;
- Indicators for measuring factors not related to non-health sector – this includes areas such as Environment Social welfare Education;
- Measurement of Efficiency and accurate data on costs and economic evaluation.
Question 5. What is the value of an electronic health record?

As this is a very topical issue, this question was addressed to two groups representative of many sectors of the health system. The electronic health record was alternatively defined as follows:

"A unified complete electronic record of a person's medical history shared across health agencies and levels of care".

or

"Patient's health information in an electronic format which can be shared if a unique identifier is available and can be used in an integrated manner across all settings to facilitate a seamless system".

An electronic health record is seen to be valuable to facilitate the following:

- The provision of integrated healthcare across a seamless system;
- Ease of access to patient data by different healthcare professionals in different care settings;
- Accurate quality data;
- Standardisation of data;
- Development of definitions;
- Computerisation of health information;
- Effective linkage of health information databases;
- The provision of data for epidemiological and health services research - linking clinical and socio-economic data;
- Payment systems;
- Responsiveness to patients' illnesses and rapid diagnosis;
- Reduction in clinical error-effective risk management;
- Reduction in duplication e.g. investigation and treatment;
- Improved quality of healthcare;
- Clinical audit.
The negative aspects of an electronic health record were identified as:

- Enormous resources required to implement at a national level;
- Inadequate IT infrastructure to maintain;
- Staff inadequately trained in information management;
- Confidentiality issues.

Four breakout groups addressed this question as it was considered to be one of the more important questions. 5 key themes surrounding the issue of quality emerged from the 4 groups as follows:-

- **Stakeholder Commitment** - To ensure all stakeholders buy in to a system it must be able to provide accurate, comprehensive and timely information and be user-friendly. People need to have confidence in the information produced and feel a sense of ownership. Adequate resources are seen to be vital if these requirements are to be met and this includes human resources and the commitment to necessary training. Stakeholder acceptance of systems will be improved if health information is collected concurrently with operational information. A commitment to training will be required from all stakeholders.

- **Standards** - Improvements must be made in the standardisation of all phases of data collection and reporting and this will require an inclusive and consultative approach. Data must be fit for the purpose it is collected for, particularly in the areas of relevance and meaningfulness. Standards will have to be agreed in many areas such as national and international definitions, data collection, timeliness and acceptability, quality assurance, analysis, dissemination and user friendliness. Once agreed, standards will need to be clear. Attention will also need to be made to the technical issues associated with the validity and reliability of data.

- **Use and Feedback** - Commitment to use of information and appropriate feedback must be made. Greater use of information to inform policy is seen as a key strategy to improve quality of data. Stronger mechanisms for feedback would strengthen the contribution of the data-policy nexus. This would require a reshaping of the professional culture in the health sector, and the more timely availability of data. Data is only able to become quality information if it is used appropriately. Issues of accessibility and acceptability of data will also need addressing.

- **Patient Identifier** - As addressed in question 5 above, the unique patient identifier is seen as a means to allow sharing of information across systems to ensure quality information for health. A willingness to share is required for this.
- Identification of Objectives – This involves the identification of appropriate objectives and the implementation of relevant review processes.
Question 7. What opportunities for the exploitation of health information are provided by recent developments in ICT?

This question and question 8 were put to a group that was specifically made up of individuals from areas associated with the use and development of ICT. The most significant opportunities for the exploitation of health information provided by recent developments in ICT are seen as the following:

- **Internet** – ongoing advances are being made in the internet and in associated technologies. These provide the ability to connect to and access sources of information at disparate sites;

- **Guidelines & Protocols** – these can be embedded into systems;

- **Mobile devices** - Mobile devices are the modern devices that offer the greatest opportunity for a new look at how technology can assist in the delivery of healthcare. They allow mobile healthcare workers to have full access to ICT facilities and databases at all times. These include mobile users within a building – e.g. doctors. This results in the provision of care in the most appropriate settings and can also facilitate the provision of care in locations where it may not have been previously feasible to provide care – e.g. care in local centres, in the home, monitoring of medical conditions while the patient is away from the care centre, self care;

- **Speed** – The turnaround of data is potentially much faster;

- **Operational Data** – Health information can be drawn from systems associated with operational activities.
Question 8. What are the obstacles for the exploitation of ICT for health information?

The following areas are those that are seen to present particular obstacles to the realisation of effective ICT use in the area of health information:

- **Change** - Organisations are perceived to be reluctant or unable to effect change;

- **Training** – Lack of or inappropriate training;

- **Systems** – There is a lack of appreciation that systems are made up more of information and processes and not just boxes and wires;

- **Access** - access to the internet is not universal especially among groups such the elderly;

- **Confidentiality** – concerns exist over the ability of systems to remain secure and confidential;

- **Bad Experiences** – These can cause reluctance to take chances again;

- **Resources** – Resources are limited – especially that of qualified personnel. There needs to be a willingness to share between organisations;

- **Speed of Change** – Technology is constantly changing.
Question 9. What legislation is needed to support using information for health?

Questions 9 and 10 were answered by a single group that had been picked as being likely to have a particular understanding of the legal issues associated with health information collection and utilisation. The main legislative needs to support the use of information for health were identified as follows:

- **National personal identifier** - Legislation is needed for a national personal identifier to identify its appropriate use;

- **Consolidation** - A consolidation of current health legislation concerning the use and transfer of information would be useful;

- **Code of Practice** – The Data Protection Commissioner’s anticipated code of practice should address among other issues:
  - Collection of patient data;
  - Transmission of patient data;
  - Use of patient data;
  - Disposal of patient data;
  - Minimum record keeping standards.

- **Statutory Requirements** - There may be a statutory requirement that that specific information be provided to the health sector (including the private sector);

- **Data Protection** – Legislation to provide further exemptions in the Data Protection Act in specified circumstances such as tracking a patient’s entire history by use of a unique patient identifier;

- **Patient Charter** – If a patient charter was drafted, this could become a bill of rights providing both patients and health administrators with knowledge of rights and duties.
Hopes for a National Health Information Strategy

Participants listed the following as the most important aspirations for a successful National Health Information Strategy:

- Good health will depend on good information – we should ensure the information is as effectively used as possible;
- Health information should include all aspects of health determinants;
- Comprehensive strategy implemented in realistic stages with effectively determined priorities;
- Proper resourcing backed by the political will to succeed;
- Effective consultation process, including all stakeholders to ensure consensus for the strategy;
- Standardised information;
- Learning form other countries;
- Effective library and informational services;
- Unique patient identifier;
- Using operational data as much as possible;
- Bottom up development providing information for operational and policy use;
- Electronic patient record;
- Legal issues properly addressed (data protection, confidentiality etc.);
- Minimum datasets the ideal;
- More cross border and international collaboration. Great opportunity to collect health on an all island basis;
- Use this as a means to make health, health information and health services more intelligible to the average citizen. Use it as an opportunity to put the patient at the centre of policy and services.