# Health Information

## A National Strategy

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# Minister for Health and Children's Foreword

Health information is a valuable resource. Many advances in health and healthcare during the last two centuries have depended upon the increasing availability and application of useful health information. Discoveries in genetics and breakthroughs in bio-engineering, health informatics and other fields are likely to transform our information base and provide more effective means to protect health, combat chronic disease and plan and deliver healthcare. Information is generated at such a pace that there is a serious risk of information gaps opening up between the public, clients/patients, the professionals, the planners, the policy makers and the research community. Keeping abreast of new information and applying it on a daily basis will remain an ongoing challenge.

The National Health Information Strategy will support the achievement of the vision, goals and objectives set out in *Quality and Fairness: A Health System for You (2001), Primary Care: A New Direction (2001)* and the Health Service Reform Programme (2003) as set out in the Brennan and Prospectus reports, by ensuring that health information becomes more readily available and appropriately used throughout the sector. The Health Information and Quality Authority will play a pivotal role in the implementation of the Strategy. The potential of modern information and communications technology (ICT) will be exploited to help health professionals provide safer and more integrated care to their clients/patients and to achieve value for money.

At its core, the Strategy is about fostering a change of culture with respect to the development and application of health information at all levels. In the hands of people with the expertise and incentive to use it, data which is defined and understood in a shared way is transformed into information. This information, set in the context of previous action, becomes evidence and evidence that is analysed and researched becomes knowledge. The potential of applied health information to transform all aspects of healthcare delivery and to effect major improvements in population health is clear and, with consistent effort, attainable. The implementation of this Strategy will contribute in a very significant and fundamental way toward achieving that goal.

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Minister for Health and Children

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# Executive Summary

The primary aim of the National Health Information Strategy (NHIS) is to recommend the necessary actions to rectify present deficiencies in health information systems and to put in place the frameworks to ensure the optimal development and utilisation of health information (see Appendix 1). This is seen as essential to the successful implementation of the Health Service Reform Programme.

The importance of progressing the information framework has received repeated emphasis in the Deloitte and Touche report on *Value for Money in the Health Services,* the Primary Care Strategy *Primary Care: a New Direction,* the Brennan and Prospectus reports and, most recently, in the Government's decision in relation to the Health Service Reform Programme.

The National Health Information Strategy (NHIS) focuses on health information in its own right rather than on information and communications technology (ICT) (an ICT strategy is being finalised by the Health Boards Executive). The National Health Information Strategy addresses the major information needs of individuals and broad interest groups within society. The use of information to support safe and high-quality client/patient care and in planning, developing, evaluating and accrediting the quality of the health services is a central theme. Special attention is given to establishing processes and infrastructures to underpin future health information developments. Furthermore, it is recognised that effective use of health information is largely dependent on the skills and knowledge of health service staff and the culture of the environment in which they operate.

## PART 1 Health Information in Context

In setting out the vision, principles and objectives of the Strategy, a wide definition of health information has been adopted to encompass the needs of all those who require such information. The vision is to ensure that all stakeholders, namely the general public, clients/patients, carers, health professionals, service staff, service managers, policy makers, Government, researchers and the media can readily access trustworthy information and can use it appropriately.

The principles of the Strategy are to:

▸ Safeguard the privacy and confidentiality of personal health information
▸ Ensure that health information systems are efficient and effective
▸ Promote the optimal use of health information
▸ Ensure the high quality of health information.

The objectives of the Strategy are to:

▸ **Support the implementation** of *Quality and Fairness: A Health System for You* (2001), and the Health Service Reform Program (2003)
▸ **Establish a legislative and information governance framework** for safeguarding the confidentiality and privacy of health information while optimising its use
▸ **Adopt an integrated, national approach** to the development and expansion of information sources and systems to best meet the strategic health information needs

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> ▸ **Establish processes and structures that ensure the fuller use of health information** in policy making, service planning and implementation processes, care provision and for underpinning quality assurance and accountability arrangements in the health system
> ▸ **Improve access to health information** for all stakeholder groups
> ▸ **Establish health information standards** that ensure the quality and comparability of health information and enable appropriate sharing of health information within the health sector
> ▸ **Exploit the enabling technologies** in the collection, processing, analysis and dissemination of health information and its application in the delivery of health services.

The overall thrust of the Strategy is based upon a consideration of the everyday health information needs of the stakeholder groups.  It is acknowledged that there are many barriers to finding, accessing and using information, especially due to the fragmented, non-standard and inconsistent way in which information is collected and processed by the agencies involved.  Client/patient care records still continue to be mostly paper-based.  Overall, the value of information systems is greatly dependent upon the quality of record keeping and the accessibility of the contents.

New or expanded health information functions have developed in the many specialist information agencies where the proper use of information is subject to Freedom of Information and Data Protection legislation.  eGovernment initiatives are changing the way information is used throughout the State.

Placing the Strategy within the context of the four national goals of *Quality and Fairness: A Health System for You (2001)* serves to add emphasis to the urgent requirement to apply a strategic approach to the development of health information.  The first national goal of 'Better Health for Everyone' requires extensive baseline information on population health and its determinants.  Health impact assessments demand information and the objectives of the National Anti-Poverty Strategy (1997) and poverty proofing and the development of social inclusion indicators are all dependent on improvements in information.  Similarly, the second national goal of 'Fair Access' must also be addressed on the basis of objective evidence of barriers to access and objective evaluation of initiatives to ensure fair access.  'Responsive and Appropriate Care Delivery' is the third national goal and information on capacity and on patient satisfaction are important and measurable components of this.  The final national goal is 'High Performance' which requires performance to be measured in terms of quality, accountability and value for money.

Ireland's commitment to, and involvement in, health protection, health promotion and health information programmes under the European Union (EU), the World Health Organisation (WHO), the Organisation for Economic Cooperation and Development (OECD) and other agencies provide the international context for the Strategy.  Critical health service decisions by national governments are being increasingly influenced through international benchmarking.  There is widespread recognition of the need for better, more accessible and comparable international health data.

## PART 2 Improving Health Information

### The information role of the Health Information and Quality Authority

While overall responsibility for health information policy and related legislation rests with the Department of Health and Children, the Health Information and Quality Authority, the establishment of which was set out in *Quality and Fairness: A Health System for You (2001)*, will be given a central role in the implementation of the National Health Information Strategy *(Action 1)*. To promote the quality of information and ensure its relevance to strategic priorities, the Health Information and Quality Authority will set standards by which it will assess and advise on the suitability of major developments in the area of health information and the supporting information and communications technology *(Actions 2 & 19)*. A multi-annual information and ICT plan will be drawn up by the Health Information and Quality Authority *(Action 3)*. A process will be established whereby the Health Information and Quality Authority will assess the business plans of relevant health agencies with information databases and assess the adherence of any other key information sources to required standards and priorities *(Action 4)*. An annual report will be published by the Health Information and Quality Authority *(Action 5)*. A health services data model and a national inventory of health information databases will be developed and maintained by the Health Information and Quality Authority *(Actions 6 & 7)*.

### Information and the Service Planning Process

A primary goal of *Quality and Fairness: A Health System for You (2001)* is to provide an equitable service that best meets the priority needs of the population. It is of critical importance that available health information, especially information that flows from operational sources (i.e. data routinely collected as an intrinsic part of service delivery), is properly integrated and firmly embedded as the evidence base in the mechanisms that have the greatest impact on the health of the nation. Service planning and implementation are of crucial importance as they lie at the very heart of these processes and it is essential that they are backed up by high-quality information *(Action 8)* and that health information requirements are a specific dimension within the plans developed by health agencies *(Action 9)*.

Human resources (HR) account for approximately 70 percent of overall expenditure on health. Improved information on HR is a necessity throughout the sector *(Action 10)*. A state of the art HR enterprise resource planning system (PPARS project) has been adopted as a national standard and the first phase has already been implemented in a number of agencies. This will help to address deficits in essential and timely human resource information including workforce planning, time management, staff retention and recruitment, benchmarking and management information.

### Population Health

To drive the process of realising the goal of 'Better health for everyone' under *Quality and Fairness: A Health System for You (2001)*, significant enhancements in the availability and quality of information in a range of domains are required, including population health surveillance. In this context, a national population health observatory function will be developed *(Action 11)*. To support the processes of health surveillance, resource targeting and narrowing health inequalities, health datasets will allow for analysis by the population subgroups identified by the National Anti-Poverty Strategy (1997) and related policies *(Action 12)*, and will also enable analysis by small local area, such as the district electoral division *(Action 13)*.

### Access to Information – the Health Information Portal

In line with its key role in setting out information priorities, the Health Information and Quality Authority will provide for the development of a Health Information Portal *(Action 14)*. The Health Information Portal will constitute a single internet-based access point to a range of health and health-related information sources and health information services for all stakeholders. Building upon the Health Boards Executive Health Services Portal and existing eGovernment initiatives, the Portal will include provision of eHealth services information, library and data access facilities as well as provision of rapid notification of urgent information to specified stakeholders.

### The Electronic Healthcare Record

The electronic healthcare record is an evolving concept and the architectural models for it are still being developed. It will, therefore, be introduced on a phased basis throughout the primary and secondary care domains on a national basis *(Action 15)*. It will include much of the data derived from operational clinical systems that are needed to support many of the information requirements of this Strategy. This includes the sharing of clinical information across multi-disciplinary care environments that transcend traditional service delivery boundaries. It has potential to support safer care delivery, clinical training and many management processes such as service planning, evaluation and demonstrating value for money. A phased approach to its introduction is required so that important lessons can be learned through the evaluation of pilot sites.

### Unique Identification

A system of unique identification will promote the quality and safety of client/patient care. The provision of such client-centred services is a key principle of *Quality and Fairness: A Health System for You (2001)*. This places a special emphasis on the importance of being able to associate all relevant health information about an individual where necessary and requires a process for unique identification to replace the variety of identifiers currently in place *(Action 16)*. It is of central importance in enabling the effective implementation of an electronic healthcare record and in supporting a range of service evaluation and management processes, including the determination of value for money. The effectiveness of *Quality and Fairness: A Health System for You (2001)* will be significantly enhanced by the implementation of unique identification. The Health Information and Quality Authority, in cooperation with the Department of Health and Children and other agencies, will develop a plan for the implementation of a unique identification system, based upon the PPS Number and its supportive infrastructure, which meets the functional requirements of the health sector. It is recognised that unique identification within the health sector must be supported by a robust information governance framework and be provided for in legislation.

## PART 3 Supporting Health Information

### Information Governance and Legislation

Existing legislation is not sufficiently supportive of some aspects of health information governance. A Health Information Bill will be published by the Department of Health and Children that will place the interests of clients/patients, the rights and duties of service providers and information processing activities on a sound and robust footing within a culture that ensures and safeguards the appropriate and best use of health information. Codes of practice will clarify issues of data sharing, and there will be a comprehensive framework enabling information flows, including those from the private sector, so that information can be used more fully and properly in the care of

clients/patients and for promoting a demonstrably first class and accountable health service. A legislative framework to underpin the Strategy will be introduced *(Action 17),* together with a framework for information governance *(Action 18).* These frameworks will support health surveillance and disease registration, quality assurance of service delivery and research processes.

### Information Standards and Quality

The adoption of health information standards is necessary for improving the quality, comparability and usefulness of health information for all stakeholder groups and for implementing the electronic healthcare record. The Health Information and Quality Authority will introduce a national health information standards framework *(Action 19),* develop common sets of indicators *(Action 20)* and establish a system of quality assurance of information services provided to the public *(Action 21).*

### Information and Communications Technology

As pointed out in the Deloitte and Touche report, *Audit of the Irish Health System for Value for Money (2001),* the outcome of under-investment in information and communications technology (ICT) in the past is an inadequate infrastructure to meet the complex information needs of a modern health service including performance management and demonstrating value for money. To reap the full benefits of investment in ICT, a shared infrastructure and a common approach will be adopted. The introduction of national ICT systems will build upon the infrastructure and wealth of knowledge and experience already in the field and include effective change management and training processes. ICT actions will be developed and included as part of a multi-annual information and ICT action plan in order to achieve a consistent, coordinated and common approach across the health service for all mainstream ICT developments, taking account of ongoing eGovernment and other initiatives *(Action 22).*

## PART 4 Implementation

### Implementation and Monitoring

The implementation of the Strategy requires cooperation and partnership between the key stakeholders. To support this process of cooperation and partnership, ongoing consultation on initiatives and participation in local, regional and national structures are required. *Quality and Fairness: A Health System for You (2001)* outlines arrangements for its implementation and monitoring at both national and local level and the need for appropriately aligned structures within the Department of Health and Children and the health agencies. The key information functions, including the implementation and monitoring of this Strategy, will fall within the scope of these structures.

To implement the Strategy, a number of essential requirements must be met, including:

▸   The development of infrastructures, and especially the empowerment of the Health Information and Quality Authority, as the central driving force behind the implementation of the Strategy
▸   The availability of skilled and trained staff, within the Department and health agencies, with the expertise to exploit available information and to support the roll-out and use of new information systems. Staffing requirements will be addressed in the context of the framework for change for improving workforce planning and action planning for people management in *Quality and Fairness: A Health System for You (2001)*
▸   A clear and supportive legislative and information governance framework that permits appropriate sharing of health information while protecting privacy and confidentiality
▸   Major investment in information systems to enable appraisal of effectiveness, efficiency and economy. A range of options including third party provision of ICT services will be considered.

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The current low level of investment in health information in general and ICT in particular is central to our difficulties in meeting the complex information requirements of a modern health service.  Future investment needs will be determined as part of the estimates process.

The Department will be responsible for regulatory legislation in support of health information in keeping with a framework for information governance.  In the context of service plans, recommendations will be made by the Health Information and Quality Authority on their adherence to relevant standards for information and ICT and the Department may chose whether to allocate funding for information developments and services based on these recommendations.

Appropriate administrative arrangements to support health information at health agency level will be established *(Action 23)*.  A system to evaluate and monitor the implementation of the Strategy at national and regional/local level will be put in place including a process for reviewing and updating of the Strategy as necessary *(Action 24)*.  The appropriate skill-mix to support the Strategy will be pursued in the context of the overall implementation of *Quality and Fairness: A Health System for You (2001) (Action 25)* and relevant training programmes *(Action 26)*.

Given the dynamic nature of the requirements for health information and the ongoing evolution of ICT, the Department of Health and Children, in cooperation with the Health Information and Quality Authority, will review and renew this Strategy on an annual basis *(Action 27)*.

## Implementation Phases

The Strategy will be implemented on a phased basis and advantage will be taken of the developing health information infrastructure.  The process is divided into phase 1 (years 1-2), phase 2 (years 3-5) and phase 3 (year 6 onwards) following the publication of the Strategy. Many of the initiatives are interdependent and may be influenced by developments outside the health sector.  While a number of the critical actions in the Strategy are achievable through relatively modest new investment, aimed at improving the quality, use and availability of existing information and introducing an information governance framework, other initiatives are more heavily dependent upon significant investment decisions, such as the implementation of major ICT solutions.  Improved access to existing information for planners, health professionals and the public will be an early objective of the Health Information and Quality Authority.

During phase 1 emphasis will be placed upon establishing essential infrastructures and processes, with priority given to establishing the Health Information and Quality Authority.  The Health Information Bill will be published and will provide the information governance framework, a national standards framework will be developed and access to available information by all stakeholders will be facilitated through the Health Information Portal.  The national ICT Plan will be completed as part of the information and ICT action plan, and national resource management projects, covering human resources (the PPARS project), financial and material management hospital information systems as well as ICT support of the *Primary Care Strategy: A New Direction (2001)* will be progressed within planned levels of resources.  eHealth services will be developed within the framework for eGovernment action plans.  The service planning process at national and regional level will be strengthened.

In phase 2, emphasis will be placed on the ongoing development of the necessary ICT infrastructure, including a secure communications system and the deployment of the infrastructure and procedures for unique identification.  New and enhanced sources of information

will be commissioned.  In addition it is planned that the ongoing roll-out of key functional systems such as for financial accounting and human resources (PPARS) will be completed during this phase.

The ongoing deployment of the electronic healthcare record will be the dominant undertaking of phase 3.  This will build on the primary care ICT developments from phase 1 and the overall electronic healthcare model addressed in the ICT action plan.

## Actions

### Chapter 6 The information role of the Health Information and Quality Authority

1 The Health Information and Quality Authority will be given a central role in implementing the National Health Information Strategy
2 The Health Information and Quality Authority will assess and advise on major developments in information and information technology
3 The Health Information and Quality Authority will draw up a multi-annual information and ICT action plan.
4 The Health Information and Quality Authority will assess information databases of all agencies which provide key health service information on an ongoing basis and enter into service agreements as appropriate for the supply of information
5 An annual report will be published by the Health Information and Quality Authority
6 A health services data model will be developed and maintained by the Health Information and Quality Authority
7 A national health information database inventory will be developed and maintained

### Chapter 7 Information and the Service Planning Process

8 Health agencies will be required to demonstrate the appropriate use of information in implementation and service plans
9 Health information requirements will be a specific dimension within implementation and service plans
10 Improved information on human resources will be made available

### Chapter 8 Population Health

11 A national population health observatory will be established
12 Health information will contribute to the process of narrowing inequalities in health and other population health priorities
13 Health information will be geo-coded by small area

### Chapter 9 Access to Information – Health Information Portal

14 A Health Information Portal will be developed

### Chapter 10 The Electronic Healthcare Record

15 The electronic healthcare record will be implemented on a phased basis Chapter 11 Unique Identification

### Chapter 11 Unique Identification

16 A system for unique identification within the health sector using the PPS Number will be introduced

### Chapter 12 Information Governance and Legislation

17  A legislative framework to support the National Health Information Strategy will be developed

18  A framework for information governance will be developed

### Chapter 13 Information Standards and Quality

19  A national health information standards framework will be developed

20  Common indicator sets (CISs) will be developed

21  Information services provided to the public will be quality assured

### Chapter 14 Information and Communications Technology

22  ICT actions will form part of the multi-annual information and ICT plan to be developed by the Health Information and Quality Authority

### Chapter 15 Implementation and Monitoring

23  Appropriate administrative arrangements to support health information at health agency level will be established

24  A system to evaluate and monitor the implementation of the National Health Information Strategy will be established

25  Human resource development will support the delivery of the National Health Information Strategy

26  Relevant training programmes will be provided

27  The Health Information and Quality Authority will review and update the National Health Information Strategy every year and submit it to the Minister for Health and Children for approval.

# 1 Introduction

*'It is vital that the development of a health information system is integrated into the agenda for change identified in the Health Strategy.  Information plays a central role in supporting strategic goals and in underpinning the principles of the Health Strategy.  It must not be seen merely as an add-on'* (Quality and Fairness: A Health System for You (2001)).

High-quality information lies at the heart of all good decisions concerning health.  Health information must be relevant and accessible to all those who require it, must be presented in the most useful formats and must utilise the power of information and communications technology (ICT) to the full in its collection and dissemination.  Good information empowers us all.  This applies equally to consumers, health professionals, researchers, managers and policy makers.  Widespread availability and use of health information will mean better informed public and patients, improved service delivery, enhanced quality and efficiency and well-targeted planning.  The cumulative effect and ultimate aim of evidence-based decision making is the continued improvement of the health of the population.  The purpose of this Strategy is to recommend the framework and actions required to make sure that all those who need health information get the information they need and are in the position to use it competently, confidently and effectively.

Access to good health information provides the tool for evidence-based decision making at all levels.  It also provides the means for ensuring that best use is made of finite resources in delivering a first class health service.  This realisation is not new and, indeed, many of the most important achievements in population health and in health service delivery over the past two centuries are attributable to the effective application of health information.  However, the scale of information requirements and uses is both qualitatively and quantitatively different from past needs and uses.  A number of factors can be identified in this including the accelerating pace of scientific advance, the increasing technical and administrative complexity of services, growing public sophistication and expectation, the requirement to ensure value for money for significant exchequer investment and to measure our performance against international standards and, not least, the rapid advances in ICT.  Advances in ICT present a greatly increased capacity to produce, access and disseminate information.  Correctly applied, in serving rather than determining information requirements, the potential of ICT is huge.

The policy context for the development of the Strategy is clear.  *Quality and Fairness: A Health System for You (2001)* recognises that a high-quality information infrastructure is a fundamental necessity for achieving its objectives.  Accurate, relevant and timely information is not an optional extra but is essential.  Each of the four national goals of *Quality and Fairness: A Health System for You (2001)* – better health for everyone, fair access, responsive and appropriate care delivery and high performance – can only be planned, supported and evaluated through the effective use of information. *Primary Care: A New Direction (2001),* launched in conjunction with *Quality and Fairness: A Health System for You (2001),* proposes a team-based approach to the delivery of primary care.  This will depend critically on the development and use of information.  It is for these reasons that *Quality and Fairness: A Health System for You (2001)* identifies Information as one of six frameworks for change.  Five of the frameworks have now been addressed in the suite of reports that provide the basis of the Health Service Reform Programme.  These are Strengthening Primary Care (Primary Care Strategy), Reform of Acute Hospital System (Hanly),

Funding (Brennan), Organisational Reform (Prospectus) and Human Resources (Action Plan for People Management in the Health Service).  This Strategy addresses the remaining framework of Information.  The establishment of an independent Health Information and Quality Authority is one of the organisational reforms proposed by the Health Strategy which will be carried out as part of the Health Service Reform Programme.  This will provide the key vehicle for achieving the necessary improvements in health information.

The National Health Information Strategy consists of four parts.  The first sets out a broad and high-level vision for an optimal health information system, looking at requirements from a user's perspective while considering the vision in the context of current realities and developments, both at national and international level.  In the second and third parts of the report, the central issues and actions required to progressively realise the vision are described.  The final part looks at the requirements for implementation including the roles of the various players, the resource implications, the critical path and the suggested time frame.  A detailed chart of the action plan with priorities, deliverables and responsibilities forms the last chapter of the Strategy.

# Part 1

## Health Information in Context

# 2 The Vision, Principles and Objectives

This chapter defines what is meant by 'health information' in the context of the Strategy, and sets out the vision for optimising the effective provision and use of information to support the implementation of the Health Service Reform Programme.

## 2.1 What is health information?

The term 'health information' is employed throughout this Strategy to refer to any information used to help make an informed health-related decision or to inform oneself of health-related issues, whether at the personal, professional, managerial or political level.

The type and complexity of the information will vary depending greatly on its purpose whether used by a patient deciding where to go for advice, a health professional weighing up the pros and cons of a particular intervention, a service manager deciding on a budgetary allocation or a policy maker devising a new strategy.

## 2.2 Transforming data to information and knowledge

Good healthcare depends upon good information.  A central theme throughout this Strategy is the importance of transforming raw data into useful information that can then be applied as knowledge in guiding decisions about the provision of care to individual clients/patients, the planning and evaluation of services and the formulation of health policies.  In the past resources have tended to focus on the collection of data that sometimes flow into 'islands of information' that are not properly exploited on an everyday basis.  This Strategy places greater emphasis on the importance of transforming data into different types of information that is readily available to meet the needs of different stakeholder groups.

While data that are routinely collected as an intrinsic part of service delivery (i.e.  operational sources) are a primary source of health information, such 'activity' data must be complemented by other types of information (such as surveys) to provide a comprehensive basis for the planning and evaluation of services, such as to identify unmet need, health determinants and the health status of the population or sub-groups.

The effective interpretation and use of information is greatly determined by the skill and knowledge of health service staff and the culture of the environment in which they operate.  The skill and knowledge of health service staff is a critical asset and must be nurtured and developed.  This Strategy depends on people using information effectively, and being supported by technology rather than being shaped by its collection, processing and distribution.

## 2.3 Scope of health information

Given the wide-ranging definition of health information, the scope of the information required to encompass the needs of the stakeholders is broad and includes:

▸    Information for the public, clients/patients and carers about health and the health services to empower them to make health-related decisions

- Information to assist health professionals in clinical decision making and to provide quality care, including access to best practice guidelines, knowledge databases and library services
- Information to support the planning, monitoring and evaluation of health services, including human resource management and planning, resource allocation and information that demonstrates service quality and value for money
- Information to support the development and implementation of policies and the allocation and utilisation of resources to promote, protect and restore the health of individuals, special needs groups and the general population
- Information to support health research
- Information on health status and health determinants.

## 2.4 The vision of the Information Strategy

The vision of the Strategy is of a trusted and valued health information environment within which all stakeholder groups, namely the general public, clients/patients, carers, healthcare professionals and service staff, health service managers, public health, policy makers and Government, researchers and the media are enabled and empowered to make informed choices to promote, protect, restore and maintain the health of individuals and of the population.

The achievement of this vision will touch the lives of all staff members in the health service and their clients/patients, and the process of making it a reality will pose a significant challenge to every part of the health sector.

## 2.5 The principles of the Information Strategy

The key principles comprising this vision are:

- **Safeguarding privacy and confidentiality.** Access, processing and use of personal health information should comply with legislative and information governance requirements. Special care should be taken to protect personal and sensitive information.
- **Efficient and effective health information systems.** The development and continuation of information systems should be driven by their usefulness to stakeholders. Data that are routinely collected as an intrinsic part of service delivery (i.e. from operational sources) should be the primary source of information and be complemented by other sources as and when required. Data should be gathered once and once only; if data are not going to be transformed into useful information, they should not be collected.
- **Optimal health information access and use.** Stakeholders need ready access to available health information that is appropriate to their needs. Available information should be fully exploited and shared in the support of safe and high-quality client/patient care, the development and evaluation of health services and policies and for legitimate research purposes.
- **Quality assurance of health information.** Health information should be of the highest quality and be demonstrably compliant with health information standards.

## 2.6 The objectives of the Information Strategy

In achieving its vision, the Strategy is centred upon a number of fundamental objectives which are elaborated upon in later chapters.  These are to:

> ‣ **Support the implementation** of *Quality and Fairness: A Health System for You (2001),* and the Health Service Reform Program (2003)
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> ‣ **Establish a legislative and information governance framework** for safeguarding the confidentiality and privacy of health information while optimising its use
>
> ‣ **Adopt an integrated, national approach** to the development and expansion of information sources and systems to best meet the strategic health information needs
>
> ‣ **Establish processes and structures that ensure the fuller use of health information** in policy making, service planning and implementation processes, care provision and for underpinning quality assurance and accountability arrangements in the health system
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> ‣ **Improve access to health information** for all stakeholder groups
>
> ‣ **Establish health information standards** that ensure the quality and comparability of health information and enable appropriate sharing of health information within the health sector
>
> ‣ **Exploit the enabling technologies** in the collection, processing, analysis and dissemination of health information and its application in the delivery of health services.

# 3 National Context

The primary aim of the National Health Information Strategy (NHIS) is to recommend the necessary actions to rectify present deficiencies in health information systems and to put in place the frameworks to ensure the optimal development and utilisation of health information.   This is seen as essential to the successful implementation of the Health Service Reform Programme.

Information is one of the six frameworks for change in the Health Strategy *Quality and Fairness: A Health System for You (2001).*  The importance of progressing the information framework has received repeated emphasis in the Deloitte and Touche report on *Value for Money in the Health Services,* the Primary Care Strategy *Primary Care: a New Direction,* the Brennan and Prospectus reports and, most recently, in the Government's decision in relation to the Health Service Reform Programme.

The National Health Information Strategy is seen as the final piece of work needed to support the implementation of the change programme envisaged for the various parts of the system.   It builds on the establishment of the Health Information and Quality Authority (HIQA) which will play a key role in this area in supporting the achievement of the necessary systems improvements.  Improved health information will, in turn, support the broader role of HIQA in its quality remit.

## 3.1 Key developments in health information

The intellectual capital that is dedicated to the analysis and interpretation of complex health information continues to increase over time and is a resource of critical importance.  Examples of important developments which have generally taken place in the context of national strategy or policy initiatives are outlined below.

▸ **Freedom of Information and Data Protection** legislation, in accordance with European Union requirements, provides a legal framework within which information can be properly used and the confidentiality and privacy of information is safeguarded (chapter 12).
▸ **Service planning by health agencies and implementation processes** continue to evolve over time and play an increasingly important role in determining the national, regional and local responses to our health priorities.  The use of performance indicators together with the introduction of service accreditation processes will promote the quality of healthcare delivery.
▸ The **Central Statistics Office** (CSO) plays a key role in the collection of demographic and vital statistics and is actively involved in developments in the area of health and social statistics. The Quarterly National Household Survey (QNHS) is a relatively new and valuable tool for surveying health issues.  In the area of social statistics, the CSO is well placed to maximise the usefulness of administrative sources in the broad context of social data needs and is currently pursuing this aim.
▸ The **National Cancer Registry**, established in 1991, provides data on the occurrence of cancer.  It already provides useful insights into the treatments and survival of those with cancer and supports the implementation of the National Cancer Strategy.  It is noteworthy that at present only approximately half of the countries in the European Union have comprehensive national cancer registration.

> ‣ **Public health departments** were established in the health boards in 1995 and provide expertise in many highly specialised areas including epidemiology, population health surveillance, needs assessment, the prevention and control of infectious diseases and service planning and evaluation.
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> ‣ The **Institute of Public Health in Ireland** was established in 1998 on an all-Ireland basis and provides a forum for addressing common public health issues.
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> ‣ The development of the **Public Health Information System** (PHIS) by the Department of Health and Children in collaboration with the Departments of Public Health has been successful in providing practical access to a common minimum public health data set compiled from a variety of sources and distributed on CD-Rom.  The PHIS also provides a working model which can be incorporated into future initiatives to widen access to key information sources and indicators.
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> ‣ The capacity for health surveillance has been greatly enhanced with the establishment of the **National Disease Surveillance Centre** (NDSC) in 1998 and the development of the Computerised Infectious Disease Reporting (CIDR) system which will electronically link the Centre to laboratories and health agencies and provide feedback to interested parties within an agreed information governance framework.
>
> ‣ The **Health Research Board** (HRB) is a central driving force in enabling and supporting high-quality research.  In partnership with the Department of Health and Children, the HRB published *Making Knowledge Work for Health, a Strategy for Health Research (2001).*  The HRB oversees the National Intellectual Disability Database which has a proven track record in providing information necessary for planning services to meet the priority needs of this group.  The HRB, in partnership with health agencies, is developing the National Physical and Sensory Disability Database and administers the National Psychiatric In-Patient Reporting System.
>
> ‣ The Hospital In-Patient Enquiry (HIPE) system, administered by the **Economic and Social Research Institute** (ESRI), has evolved over time to become an essential tool for the analysis of acute hospital activity and for the allocation of resources by the Department of Health and Children to hospitals through the Casemix Model.  The system also provided data for the report *Acute Hospital Bed Capacity: A National Review (2002)* that identified the secondary care resources for meeting the future needs of the population.  The ESRI also administers the National Perinatal Reporting Scheme (NPRS) and is progressing toward improving the timeliness and quality of the NPRS and ensuring it is closely linked with the HIPE system.

There are many examples of creative information systems that demonstrate the potential of modern information and communications technology (ICT) in supporting the planning, evaluation and delivery of health services.  Examples include electronic healthcare records, child health and child care, oral health, hospital information systems, the transfer of information between hospitals and general practice, eHealth initiatives and the roll-out of intranets.  Significant progress is being made in implementing enterprise-wide management information systems in areas such as finance, materials management and human resources.

eGovernment initiatives are beginning to change the way information is used throughout the State.  The eGovernment action plan – *New Connections (2002)* – sets out a strategy to realise the potential of the 'Information Society' and sees eGovernment as giving a key leadership role to Government in driving wider engagement with ICT through its own business processes and service delivery arrangements.  The target is to have all public services which can be delivered online available online by 2005 through the Public Services Broker.  eGovernment projects included in

*New Connections (2002)* relating specifically to the Department of Health and Children and including the health agencies include Integrated Services, eHealth Pilot Projects, Medical Services Pharmacy Payments and Electronic Civil Registration within the General Register Office.

## 3.2 Core Principles and Goals of the Health System

*Quality and Fairness: A Health System for You (2001)*, with its core principles of equity, people-centredness, quality and accountability, highlights the essential and demanding role that good quality health information plays in its successful implementation.

Four national goals are identified and, together with the information requirements of other major policies and strategies, provide the national context for the Strategy. These aims and principles remain key to the implementation of the Health Service Reform Programme, and it is useful to summarise the ways in which information is essential to the achievement of each goal.

### 3.2.1 National Goal No. 1: Better health for everyone

**Information for population health**
Without an assessment of population health and the factors that influence it, the task of determining health priorities, supporting an evidence-based approach to targeting resources through the service planning and implementation processes to meet local needs, carrying out health impact assessments and demonstrating improvements in health in line with national targets are impossible (chapters 7 and 8).

**Information for health impact assessment**
Health impact assessment (HIA) is in the process of being introduced as part of public policy development process. HIA is a process by which a policy, programme or project can be judged as to its potential effects on the health of a population and the distribution of those effects within the population. The core purpose of HIA is the promotion of equity and health enhancement as well as the prevention of ill-health by identifying factors that may have a potential impact on health. It has special relevance for initiatives to combat poverty. HIA generally assesses the effects on health of interventions that are not primarily aimed at affecting health. Before an effective HIA can be carried out, a wide range of relevant health information must first be available (chapter 6).

**Information for reducing inequalities in health**
The link between poverty and poor health status is well established. As well as the significant gap in mortality between the poorest and richest (overall mortality in the lowest socio-economic group is twice that of the highest group), the risk of ill-health (e.g. from cancer, heart disease and accidents) increases as socio-economic status decreases. In the context of the *National Anti-Poverty Strategy (1997)* (NAPS) and the *Programme for Prosperity and Fairness 2000-2006 (1999),* it is essential that information can be analysed by socio-economic group so as to support and monitor the implementation of strategies aimed at reducing inequalities in health (chapter 8).

### 3.2.2 National Goal No. 2: Fair access

To promote the uptake and utilisation of services, the availability of information on entitlements will be improved, including the use of information technology *(Quality and Fairness: A Health System for You (2001)).* The development of the Health Information Portal, with its philosophy of making useful health information much more accessible to all the stakeholder groups will be critical in this regard (chapter 9). Particular attention will be given to disadvantaged groups,

older people and people with disabilities in order to help them overcome literacy and language barriers.

The accessibility of services is an important issue of equity. There are three main barriers to access: cost barriers (cost of travel and indirect costs such as loss of work time), structural barriers (inconvenient opening hours, queues) and individual barriers (personal choice of service provider). Issues of fair access are also related to the design and delivery of services in ways that meet the specific needs of client groups. For a proper assessment of service accessibility, the appropriate tools to carry out geographical analysis are required. It is a key requirement that routine health information is geographically coded by small area and that it can be analysed by subgroups of the population (chapter 8).

### 3.2.3 National Goal No.  3: Responsive and appropriate care delivery

Responsive and appropriate care delivery aims to ensure that the health system responds appropriately and adequately to the needs of individuals and families. This requires the public to be informed, to have their views taken into account and to be partners in decision-making about the services they require. It is also concerned with ensuring that the various parts of the system are used to their maximum effectiveness and efficiency.

**People centredness**
One of the guiding principles of *Quality and Fairness: A Health System for You (2001)* is that of a people-centred health system. A responsive system must develop ways to engage with individuals and the wider community receiving services. At an individual level, there are now greater expectations about openness and shared decision-making in relation to individual care and recognition that the wishes of individual clients/patients must be listened to and accommodated as appropriate. At community level, this means allowing the wider community to participate in decisions about services at national, regional and local level. Better information is required, therefore, about the requirements of individuals and special needs groups and their views on the services they receive. Such information should play an important role in the planning and delivery of services in the future (chapter 7).

**Care in the appropriate setting**
A further dimension of responsive and appropriate care delivery is ensuring that people are receiving services in the most appropriate setting. Primary care is the appropriate setting for 90-95 percent of all care requirements. *Primary Care: A New Direction (2001)* describes how this health domain will be developed and the crucial role that will be played by the inter-disciplinary team. Key to this will be the development of the electronic healthcare record allowing communication between team members and with the secondary care services for the support of quality care (chapter 10). *Primary Care: A New Direction (2001)* also commits to providing the public with direct telephone and internet access to information, advice and triage services. Primary care, therefore, requires considerable investment in the information and communications technology infrastructure.

**Capacity**
A responsive and appropriate service also encompasses the issue of capacity. The health system does not have the capacity to meet the current demands being placed on it. This point has been highlighted in *Audit of the Irish Health Sector for Value for Money (2001)* and *Acute Hospital Bed Capacity: A National Review (2002).* It is essential, therefore, that management information

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systems provide real-time information about current capacity and support the planning process to meet future trends in capacity and identify human resource requirements throughout the sector so that maximum access to appropriate services are maintained and value for money is assured. Information must also be available on health status and health needs as these are the drivers for health demand that in turn must be matched by capacity. It is of central importance that information be integrated from all these domains so as to support the service planning and implementation processes (chapter 7).

### 3.2.4 National Goal No. 4: High performance

**Supporting quality**

High-quality care requires the availability and use of evidence tailored to the needs of health professionals at the point of decision-making. Local libraries have an important role here, but a more accessible and systematic means of addressing this issue through the provision of best practice guidelines, electronic library services (chapter 9) and decision support systems for health professionals is also required. The deployment of the electronic healthcare record across the sector will be of special importance (chapter 10). These developments will lead to improved consumer satisfaction with the care provided, and safer and more cost-effective service provision. Significant investment in such technologies and infrastructure throughout the sector is required (chapter 14).

**Measuring quality**

The central conclusion of *Audit of the Irish Health System for Value for Money (2001)* was that value for money (i.e. effectiveness, efficiency and economy) in the health system cannot be measured, monitored or assured because of insufficient and inappropriate information. The setting of standards and the measurement of performance using appropriate indicators are indispensable elements in ensuring a high-quality service.

At present, our information systems and infrastructures cannot adequately provide the complex information that is required to allow comparisons to be made between similar services in terms of outcomes and to drive the processes of quality improvement and risk management. It is not possible, for example, to identify across the entire health sector where high-quality healthcare is being provided or where significant deficits may lie. As discussed in chapter 14, significant investment in information systems and infrastructure is required to address these information deficiencies and to be able to provide assurance to the public and to the political system about the quality of our health services.

**Accountability**

*Quality and Fairness: A Health System for You (2001)* places a strong emphasis on accountability as one if its four key principles and, together with the support and measurement of quality, it is an essential component of a high performing system. In order to ensure that appropriate accountability arrangements can be supported, information is required that relates to system, financial and professional accountability. Baseline information about each of these dimensions is necessary for the introduction of any accountability and measurement systems.

*Audit of the Irish Health System for Value for Money (2001)* highlights the urgent need to develop the service planning and implementation processes that support the accountability function and to ensure that available resources are objectively matched to the priority health needs of the population.  The report highlights the need for information to be available to demonstrate quality of care and value for money through the use of practical and effective performance indicators.  These indicators are also considered a key element in the modernisation of the health sector as part of the partnership process under the *Programme for Prosperity and Fairness (1999).*  To enable these functions, a wide range of information to support needs assessment, service evaluation and the assessment of the evidence are required.  *Audit of the Irish Health Sector for Value for Money (2001)* places great emphasis upon the necessity for significant investment in our information infrastructure to meet these challenging needs.

**Shared Services**
The proposals in the National Health Information Strategy in relation to common standards, definitions and, in particular, common system-wide ICT developments lend themselves to the implementation of a shared services solution.  This is in line with the Health Service Reform Programme proposals for a National Shared Services Centre (NSSC).  The actions in the National Health Information Strategy strongly complement the implementation of the NSSC and add significantly to the efficiency and effectiveness of that development.

# 4 International Context

Ireland's commitment to and involvement in health protection, health promotion and health monitoring programmes of the European Union (EU), the World Health Organisation (WHO) and other agencies provide an international context for the Strategy. The experiences of other jurisdictions in the development and application of national health information systems have been very important in guiding the development of this Strategy. The paragraphs below discuss the involvement of international organisations in health information and provide a brief general overview of national approaches to improvements in the area.

## 4.1 International organisations

There is widespread recognition of the need for better and more accessible EU and international health data at all levels to meet the requirements of all stakeholders. The EU report *The Health Status of the European Union: Narrowing the Health Gap* concluded that the need for comparable data remains the central issue and that the lack of reliable data on morbidity, disability and health services points to the need for data and information-related improvements.

The Sevilla European Council in June 2002 agreed *eEurope 2005: An Information Society for All.* In relation to eHealth a number of actions are listed covering electronic health cards, health information networks and online health services. By the end of 2005 it is intended that online health services will be provided to the public. In relation to electronic health cards, the European Commission has developed a European health services entitlement card which initially will replace the E111 form.

While the EU does not have a mandate for the organisation and delivery of health services in member states, it does have a wide and growing remit in the area of public health and health protection issues and in the impact of community policies on health. Serving this remit necessitates having effective information systems on health, on health services and on the effectiveness of health systems. The directive (95/46/EC) of the European Parliament in October 1995 governs the processing and movement of personal data and has resulted in the Data Protection (Amendment) Act (2003) being enacted to bring Irish law in line with this directive.

Some of the key deficiencies identified at EU level, and further afield, are:

▸ The absence of baseline data and data systems, particularly in the areas of morbidity, needs assessment and community services
▸ The lack of comparability and data standards between member states
▸ Poor timeliness and poor incentives for data provision
▸ Slow progress in the development of electronic data dissemination systems
▸ An inadequate infrastructure at EU level to support the development of the key information functions
▸ A need for further developing of information governance rules and frameworks.

International organisations, in particular the WHO and the Organisation for Economic Cooperation and Development (OECD), have had a longstanding experience in and commitment to the collection, dissemination and use of health data to inform public health policy and in the

understanding of health systems.  These organisations will have an important part to play in the strategies adopted by the EU to improve health information.  As at national level, coordination and cooperation will be required to ensure the best use of existing expertise, the avoidance of duplication of effort and the optimisation of data sharing.

## 4.2 European Union

The Maastricht Treaty, which came into effect at the end of 1993, gave the EU a new and extended remit in the area of public health which led to the First Framework for Community Action in the Field of Public Health.  One of the principal priorities of the framework was the collection of reliable and comparable health statistics, and this goal resulted in turn in recommendations for the establishment of a Community Action Programme on Health Monitoring (HMP) 1997-2002.  The programme, under the auspices of DG SANCO, is founded on three pillars for action:

▸   Identification and assembly of a set of essential health indicators
▸   Deployment of an effective electronic system for the collection and dissemination of data
▸   Provision for the analysis of and reporting on EU public health issues.

The programme supported many projects designed to promote these three aims.

The Amsterdam Treaty further broadens EU responsibilities in the area of health and this is now reflected in the new Programme of Community Action in the field of Public Health 2003-2008. The three main strands of action are:

▸   Improving health information
▸   Establishing a rapid response mechanism for health threats
▸   Tackling health determinants through prevention and health promotion.

This programme is much more ambitious than the first framework and has a very strong emphasis on health information.  Health information is recognised as fundamental in securing improvements in health and, accordingly, the first main objective of the new public health programme is: *'to improve information and knowledge for the development of public health and the strengthening and maintenance of effective health interventions and efficient health systems, by developing and operating a well-structured and comprehensive system for collecting, analysing, evaluating and imparting health information and knowledge to competent authorities, health professionals and the public, and by undertaking assessments of and reporting on health status and health-related policies, systems and measures'.*

The Public Health Programme (2003-2008) has adopted a broad work programme including completing the development of a core set of health indicators, engaging in actions to improve data collection and dissemination in key areas such as injury, impact of ageing and reproductive health and putting in place a Public Health Portal.  The latter is seen as a critical development in facilitating information collection and transfer based on a flexible information technology (IT) platform.  It will provide information for a range of stakeholders and will support many citizen-oriented health information actions.  The Public Health Programme also has an important remit in promoting the development of eHealth in Europe and the Portal will have a central role in realising this aim both as a vehicle for exchange of information on eHealth but also in furthering developments such as seals of approval for health-related web sets and in defining, identifying

and disseminating best practice among member states.  The parallels and links with a national Health Information Portal as recommended later in this report (see Chapter 9) are substantial, the timing is opportune, and there is considerable potential for achieving efficiency and synergy.

## 4.3 World Health Organisation

The World Health Organisation (WHO) has widely acknowledged expertise in the codification and collection of health data and in its use to advance public health issues.  The European health for all database is a widely used resource for international health indicator dissemination and comparison.  The WHO Regional Committee meeting for Europe agreed a resoultion *'to continue to develop new and more effective ways of managing and using information, in order to meet changed circumstances in the domain of health knowledge, to enable the Regional Office to operate as a knowledge-based body and to provide better information services to the member states and the international community'.*

All the countries of the EU are members of the WHO and the full European Region membership covers more than 50 countries.  The enlargement of the EU, as well as the very large variations in health throughout Europe, make the WHO's work particularly relevant.  Equally importantly, the WHO's work allows us to look at health issues in a world-wide context.

## 4.4 Organisation for Economic Cooperation and Development

The OECD collects and disseminates wide ranging information on health and, more particularly, on health systems and health expenditure.  The OECD points out that health systems represent one of the largest service industries in most OECD countries, accounting for 8-10 percent on average of national income.  For this reason alone it is essential to monitor the organisation, effectiveness and fairness of health systems.  The OECD is involved in a three-year health project which has the improved measurement of performance as one of its key aims.

The Department of Health and Children currently supplies data separately to EUROSTAT, WHO and OECD, but it is worth noting that there is an agreement between WHO and OECD to work closely in order to avoid imposing undue burdens, conflicting information requests and unnecessary duplication of effort on member states.

## 4.5 Implications

The national picture has much in common with the issues and tasks faced in improving the availability and comparability of health information at EU and international level.  Perhaps more importantly, the EU now has a strong and increasing mandate for the improvement of health information and this is likely to have considerable implications at national level in the immediate future.  The importance of improvements in the timeliness, comprehensiveness and comparability of international health information should not be underestimated.  Benefits include:

- ▸ Ability to benchmark ourselves against EU and international standards
- ▸ Improved communication and data dissemination between member states
- ▸ Better understanding of common problems and effective solutions
- ▸ Elimination of duplication in data provision
- ▸ More effective response to health threats.

Some of the most important implications arising from the EU and international contexts in which we operate are as follows:

▸ Data standards, indicator definitions, information governance and performance measurement guidelines need to be harmonised with EU and international standards
▸ Analysis for policy must take into account EU data and the EU policy context
▸ Health impact assessment protocols need to closely follow EU standards in this area
▸ EU directives on data protection and confidentiality must be adhered to
▸ EU-wide developments concerning ICT issues and communication standards will need to be followed
▸ The proposed national Health Information Portal (see Chapter 9) should link in closely with the EU's development of a Public Health Portal.
▸ Participation at EU level in health information developments is a necessity to keep abreast of developments and to ensure appropriate input to decisions.

It is essential that we bring our health information systems to the level of development where they can effectively meet national needs for health monitoring, health service delivery and policy development, while also meeting EU requirements.  In turn, we must draw on EU and international health information to provide an objective assessment of the health of our population.

## 4.6 Health information systems in other countries

Many countries, both within the EU and further afield, are engaged in the development and implementation of strategic initiatives with a view to improving health information.  In addition, much of the impetus behind these developments is common across countries, including Ireland.  For example, the demands for better consumer information on health are present everywhere as is the increasing need to ensure effectiveness, accountability and value for money in the provision of services.  Likewise, the potential of ICT, the need for training in the use of information and the requirement for well developed information governance frameworks are also widely recognised.

As part of the preparation for this Strategy, a research project was undertaken to survey the health information systems of a selected group of countries with a view to learning from the experiences of others facing similar challenges.  Given time and resource constraints for the project, countries were chosen on the basis of prior knowledge of systems development, availability of information and existing personal contacts.  These included the countries of the United Kingdom, Nordic countries (i.e.  Norway, Sweden and Finland), France, the Netherlands, Canada, Australia and New Zealand.  Elements of the systems in New Zealand, Finland, Scotland and Canada were highlighted as providing potential models for further development in Ireland.

The report found that, in general, while many components of health information systems in this country work well and compare favourably with those of the other countries surveyed, the Irish system as a whole remains fragmented, under-resourced and under-utilised.  Summarising its findings, a number of key themes can be identified in modern and effective health information systems:

▶ Data usage: sharing of data, training in its use and effective information governance are essential.

▶ Data collection: data should be entered only once and as close to the point of patient contact as possible.

▶ Data content: the most advanced and effective systems utilise a unique identifier throughout the system.  Finland provides a good model where linkage between a population register and address registers simplifies geo-coding, shared-care arrangements and research applications for health data.

▶ Data collection systems: systems must meet the purposes for which they were designed, and a single agency/body should have overall responsibility for ensuring data quality, access and reporting.

▶ Legal issues: all countries with effective health information systems have paid careful attention to the legislation required to protect confidentiality and facilitate appropriate access and use.

▶ Technical issues: optimisation of ICT and application of advances in secure data transmission are features of high-quality health information systems.

Ireland can select the best from the experiences of other countries in order to put in place a modern and effective health information system.  As evidenced elsewhere, the most important high-level requirements are the commitment of politicians and senior managers, adequate resourcing of systems and training, and explicit policies and responsibilities for data standards and data use.

# 5 The Information Needed by the Public and the Health System

The Strategy is driven by a consideration of the general health information needs of the stakeholders, as identified in the previous chapter, which in turn can be expanded to include more specialised requirements.  While the required information might be available to some degree, it certainly is not comprehensive and standardised on a national basis.

Although there are many common data requirements between the stakeholder groups, there are differences in their information and knowledge requirements.  The need to support health research with good quality information is a theme running through all the areas outlined.

Stakeholders are faced with many barriers in finding relevant and reliable information.  This is largely due to the fragmented way in which information is held and the under-use or availability of electronic systems.

## 5.1 General public, clients/patients and carers

The goal of this Strategy is better healthcare delivery and better health-related decision making by members of the public and clients/patients who are seeking advice on health matters or are in need of healthcare.  Within the health sector in general, there is a non-integrated approach to the provision of information to the public.  Members of the public have a keen interest in health issues that relate to where they live or work, e.g. local patterns of cancer, asthma, or road accidents, but at present little of our health information is available on a local area basis (chapter 8).

In keeping with the general development of eServices that improve the delivery of services to the public, such as in banking and internet services, there is increased expectation that such innovation should be applied within the health sector as appropriate.  Examples include finding out about eligibility for public services and the processing of applications and appointments online.

Consumer health information is the fastest growing area of health information provision, and there is increasing demand for knowledge on all matters related to health as consumer expectations rise.  Many sources of 'good' health information do exist but there are significant barriers to accessing them.  The effort to obtain even basic health information, such as that on eligibility or local service availability, can be a daunting task.  One reason for this is the fragmented way in which health information is made available by the numerous agencies involved.  The quality of health information in the public domain, including the Internet, can be of dubious and unknown quality, with great variations in the content and format.  There are also those in society who have difficulties in communicating, are reluctant to seek out information, are unaware that the information is available or of how to access it, or do not have the resources to seek it out.  Furthermore, information and advice are generally available only during office hours.  Typical information requirements include the following:

▸ **Health and health determinants**
▸ **Health services**
▸ **eHealth services**
▸ **Electronic healthcare record**
▸ **Assurance of privacy and confidentiality**

## 5.2 Health professionals and health service staff

Health service staff require a wide array of often complex information about their clients/patients to be immediately available.  The information can be held in many different locations (laboratories, primary care files, hospital files) and reliance on the traditional paper record limits the extent to which care providers can share information in a useful, timely and seamless way.  This is especially true in maternity and child health when many service providers are involved or in the management of chronic conditions such as diabetes, cancer or cardiovascular disease.

Missing records or referral letters, delayed test results, incomplete histories, an inability to exchange information with colleagues out of hours and difficulties in accessing up-to-date best practice guidelines, eLibraries and evidence-based practice resources all pose challenges to delivering quality care.  In addition, clinical decision support systems are only used in a limited way.

Health professionals also need to be quickly informed about urgent health matters such as major changes in practice guidelines, an infectious disease outbreak in the area or a drug or vaccine withdrawal.  Frontline staff may be unaware of a 'new' health issue, such as new treatments or diagnostics until informed by their clients/patients or the media.  At the same time, it is clearly essential to avoid information overload given the great volumes of health information that emerge on a daily basis.  Health professionals will increasingly require information in the following areas:

> ▸ **Quality of care**
> ▸ **eHealth services**
> ▸ **Access to eLibraries and best practice guidelines**
> ▸ **Electronic healthcare record and clinical support systems**

## 5.3 Health service managers

Service planning, management and evaluation functions cover a very broad canvas and are highly dependent upon the availability of good health information.  While the functions differ in emphasis, there is significant overlap in their information requirements.  It is essential that good health information be fully utilised in the decision-making processes at all levels.  However, the information that is available today is limited in its scope and depth and tends to be poorly integrated and structured so that it cannot fully support these functions.

Developments in the service planning and implementation processes, and in the monitoring and evaluation functions, are drivers for improved health information.  It is becoming increasingly recognised that there is a need to be able to support and demonstrate quality of care.  This brings into sharp focus the requirement of corporate accountability for clinical performance, and is supported by developments in service accreditation, accountability legislation and the requirement to demonstrate value for money and overall service performance.  All these initiatives demand the availability and use of more comprehensive and comparative health information than has been the case in the past and the development of relevant and practical performance indicators for use across the sector.

Furthermore, *Quality and Fairness: A Health System for You (2001),* and *Primary Care: A New Direction,* the national strategies targeted at reducing cancer, cardiovascular disease and poverty are redefining the priorities for action and the setting of specific targets.  It is apparent that the

success of these initiatives is greatly dependent upon the availability of good health information. Key areas where information is needed by health service managers include:

▸ **Service planning and evaluation**
▸ **Needs assessment**
▸ **Human resource management**
▸ **Information and communications technology development**

## 5.4 Public health professionals, researchers, policy makers and Government

In addition to the information needs described for other stakeholders, there is a special emphasis on national oversight, value for money and the forecasting of future trends and priority needs so as to best position the health service to respond to those needs.  The development of policies to influence the future direction of the health service requires that a range of quality health information is available including, for example, information on the performance of the health services, on health determinants and on needs of the population and special groups.  This information is essential for the identification of the real health and social priorities and is invaluable in formulating the legislative basis, when required, to direct new health policies.  Good quality health information is also essential on an ongoing basis to provide support for the Minister for Health and Children, to assist in preparation of the annual Estimates for the Department of Finance and to support the Government and the Oireachtas by supplying information in response to specific questions about health and the health services.

Allocating resources in ways that are efficient and effective requires good information on competing areas of priority.  In order for additional or changing health needs to be appropriately addressed, high-quality information must be at the core of the annual Estimates presented to Government.

The Department of Health and Children and other health bodies are accountable to the public for the ways in which they spend public funds and for the decisions they make in respect of health policy and service provision.  Service managers should, therefore, be able to answer detailed questions relating to the quality and the accessibility of health services and to demonstrate value for money in the delivery of services.  The Government and the Oireachtas require and expect rapid and comprehensive responses to queries on such matters.  At present, apparently simple and straightforward questions can trigger significant effort and time on the part of the service providers to produce the necessary information.

The following are high priority areas for these stakeholders that require quality, timely information:

▸ **Service performance**
▸ **Monitoring the implementation of national strategies and policies**
▸ **Needs assessment**
▸ **Service developments**
▸ **Human resources**
▸ **Setting of targets**
▸ **Horizon scanning**
▸ **International health information requirements**

## 5.5 The media

The media are among the most important sources of information for the public and increasingly for health professionals in many areas. Accessing up-to-date and reliable information on issues of current interest, such as the implementation of national strategies and obtaining a good background to current issues of interest to the public, can be challenging for the media, as for other stakeholders. The development of the Health Information Portal (chapter 9) that integrates and assimilates information on a national basis will be a significant source of information for the media. In addition, the publication of an annual report by the Health Information and Quality Authority (chapter 6) will provide information on the use and impact of health resources, the implementation of strategies and new services, together with a broad range of health statistics.

# Part 2

## Improving Health Information

# 6 Information Role of the Health Information and Quality Authority

Significant progress has been made in improving and expanding information systems and functions across the health sector.  In summarising these developments in chapter 3, however, attention has also been drawn to persistent deficiencies and omissions in existing systems, to continuing difficulties in accessing and utilising information and to the requirement for an integrated, strategic approach to addressing current and future health information needs.  This chapter provides a summary of the present position and proceeds to describe the key functions of the new Authority in the area of health information.

## 6.1 Assessment of the current position

Many significant health information deficiencies exist.  In some instances, this may be due to the information being relatively inaccessible or not being in a format relevant to the stakeholder groups.  In others, it is due to information 'black-spots' where the information is limited or very fragmented.

In the process of developing this Strategy, together with *Quality and Fairness: A Health System for You (2001), Primary Care: A New Direction (2001), Audit of the Irish Health System for Value for Money (2001)* and the Prospectus and Brennan reports, a number of key areas requiring development were identified.  These include:

**The information role of the Health Information and Quality Authority** (chapter 6)
▸   A health services data model
▸   A national health services database inventory.

**Information and the service planning process** (chapter 7)
▸   Value for money and service performance information
▸   Human resources information
▸   Hospital waiting lists/times information
▸   Client satisfaction.

**Population health** (chapter 8)
▸   Information for supporting population health surveillance, for narrowing inequalities in health and for health impact assessment
▸   Accident and emergency surveillance information
▸   Morbidity data (e.g. from primary care)
▸   Information flagged by appropriate indicators of disadvantage/deprivation, small geographical area etc
▸   Private sector information to complement that from the public sector.

**Access to health information** (chapter 9)
▸   Health information and eHealth services for the public, clients/patients.

**Electronic healthcare record** (chapter 10)
▸   Clinical information and support systems
▸   Risk management information to support robust safe-system processes.

## 6.2 The way ahead

While overall responsibility for health information policy and related legislation rests with the Department of Health and Children it will be the job of the Health Information and Quality Authority, working with the Department, the Health Service Executive and other health agencies, to address information deficits and the use of information in the role envisaged in *Quality and Fairness: A Health System for You (2001)* and re-emphasised in the Prospectus report. As a matter of priority, the Health Information and Quality Authority will, in partnership with health agencies, identify and specify in detail the deficiencies which must be addressed. This will be done in the light of strategic priorities within the health system. *Quality and Fairness: A Health System for You (2001)* outlined a broad range of health information functions to be undertaken by the Authority as follows:

▸ Provide the lead on information development, in line with this Strategy
▸ Specify information standards, definitions and data dictionaries to be adopted
▸ Develop and agree the overall Health Service Data Model and minimum datasets
▸ Quality-assure data and information
▸ Assess proposed information developments relating to data and technical standards
▸ Promote education, training and skills development for information staff
▸ Promote and coordinate national research and development of eHealth
▸ Develop a national eHealth library to guide decision-making
▸ Promote a common approach to security, privacy and confidentiality
▸ Carry out information audits
▸ Develop and agree guidelines governing access to information held by health agencies
▸ Assist efficient and effective procurement of health information technology for the health system.

The Health Information and Quality Authority will have a central role in the implementation of this Strategy in all its dimensions including in-depth monitoring and evaluation of the implementation process. This will involve ensuring that a national approach is taken to the collection, processing, analysis, availability, use and sharing of health information within a legislative and governance framework that safeguards confidentiality and privacy. This role will be enabled and empowered by means of a multi-annual information and ICT action plan prepared by the Health Information and Quality Authority and adopted by the Department of Health and Children for implementation by the Health Service Executive and other relevant agencies. This will be based upon the Action Plan set out in Chapter 17 incorporating updates, as necessary, in the light of strategic priorities within the health system.

To ensure a cohesive, national and value-for-money approach to implementing the Strategy, the Health Information and Quality Authority will specify the content of service agreements with individual or groups of health agencies on an annual or multi-annual basis which will be the basis for the development, commissioning or roll-out of new or improved information systems which are to be founded upon identified need in line with national health priorities, information standards and the national health data model (see Chapter 13 Information Standards and Quality).

The Health Information and Quality Authority will establish processes to support a range of information functions including:

- Providing leadership and guidance in the implementation, monitoring and evaluation of the Strategy at the national and regional level
- Supporting and enabling the implementation of the information governance framework (chapter 12)
- Undertaking and providing for the analysis of data for policy and planning requirements
- Publication of an annual report
- Maintaining a health services data model
- Developing a national health information database inventory
- Identifying the priority areas for improved health information and investment
- Demonstrating value for money in information-related investments
- Providing advice on international best practice in the areas of health information and information and communications technology
- Providing representation for the stakeholder groups in the area of health information
- Advising on updates of the Information and ICT action plans as appropriate.

In order to fulfil its role the Health Information and Quality Authority will need to have access to all the necessary information and data available within the health area, including information from private healthcare sources where essential to enable national policy development and integrated service delivery with the public sector, whilst ensuring confidentiality and privacy are respected fully.  The legal framework that will be put in place to ensure this access is set out in chapter 12.

Where necessary the Health Information and Quality Authority will identify database developments to deal with gaps in the information it requires to fulfil its role.  It will collect and hold data, as appropriate, where this is identified to be the best way of addressing information deficits.

In its role to disseminate information within the health system and to the public, the Health Information and Quality Authority will seek at all times to enable and encourage the evidence based approach required for healthcare envisaged in *Quality and Fairness: A Health System for You (2001)* and in the Prospectus and Brennan reports.  The analysis of information to support the Department of Health and Children and the Health Services Executive will form an integral part of this role.

To better enable use of information in support of an evidence based approach the Health Information and Quality Authority will work with existing agencies such as the Office for Health Management to ascertain and address the training needs of staff in the health services. The primary objectives will be to:

- Develop the system-wide capacity to use information to the maximum for health gain and value for money in service delivery, management, planning, policy making and evaluation
- Enhance information governance skills and knowledge at all levels throughout the system.

To inform the Department of Health and Children and the Health Services Executive, the Health Information and Quality Authority will carry out audits and evaluations of information use, availability and governance arrangements in the health system generally and in specific areas as required as part of its programme of work agreed with the Department.

As well as its quality role the Health Information and Quality Authority will ensure that Health Technology Assessment (HTA) is used to inform policy making, service planning and service delivery. Delivering on its health information brief will be an essential prerequisite to action in these areas of responsibility.

This Strategy will be implemented through a phased process, and it will be reviewed and updated as necessary. The overall philosophy of the Health Information and Quality Authority will be to recognise and build upon existing experience and expertise in the field of health information, and to focus on initiatives to enhance the availability and effective use of good-quality health information by the stakeholder groups. Emphasis will be placed upon fostering a culture of cooperation, partnership, coordination and inclusiveness rather than one of competition or duplication.

The Health Information and Quality Authority will develop a consultative process with the stakeholder groups, including the Department of Health and Children, the Health Services Executive, the health agencies, the general public, the national health information agencies and other relevant agencies. Representation on standing committees in specialist areas will be drawn from many fields including customer representation, information, management services, management, public health and clinical service delivery. Representation will also be included from national initiatives such as eGovernment, REACH and the Data Protection Commissioner as appropriate.

# Actions

## Action 1 The Health Information and Quality Authority will be given a central role in implementing the National Health Information Strategy

The Health Information and Quality Authority will be given a central role in the implementation of this Strategy with a view to ensuring that a national approach is adopted in all new information policies and initiatives. The preparation of a multi-annual action plan by the Health Services Executive in line with standards set by the Health Information and Quality Authority and the requirements of the Department of Health and Children and the Health Information and Quality Authority, which will be subject to approval by the Minister for Health and Children, is essential to enable the Authority to carry out this function (see Action 3).

## Action 2 The Health Information and Quality Authority will assess and advise on major developments in information and information technology

Major health information enhancements and initiatives will be assessed by the Health Information and Quality Authority in the light of priorities identified in the multi-annual information and ICT action plan (see Action 3) and to ensure their conformity with the national health information standards framework (chapter 13).

The Health Services Executive, or other agencies as appropriate, will submit detailed proposals for major information and ICT developments to the Health Information and Quality Authority which will examine them to determine if they effectively address national information priorities. The Department may require that information and ICT plans are revised in line with recommendations from the Health Information and Quality Authority.

Further domains within which the Health Information and Quality Authority will carry out assessment of proposed developments may include:

▸ Overall health service developmental priorities
▸ Value for money
▸ Compliance with national health information standards (chapter 13)
▸ Data/information to be made available in the light of strategic priorities
▸ Agreed timeframes for the provision of data/information.
▸ Arrangements for dissemination and sharing of data/information
▸ Governance arrangements for data/information
▸ Indicators of data/information quality
▸ Hardware and software platforms to be used.

The Health Information and Quality Authority will develop mechanisms that actively engage health agencies in the process of identifying the optimum ICT solutions for selected areas.  This will include compliance with the Department of Health and Children's policy on Shared Services in order to facilitate the deployment of Common ICT systems at the national level for major applications such as finance, human resource and hospital information systems.

## Action 3 The Health Information and Quality Authority will draw up a multi-annual information and ICT action plan.

This action will be addressed by way of a multi-annual information and ICT action plan, which will have a 5 year horizon, prepared by the Health Information and Quality Authority. The action plan will set out information and ICT priorities following full consultation with the Department of Health and Children, the Health Services Executive, and other relevant agencies. These priorities will then be addressed by the process set out in Action 2 above.  The information and ICT action plan will be reviewed annually and updated as required. The ICT elements of this action plan are dealt with in more detail in chapter 14 (action 22)

## Action 4 The Health Information and Quality Authority will assess information databases of all agencies which provide key health service information on an ongoing basis and enter into service agreements as appropriate for the supply of information.

In the cases of agencies supplying key health service information for the health services, the Health Information and Quality Authority will be required to ensure on a continuing basis, on behalf of the Minister, that the databases concerned and information supplied from these databases are in accordance with national standards, the national data model (as far as it is specified) and the relevant priorities of the multi-annual information and ICT action plan.  This will inform the service plans that will be agreed between the Department and the suppliers of health information.  These assessments by the Health Information and Quality Authority are likely to cover the same domains as itemised in Action 2.

## Action 5 An annual report will be published by the Health Information and Quality Authority

An annual report will be published by the Health Information and Quality Authority each year. The report will integrate and summarise key strategic information on a range of topics, including population health status, value for money, performance indicators and hospital waiting lists.

## Action 6 A health services data model will be developed and maintained by the Health Information and Quality Authority

To provide a key instrument for understanding the nature and use of information required to deliver and manage effective health services and to better inform systems developments, in particular the definition and adoption of a national electronic healthcare record (see Chapter 10), a comprehensive health services data model will be developed and maintained by the Health Information and Quality Authority. This will be accomplished by reference to appropriate data-modelling techniques and international standards, and will draw upon the lessons learned from similar exercises carried out elsewhere. The model will hold key data definitions and relationships between data in the most effective way possible, commensurate with the imperative to inform all stakeholders, including the public, as well as supporting systems, research and knowledge development.

## Action 7 A national health information database inventory will be developed and maintained

The Health Information and Quality Authority, in partnership with the relevant health agencies and groups, will develop and update a national health information database inventory. This database will be used to identify the full range of existing health information sources and assist in the identification and prioritisation of information deficiencies.

The database inventory will include all the domains in the model of health described in *Quality and Fairness: A Health System for You (2001).* Primary and secondary sources of information within and outside the health sector that are routinely gathered (such as service activity) or occasionally gathered (such as household or lifestyle surveys), clinical, management and population health systems and disease-specific registries and databases will be included.

The inventory will specify the data content/items/coding/classification systems, quality of the data (such as timeliness, coverage) and the file layouts. It will be indexed to enable searching e.g. by agency, topic and data items. The information will be categorised as set out in a health services data model (see Action 6) and grouped under the appropriate headings, recognising that systems can support a range of functions. Access to the inventory will be provided through the Health Information Portal (chapter 9).

The inventory will also support a number of other processes including:

▸ Promoting better use of available health information (chapters 7, 8, 9)
▸ Supporting the national information standards initiative and underpinning data translation requirements in the interim (chapter 13)
▸ Supporting the use of Common Indicator Sets (chapter 13)
▸ Supporting the development and use of health indicators in population health surveillance in line with national and international requirements (chapter 8)
▸ Supporting the process of carrying out health impact assessments (chapter 8)
▸ Identifying information governance/data access procedures/business rules, both for aggregate and disaggregated data (chapter 12)
▸ Supporting the development of eHealth services through describing the routine data flows (chapter 10).

# 7 Information and the Service Planning Process

A primary goal of *Quality and Fairness: A Health System for You (2001)* is to provide an equitable service that best meets the priority needs of the population.  To achieve this goal, emphasis is placed upon the need to strengthen accountability by developing multi-annual implementation and annual service planning processes.  Implementation plans enable health agencies to communicate to the Department of Health and Children, the public and their staff how they intend to implement national policies.  Annual service plans of agencies funded directly or indirectly by the Department of Health and Children detail how resources will be spent in the current year on specified services and developments.

Service planning is a key management process which must be supported by reliable, timely, well defined information if it is to be effective.  The Brennan and Prospectus reports have highlighted the need to enhance service planning through the better use of information.  This Strategy is therefore crucial to the further development and effectiveness of service planning which must take place at all levels in health agencies using appropriate information.

The health service is the largest employer in the public sector and one of the largest employers in the country.  A key focus of *Quality and Fairness: A Health System for You (2001)* (Actions 100-106) is to develop the human resource function and to move from a traditional personnel administration model to a modern human resource management model.  Human resources accounts for approximately 70 percent of the overall expenditure on health, and it is essential that detailed, accurate and up-to-date information on human resources be available on a local, regional and national basis.

## 7.1 Assessment of the current position

Service planning processes have developed quite significantly in recent years including the definition of performance indicators used in the monitoring and evaluation of service plans. It has been recognised in these service planning developments that information sources need to be very significantly improved. While service planning skills are developing and a performance measurement culture is growing around service planning, the information to make really effective performance management a reality is not there in many areas.

In this context there is wide acceptance of the need for the health system to deliver value for money.  Value for money includes economy of expenditure, the efficiency of activities and effectiveness, including the fundamental issue of the extent to which it can be shown that health is improved (outcome).  It is an essential part of public reporting and accountability.

*Audit of the Irish Health System for Value for Money (2001)* stated that it is hard to conceive of an operation of such complexity as health and involving such a level of commitment being managed effectively with the current level of investment in information systems.  There are pointers, however, to suggest good value for money in some areas such as hospital capacity, use of daycare, the Casemix programme and improved materials management and purchasing functions.  The Report suggested a number of reasons for the inability to demonstrate value for money, including the following:

- The legacy of lack of investment in ICT has provided an inadequate infrastructure to support information requirements including performance management and value for money.
- Value for money has not been an integral part of the ongoing evaluation processes. A major intention of service planning and the accountability legislation was to emphasise this issue, and significant progress has being made in developing performance indicators (for service plan monitoring and evaluation).
- The current incremental approach to funding militates against long-term planning of infrastructure and service development, reinforces the status quo and may focus management on projects with short-term rather than long-term benefits that are unlikely to best match the needs of the population nationally.
- There is a lack of joint working between agencies, with competition for funding, staff and infrastructure and lack of willingness to share knowledge and experience.
- There is a reluctance and inability (due to resource and skill constraints) to use and analyse available data to inform decision-making and the performance management process.
- The introduction of clinical audit is very slow.
- The interplay and influences between the public and private sectors are unclear due to the absence of systematic information sharing between the sectors.
- A highly fragmented approach to implementing information systems and the non-standardisation of data within and between agencies militate against benchmarking, the comparability of data, and the sharing of information between various stakeholders and agencies.
- A lack of a centrally cohesive and consistent approach contributes to an uneven pace of development of services.

Financial systems throughout the health sector are sufficiently robust to account for the use of resources as allocated in the Estimates. Health agencies are clearly moving in the right direction from the viewpoint of providing information for financial management, with significant progress being made by the health boards/Authority in recent times in installing state-of-the-art financial and human resource/payroll systems that will provide higher quality information, although the roll-out of such systems across the sector remains far from complete.

Detailed value for money measurement requires the integration and analysis of a broad spectrum of information from a range of sources and is not limited to financial information. There is a need to develop integrated information systems that can provide consistent and comparable measures of value for money – in all its dimensions – across the health sector and within a cohesive value for money framework in which health professionals and service managers are integrally involved and where audit and accreditation play a central role.

Given the existing difficulties in the health service in recruiting and retaining personnel, the absence of coordinated human resource planning has proven to be a major difficulty. The reports *Current and Future Supply and Demand Conditions in the Labour Market for certain Professional Therapists (2001)* and the *Interim report of the steering group of The Nursing and Midwifery Resource (2000)* conclude that it is not possible to make reliable predictions of staffing requirements to meet future demands because of information deficits. The data held by the agencies are not standardised, and obtaining detailed accurate data by speciality remains difficult and time-consuming.

## 7.2 The way ahead

It is essential that multi-annual implementation and annual service planning processes align with the priorities identified in national strategies and policies of the Department of Health and Children. The processes should also effectively and objectively target health inequalities and specifically demonstrate value for money in healthcare delivery. These processes should be supported by comprehensive needs assessment of the local population together with a balanced set of performance indicators that systematically measure service outcomes against explicit targets. In this way, decisions on funding will promote equity as a whole and create incentives for the implementation of *Quality and Fairness: A Health System for You (2001).*

To meet the above requirements, financial and human resource information should properly integrate with service activity, clinical and population health data. This composite information, together with information derived from ongoing research and evaluation in the regional, national and international context, should form the evidence-base in service planning and implementation processes. The tools and processes to undertake value for money analyses from existing and newer datasets need to be developed, building incrementally upon the valuable work already done in this area.

Achieving this goal will involve a phased process. It is clear that a very significant investment in interactive information systems and infrastructure is required if the sector is to perform in the way it is now expected to and if service planning is to be properly supported and there is to be a recognisable improvement in managing value for money. Major enhancement and integration of the analytical and interpretive skill-mix that is currently spread across several areas of responsibility, such as finance, management, public health and ICT is required.

There is an urgent need for greatly improved and comparable information that is continually being updated and used locally on a daily basis to better enable management. The solution lies in the proper use of ICT and the adoption of information standards. For example, it is essential that human resource information be integrated with payroll and other systems, and that it supports workforce planning, time management, staff retention and recruitment, benchmarking and management information processes. Such a system would allow in-depth analysis where economic and demand factors can be incorporated into forward extrapolations to make reliable predictions of future staff and skill-mix requirements. An integrated human resources system – Personnel, Payroll, Attendance and Recruitment System (PPARS) – is currently being implemented in a number of health agencies with a view to general roll-out. The scale of the task presents significant management, cultural, organisational and standardisation challenges, and is as much about change management as it is about implementing an ICT solution.

# Actions

## Action 8 Health agencies will be required to demonstrate the appropriate use of information in implementation and service plans

A core theme of *Quality and Fairness: A Health System for You (2001)* is that there will be more effective service planning and development over a period of years. It sets out how multi-annual budgeting and implementation plans will be put in place on an ongoing basis. It is essential that the planning and evaluation processes make better use of available health information and that there is no disconnection between the short-term annual plans for operational service delivery and

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the longer-term view encompassed in the national policy objectives and strategy as signalled in the three to five year implementation planning process described in Action 71 of *Quality and Fairness: A Health System for You (2001).*

There will be a requirement for implementation and service plans to be demonstrably and firmly based on available and high-quality information.  This will result in planning which is:

▸ Clearly supported by high-quality information derived from appropriate needs assessment, including information that reflects the present and projected population structure, local determinants of health, health status, health inequalities, deprivation, rurality, priority needs and the quality of service provision and cross-boundary flows of clients/patients
▸ Shown to be evidence-based
▸ Supported by health technology assessment evidence where appropriate
▸ Related to current and projected capacity requirements
▸ In line with specific national policies, strategies and targets
▸ Based on information on existing service provision that demonstrates quality of care and value for money through the use of performance indicators of efficiency, effectiveness (impact) and cost benefit.

## Action 9 Health information requirements will be a specific dimension within implementation and service plans

*Quality and Fairness: A Health System for You (2001)* requires health agencies to prepare implementation and service plans.  Reforms will be required in the planning processes described in Action 8 to enable the delivery of this Strategy.

An additional dimension to the planning process, therefore, will be the requirement for health agencies to specify the priorities and actions for health information in the global context of these plans.  These should include:

▸ Implementation of this Strategy on a regional and local basis
▸ Health information and ICT requirements of the overall implementation/service plan
▸ Human resource requirements to support the health information and ICT requirements
▸ Change management programmes to enhance the use and appropriate sharing of information
▸ The implementation of national health information standards (see Action 19)
▸ Developments required in areas such as disease surveillance/registration to support national strategies
▸ Other information-related plans and developments.

## Action 10 Improved information on human resources will be made available

To support the enhanced arrangements for human resource management and planning as set out in *Quality and Fairness: A Health System for You (2001),* a minimum dataset on human resources that is timely, standardised, comprehensive and accurate will be made available across the sector on an ongoing (e.g. monthly) basis.  To ensure compliance, the Department of Health and Children will only be able to approve staffing adjustments for agencies providing such information.  In the interim, the Health Information and Quality Authority will work with the Department of Health and Children to ensure that the appropriate technical, staffing, training and management infrastructure is in place to support this requirement.

# 8 Population Health

Population health is the assessment of the overall state of health of all the members of a given population, and lies at the centre of public policy. *'Better health for everyone'* is the first goal of *Quality and Fairness: A Health System for You (2001).* The aim is to improve the health of the entire population or subgroups of the population and to reduce inequalities among population groups.

## 8.1 Assessment of the current position

The assessment of population health and of the factors that influence health requires the availability and analysis of a diverse range of information from within and outside the health sector, including the following:

‣ Trends and patterns in the demographic profile of populations and subgroups
‣ Trends in the determinants of health (lifestyle, social and physical environment, education etc) in populations and subgroups. Ability to monitor health behaviours, self-perceived health, mental health status etc, through the use of rolling/periodic surveys in line with national and international requirements
‣ Trends in mortality and morbidity of populations, subgroups and sub-regional areas
‣ Trends in the utilisation of services by populations, subgroups and sub-regional areas
‣ Effectiveness of health promotion, protection and intervention initiatives.

A number of very important and good quality data sources already exist which are essential in addressing the issues listed above. These include:

‣ Demographic and vital statistics information from the Central Statistics Office
‣ Acute hospital data from the Hospital In-Patient Enquiry
‣ Infectious disease notifications from the National Disease Surveillance Centre
‣ Cancer prevalence from the National Cancer Registry
‣ Results of the National Health and Lifestyle Surveys.

In addition, a range of data, including much collected from the above sources, is brought together in the annual updates of the Public Health Information System (PHIS). This allows trends to be measured and monitored in demography, mortality and some areas of morbidity at both national and regional level. Nevertheless, the PHIS requires to be further developed and incorporated within an integrated population health surveillance system.

In general the population health surveillance function is under-developed, and information on morbidity, health inequalities, health status and health determinants of the population and subgroups is limited and fragmentary. At present, information on the health needs and health status of disadvantaged groups, such as Travellers or asylum seekers, is not routinely available.

Health information is usually geographically coded (geo-coded) by where care is delivered (e.g. hospital, surgery or clinic) or by relatively large administrative areas, such as postal areas, counties, community care areas or health boards. Postal areas are too large and ill-defined to permit detailed analysis. As a result, it is generally not possible to see the interplay between

health status (local mortality and morbidity patterns), health determinants (such as deprivation), service utilisation and the effectiveness of services on influencing the health of populations at the sub-regional level.

Without such information, the tasks of determining health priorities, supporting the evidence-based approach for targeting resources through the service planning and implementation processes (chapter 7), carrying out health impact assessments, narrowing inequalities in health and demonstrating improvements in health in line with national targets are virtually impossible.

## 8.2 The way ahead

As previously stated, there is a need to draw together the numerous strands of information originating within and outside the health sector that contribute to the overall process of describing and explaining population health.  The range of information and relevant skills necessary to adequately address this requirement is substantial.  The establishment of specific population health functions in the health services including a population health division in the Department of Health and Children will significantly contribute towards developing our capacity to carry out population health surveillance.  As many issues of population health and health determinants are common to the island of Ireland, the potential benefits of an all-Ireland approach to population health surveillance will be explored.

Health impact assessment (HIA) or 'health proofing' will be introduced as part of the public policy development process under *Quality and Fairness: A Health System for You (2001).*  HIA is at an early stage of development in Ireland, and a phased programme for its introduction is required involving inter-departmental, inter-sectoral and multi-disciplinary working.  To support the process, a national health information database inventory (chapter 6) is needed, along with a central HIA databank allowing web-enabled access to cross-sectoral HIAs linked to national and international HIA resources.  Additionally, in order to quantify the impact of interventions to reduce inequalities in health, a database/bibliography of systematic HIA reviews and related literature is required, together with existing work and the commissioning of systematic reviews on appropriate issues, such as health determinants and the components of deprivation.

The link between poverty and poor health status is well established.  There are attributes which on their own or through their association with poverty or social exclusion increase the risk of poor health, e.g. being disabled, being homeless, being a member of the Traveller community or another ethnic minority group, particularly if one is a refugee or asylum seeker.  Inequalities arising from gender, age or family status, e.g. being a lone parent, can also increase the risk of poverty and of ill-health.  The Equal Status Act (1998) recognises nine grounds on which discrimination can take place, including disability or belonging to the Traveller community.  In the context of the *National Anti-Poverty Strategy (1997)* (NAPS), the *National Development Plan 2000-2006 (1999)* and the *National Strategy for Traveller's Health,* it is essential that information systems record the appropriate indicators to allow subsequent analysis of data in terms of health determinants, health status and service access and outcomes etc for disadvantaged groups, in order to drive the process of narrowing inequalities in health.  Without such information, poverty proofing, the setting and monitoring of NAPS health targets and the allocation of resources at those most in need will not be feasible.  These requirements receive further emphasis in the report of the National Statistics Board on *Developing Irish Social and Equality Statistics to meet Policy Needs (2003).*

Ireland is divided into approximately 3,440 district electoral divisions (DEDs). These are the smallest administrative areas for which population statistics are published by the Central Statistics Office and can be used for geo-coding health data. Use of the national grid coordinates, if highly accurate, allows a finer but more complex level of analysis. Geo-coded data and the use of modern geographical information systems and spatial analysis techniques will support the following:

▸ Service planning and evaluation
▸ Providing an evidence base for accurately and objectively allocating resources to meet the priority needs of local populations
▸ Comparing access to and viability of health services across geographic regions (see *Quality and Fairness: A Health System for You (2001)* – National Goal No. 2)
▸ Rapid investigation of local health concerns about the environment such as suspected cancer or asthma clusters
▸ Identifying areas of low uptake of services (such as vaccination) or with high levels of morbidity and mortality (e.g. road accidents, cancers) for better targeting of preventive measures
▸ Transport planning and the provision of emergency services
▸ Formulating realistic disaster plans for responding to chemical and other incidents.

# Actions

## Action 11 A national population health observatory will be established

The availability of health information will be enhanced by the establishment of a national population health observatory. It is envisaged that the observatory will be developed as a new function within existing infrastructures and would include North/South and international dimensions as appropriate. The observatory will be enabled to carry out strategic and advisory functions, on an independent basis, such as:

▸ Population health surveillance – including the monitoring of trends in health status, health determinants, morbidity and mortality etc
▸ Advising on initiatives and progress towards reducing inequalities in health
▸ Advising on health impact assessment
▸ Providing early warning of future public health problems
▸ Identifying gaps in health information.

## Action 12 Health information will contribute to the process of narrowing inequalities in health and other population health priorities

As part of the process for building an inclusive society, the Health Information and Quality Authority will work with health agencies, the Central Statistics Office and other relevant agencies to ensure the availability of the health information necessary to effectively monitor and review targets, indicators and implementation strategies for the National Anti-Poverty Strategy and health.

To allow for the analysis of health data by key sub-groups as described in the National Anti-Poverty Strategy (1997) and related policies, relevant health information systems will incorporate

the required degree of functionality and record, as appropriate, the attributes that on their own or through their association with poverty or social exclusion contribute to inequalities in health. These attributes include: age, gender, socio-economic group, being disabled, being homeless, living in institutions, race, membership of the Traveller community or other ethnic minority group, including refugee or asylum seeker and family status (e.g. lone parent).

## Action 13 Health information will be geo-coded by small area

Major health information systems will include the geo-codes of addresses for the appropriate administrative boundaries and by small geographical area (e.g. district electoral division) using the most accurate and up-to-date geo-coding databases and software available, such as the Eastern Region Electronic Street Index and GeoDirectory.  It is envisaged that health data will be geo-coded at source, i.e.  the client master index used for unique identification at national level (chapter 11).

The accurate and standardised format for recording addresses is of crucial importance as is a standardised approach to classifying addresses such as the home address, 'usual' address, business address, current address, 'care-of' addresses, living in institutions, homelessness, location at the time of an accident etc.  In terms of analyses carried out over longer time periods it is also important that address histories are recorded.

# 9 Access to Information – Health Information Portal

*Quality and Fairness: A Health System for You (2001)* emphasises the need for significant improvements in the accessibility and usefulness of health information for all stakeholder groups. As outlined in earlier chapters many sources of health information exist, many having been developed in recent years, but the value of this information is limited by the absence of standard, reliable and integrated solutions for accessing and utilising these sources. Furthermore, it is clear that widespread application of information in evidence-based decision making is the best means of ensuring that its quality is monitored, maintained and improved. Modern technology, and in particular internet-based technology, provides a practical solution to the delivery and use of health information for those who require it, when they require it and in appropriate formats. This chapter recommends the development of an internet-based Health Information Portal to provide a range of information and information-based services for the public, for health professionals, for researchers and for policy makers. This will build on the work already carried out in the development of a Health Services Portal by the Health Boards Executive.

## 9.1 Assessment of the current position

Stakeholders are currently faced with many barriers in gaining straightforward access to the information they need whether in paper or electronic format. The reasons for this include the following:

> ‣ The great diversity of systems and sources results in a lack of awareness of the scope and depth of the information available and how it might be accessed.
> ‣ Information may not be fully analysed and interpreted or widely distributed in a relevant format and its quality may be unclear.
> ‣ The differing roles, priorities and histories of the agencies involved may contribute to a cultural hesitancy towards the sharing of health information, together with the general absence of agreed mechanisms and guidelines for doing so and uncertainties over issues of privacy and confidentiality.
> ‣ There is no effective mechanism at present to draw the myriad strands of information together enabling their fullest use on a national basis.
> ‣ Application of IT capacity to facilitate the delivery of information and other eHealth services to patients and professionals remains underdeveloped.

In setting out the National Context (Chapter 3) in relation to key developments in health information, it is clear that many initiatives and improvements continue to take place. These range from the continuing development of information from such sources as the National Cancer Registry, the National Disease Surveillance Centre and the Hospital In-Patient Enquiry through to efforts to facilitate integrated access to information such as the Public Health Information System and the eGovernment initiative. They also include the development of the Health Services Portal and a National ICT strategy by the Health Boards Executive (HeBE). Nevertheless, the health information landscape remains characterised by numerous databases and systems that are essentially isolated and uncoordinated. In addition, there is a need for standards to be developed and applied both in relation to the content of the information itself but also in relation to its access and use.

The current situation, therefore, means that the potential of available information in supporting evidence-based decision-making at all levels and for all stakeholders remains under-exploited, and the potential of internet-based ICT solutions to play a major role in redressing these shortcomings remains to be fully realised.  This applies not only to bringing the disparate elements of the information jigsaw into alignment, but equally importantly to exploiting the power of ICT in facilitating the delivery of eHealth services to patient and professional alike.

## 9.2 The way ahead

The development of a Health Information Portal to provide a single point of internet access to health information and eHealth services to all stakeholder groups is necessary.  Many health information initiatives currently taking place add urgency to this requirement and the capacity, speed and facility now available in ICT mean that the time is right for implementation.

In close collaboration with the Health Service Executive and the Department of Health and Children, it is envisaged that the Health Information and Quality Authority, given its remit in producing a multi-annual information and ICT action plan, will take the lead role in coordinating the development of the Health Information Portal.  In addition, the Portal should be seen as an integral part of other ICT initiatives in health (see Chapter 14), and, in particular, as part of the development of eHealth services in line with the eGovernment initiative and the progressive development of eBroker services.  As the capacity of ICT continues to develop, as information sources become more standardised and as the framework for eHealth service delivery is extended, so the range of services made available directly through or linked via the Health Information Portal can be extended and improved.  Given the rapid pace of change in this area, it would be unwise to try to provide an exhaustive list of what the Health Information Portal might offer, but the following areas will certainly feature centrally.

The Portal will provide accurate and timely access to information about health services and about health issues and concerns.  Information about health services will include information on the availability of local statutory, private and voluntary services on a national basis in standard formats including details such as opening hours, eligibility, contact information, 'how to get there', as well as relevant indicators on quality of care/accreditation, waiting list data etc.  The information on health issues and concerns will cover topics such as best practice guidelines in areas of preventive health (e.g. screening, vaccination, oral health and lifestyle) and the personal management of health concerns (e.g. asthma, hypertension, diabetes and cancer).  It will be undertaken on a phased basis, should draw extensively on national and international expertise and will require that procedures are in place to ensure information is kept accurate and up-to-date.

The Portal will be the point of access for the public to eHealth services.  These will be introduced progressively in line with the eGovernment and Reach initiatives.  eHealth services will bring mutual benefits of efficiency and effectiveness to both the public and to health service providers and can be expected to include the following:

▸  The determination of eligibility online and the processing of applications for health services such as the European Health Insurance Card (E 111), medical cards, home modifications, disabled drivers etc
▸  Payment of health service grants and allowances
▸  Booking appointments online and receiving electronic reminders for primary and secondary care services

> ▶ The ability to submit queries to health agencies about services through email (as with telephone or written communications).

With the proposed development of electronic healthcare records (Chapter 10) and the introduction of unique identification (Chapter 11), many additional benefits both for patients and health professionals in terms of patient safety, shared care and personal access to health information including test results, prescribing information etc would be achievable.

The Health Information Portal should also facilitate and promote the availability of information and services to people who may not have access to or experience of internet applications. Many people most in need of services will fall into this category, and it is critical that the benefits provided by the Portal can be extended through telephone facilities, walk-in centres, information leaflets and campaigns and other appropriate media and formats. It will also be essential that information for the public is both timely and accurate (see Action 21).

In support of the requirement for evidence-based practice and policy making at all levels in the health system, access to a national eHealth library by all stakeholder groups will be provided through the Health Information Portal. Cooperation on an all-Ireland basis will be explored as a means of ensuring cost savings, such as the North/South initiative which has made the Cochrane Collaboration Library available throughout the island. Directories of health service reports, service plans, best practice guidelines, conference programmes etc should all be indexed and searchable via the Portal. It will be essential that these developments take place with the active involvement and participation of the traditional library services and are seen to complement that role, particularly given the increasing need for the skills of information specialists and the requirement, expressed above, for information to be available in a range of formats.

A key objective of the Health Information Portal will be to facilitate access to statistical data and databases to serve the needs of policy analysts, service planners, researchers, epidemiologists and others with health data requirements. General access to aggregate statistics will be available online, and restricted/authenticated access to disaggregated data for more in-depth research will be authorised in line with information governance requirements and agreed mechanisms with source agencies. Comprehensive and interactive metadata describing data sources and data analysis tools will form an integral and essential component of the Portal. The national health database inventory, which will be developed and maintained by the Health Information and Quality Authority (see Action 7), will support and enable this development. Linked with the proposed Population Health Observatory function and building on the Public Health Information System, which currently brings together many key public health data sets, the new and extended access offered through the Health Information Portal will take the form of a National Health Atlas. This will be developed on a phased basis and, over time, is envisaged to link with regional health atlases to allow more detailed drill-down into sub-regional levels such as district electoral divisions as appropriate. Development will take place in partnership with health agencies, the Central Statistics Office, Government Departments and other interested stakeholders.

In addition to providing for national and sub-national access to health data and analysis tools, the Portal will also be linked with other national and international health information systems. National links will include the Central Statistics Office, other Government Departments, relevant agencies, academic and research institutes. Since many factors, including environmental and social factors, are relevant to health, the range of cross-sectoral links can be expected to be

extensive.  International links will include the EU, WHO and OECD systems among others.  A Public Health Portal for the EU is currently under development which makes it timely for the national Portal to contribute to and to align itself with EU standards adopted for indicators, information presentation etc.  The WHO links will also be important not only in the context of access to the WHO's Health for all database but also for their work towards providing quality approval/accreditation for internet sites in areas of health advice and consumer information.

The Health Information Portal will be the vehicle for the rapid notification of essential and urgent information to specific stakeholders and special interest groups.  This feature/framework can be referred to as a Health Information Cascade System by which is meant that those who need to know about an emerging issue can be informed as and when appropriate.  Some examples of 'breaking news' would include a vaccine batch withdrawal, an outbreak of infectious disease in a hospital or community, major changes to best practice guidelines, the launch of an important report etc.  Contingency arrangements would need to be maintained to continue to allow rapid and comprehensive dissemination by more traditional communication and delivery methods.

# Action

## Action 14 A Health Information Portal will be developed

In line with its key role in setting out information priorities, the Health Information and Quality Authority will provide for the development of a Health Information Portal as part of its multi-annual information and ICT action plan.  The Health Information Portal will constitute a single internet-based access point to a range of health and health-related information sources and health information services for all stakeholders and will include the following:

▸ Access to information about health services and quality-assured information on health issues and concerns.
▸ Provision of eHealth services for the public to be developed on a phased basis in line with the overall eGovernment and Reach initiatives.
▸ Facilitating and providing access to health information and transactions in appropriate formats as required ensuring inclusiveness and equity.
▸ Electronic health library services to be developed in cooperation with traditional library services and with health and educational agencies.
▸ Access to statistical data and databases essential for service planning and evaluation, population health surveillance and research functions.
▸ Links with other national and international health information portals.  Close alignment with the development of the EU Public Health Portal will be of particular importance.
▸ A system for the rapid notification of essential and urgent information to specific stakeholders and specific interest groups.

# 10 The Electronic Healthcare Record

The electronic healthcare record is the digital equivalent of the client/patient's paper chart and will be introduced on a phased basis (see *Quality and Fairness: A Health System for You (2001)* Action 118 and *Primary Care: A New Direction (2001)* Action 8).  It varies in complexity from supporting basic administrative functions, ordering and receiving test results and providing clinical decision support to digitising case notes fully, including images and video.

The term 'electronic healthcare record' is used in this Strategy to include two types of record, namely the electronic patient record (EPR) which is typically maintained by the individual healthcare provider as with today's paper record, and the more complex version which is referred to as the electronic healthcare record (EHR), where individual EPRs are linked in part or in whole to build up a fuller health picture over time and to create a longitudinal record that could run from birth onwards.  Technologies also exist that allow clients/patients to retain their health data, for example on 'smart cards' or on personal and confidential web sites.  Phase 1 of the European Health Insurance Card initiative saw the implementation of a card based E111 in June 2004.

The electronic record is an evolving technology and architectural models for it are still being developed.  Internationally, its implementation is still at a very early stage.  In the Irish context the acute hospitals that have web-enabled modern ICT systems using relational database technologies with order entry and results communications functionality, would appear to have a good basis for its application.  As discussed in chapter 11, unique identification is a key requirement for its full implementation.

## 10.1 The potential of the electronic healthcare record

The general use of the electronic healthcare record will fill many of the health information deficiencies identified elsewhere in this Strategy.  Its primary function is to enable the delivery of safer, higher quality and more person-centred healthcare and especially to enable seamless care across the traditional health service boundaries.  By providing a more comprehensive picture of health demands and resource utilisation, it also greatly supports the management information function.

### Clinical support

▸ The greatest advantage of the electronic healthcare record for the individual client/patient and health professional is in bringing together the global, integrated and up-to-date health history of the client/patient at the time of consultation so that critical decisions can be much better informed.  It also provides the potential for a much greater level of clinical decision support in the future.

▸ It supports clinical decision-making by linking the clinical details to decision support software.  This can help prevent potential adverse clinical events, e.g. through real-time alerts about drug interactions.

▸ It supports and enables shared care through quick and easy access to data where there are overlapping areas of interest, e.g. between primary and secondary care in managing referrals, ePrescribing, or the care of clients/patients with chronic conditions such as diabetes, heart disease or cancer.

### Health surveillance

‣ It supports and replaces much of the data collection activity currently required for clinical registries, e.g. cancer, cardiovascular disease, surgical procedures; this frees up resources that can be dedicated to the intelligence function in analysing and using the information that is collected.

### Health promotion

‣ It supports health promotion processes by enabling call and recall of high-risk patient groups for vaccination, screening, or cardiovascular assessment etc as well as the potential to inform patients about new and improved options for treatment.

### Management function

‣ It supports enterprise-wide resource planning and management through integration with other information systems such as waiting lists, appointment bookings, human resources, bed management, operating theatre sessions, resource management systems (finance, personnel and facilities) and patient information.
‣ It supports risk management processes by retrieving comprehensive client/patient information.  Reliance upon the traditional record management systems can expose agencies to risk in the day-to-day care of clients/patients and in particular during investigation of untoward clinical incidents and/or poor outcomes.

### Research

‣ It supports clinical audit, research and epidemiological processes where analytical techniques allow flexible ways to answer new questions in response to changing information needs and priorities.

*Primary Care: A New Direction (2001)* provides a clear roadmap for the development and national roll-out of the electronic healthcare record within the primary care domain, building upon a number of mainly EU-funded pilots and the training initiatives of the General Practice Information Technology (GPIT) group.  Many initiatives are also underway within secondary care. A phased and coordinated approach to its general introduction on a national basis is required and important lessons can be learnt through the evaluation of 'showcase' sites both in this country and abroad (chapter 14).

Given the importance of inter-operability of the electronic record (i.e.  the ability of the record to work seamlessly in all healthcare settings throughout the sector) and that modules will be required to meet the specialised information requirements of the users (doctors, nurses, dentists, physiotherapists, occupational therapists, care assistants, social workers, support staff etc), a national, integrated and coordinated approach is required.  In the case of the acute hospital sector, because ICT capital funding for mainstream developments including hospital information systems will be based on a common national approach (chapter 14),  the progressing of the electronic record can be facilitated by ensuring that the relevant specifications are directed ultimately towards the type of functionality set out in this chapter.

The successful transition from the traditional paper-based systems to a digital environment will require robust change management processes and training arrangements, hardware and software

support and support of information governance processes to ensure confidentiality, privacy and security.

The generic requirements of the electronic record are outlined below, some of which are of greater importance in certain care domains. In building up the system, it is important that the potential of emerging technologies is harnessed, e.g. speech recognition, touch screens and integration with medical devices and telecare/telemedicine solutions.

## Supporting infrastructure
▸ Is based on unique identification in the primary and secondary care domains (chapter 11)
▸ Requires the appropriate levels of authentication in line with information governance standards
▸ Provides a secure communications infrastructure.

## Clinical care and information sharing

▸ Provides a clinical record system supporting the work of all health professionals operating in the primary and secondary care domains with advanced speciality modules to meet specialist needs
▸ Supports multi-disciplinary use by allowing selective access on a 'need to know' basis such as access to a subset of data to support out-of-hours and emergency care at the level of the cooperative in primary care
▸ Allows inter-operability between and within primary and secondary care information systems such as the electronic transfer of test results, referral and discharge information etc
▸ Provides appropriate clinical decision support including reminders/alerts/warnings
▸ Supports targeted call and recall of clients/patients
▸ Supports clinical audit and research in primary and secondary care
▸ Supports the development of care pathways, care planning and workflow
▸ Supports risk management processes.

## Electronic prescribing

▸ Supports ePrescribing with transfer of data between hospitals, general practice and pharmacists.

## eServices

▸ Supports electronic claims and payment, e.g. from the GMS Payments Board, health board, GMS services, vaccination claims etc
▸ Supports order entry and results reporting, including the electronic transfer of data between primary and secondary care (pathology and x-ray results etc)
▸ Supports the booking of hospital appointments for consulting rooms and/or practice offices.

## Other

▸ Supports image archiving, communication and document imaging (e.g. referral/discharge letters).

# Action

## Action 15. The electronic healthcare record will be implemented on a phased basis

There will be an incremental transition to electronic healthcare records throughout the health sector. The Health Information and Quality Authority will facilitate this in a coordinated manner throughout the primary and secondary care domains and ensure adherence to appropriate standards in partnership with the Department of Health and Children, the health agencies, the National Primary Care Task Force and other groups.

Best practice guidelines will be developed by the Health Information and Quality Authority to control the transfer, use and maintenance of electronic records in line with legislative and information governance requirements (chapter 12).  The electronic healthcare record will be dependent upon the availability of a unique identifier (chapter 11).

Electronic cards developed within, for example, the framework of the Reach/eBroker initiative may support the processes of client/patient identification and verification of eligibility status.  Such cards may evolve over time to provide access to include personal health data by a link to the electronic healthcare record.

The development of the electronic healthcare record will be subdivided into a number of tasks as follows:

▸ The full electronic healthcare record will be defined and adopted
The work on defining the electronic healthcare record will proceed in parallel with the work on the health services data model (chapter 6).  The first version of the record will be adopted as the standard as soon as possible after the data model is agreed.  Various initiatives in this country and internationally will inform this process.  It is essential that the 40-60 initial primary care implementation projects (see below) and major ongoing hospital system replacement programmes are actively involved in the process so that all modules within their systems are harmonised with the requirements of the standard electronic record.

▸ Implementation sites with supporting ICT infrastructure for the electronic healthcare record in primary and secondary care will be established
Under *Primary Care: A New Direction (2001),* the electronic healthcare record, with supporting ICT infrastructure, together with the capacity to interface with secondary care domains, is seen as essential for the successful roll out of the primary care model.

▸ The electronic healthcare record and supporting ICT infrastructure will be rolled out nationally
Based upon the definition of the standard electronic healthcare record, the development of the data model and the experience gained from the implementation sites as outlined above, the electronic healthcare record and supporting infrastructure will be rolled out nationally on a phased basis in accordance with the multi-annual information and ICT action plan (see chapter 14).

# 11 Unique Identification

The provision of client-centred services is one of the key principles of *Quality and Fairness: A Health System for You (2001).* This places a special emphasis on the importance of being able to associate, through unique identification, all relevant health information about a given client/patient as and when required.

It is important to note that the use of a particular identifier does not in any way presume the sharing of information with other users of that identifier. Information sharing is a completely separate issue and is discussed in Chapter 12 (Information Governance and Legislation). Rather, the use of a unique identifier should be considered as a logical extension of the use of a person's name for identification purposes.

## 11.1 Assessment of the current position

Apart from a national approach adopted by agencies such as the General Medical Services Payments Board (GMSPB) and the private health insurance sector and regional systems operated in some health boards, client/patient identification systems tend to be unique within each agency or department in the primary and secondary care domains. To identify each person, basic demographic information is usually collected repeatedly at every client/patient contact with the health service. The GMSPB, which is funding the development of a new Central Client Index project from the Information Society Fund, has included the use of the PPS Number as an identifier. However, arising from the interpretation of Data Protection legislation there were practical difficulties in implementing the project.

Currently, parts of a client's/patient's health record are held in numerous paper or electronic systems and locations. Each piece of the record tends to carry different record/chart numbers. At present, it is virtually impossible for a health professional in one location to collate all the parts and to see the global health history at the time of consultation. This limitation can be of special importance in the provision of shared care (e.g. involving primary and secondary care) or in an emergency situation where safer decisions might be taken if the full history were available. The absence of unique identification also severely impedes the development and use of a range of information for management purposes.

## 11.2 The way ahead

The only safe and practical method of being able to draw together the separate parts of an individual's health record is through the use of unique identification. In the absence of this it is not feasible to plan, manage, deliver or evaluate services on a person-centred basis since this can only be achieved by associating records belonging to the same client/patient.

Unique identification promotes the quality and safety of client/patient care in many ways:

- Providing for a more definite association to be made between the client/patient and his/her records which in turn promotes client/patient safety through the correct identification of the individual
- As a key requirement for the proper implementation of the electronic healthcare record (chapter 10) upon which many other benefits will accrue (Quality and Fairness: A Health System for You (2001) – Action 118)

> ▸ Supporting the provision of shared care by allowing records for one individual to be associated or collated together, thus enabling different care providers to 'see' all or parts of the same health record (chapter 10). This attribute is especially important for the management of chronic diseases such as diabetes, cancer and heart disease that involve many contacts with different health professionals in a range of settings over long time periods
> ▸ Enabling good record management that in turn supports clinical audit and risk management processes.

Other advantages of unique identification are that it will:

> ▸ Largely obviate the need for clients/patients to provide personal details at every contact with the health service, a procedure that clients/patients can find quite irksome, unnecessary and time consuming
> ▸ Allow the identification of duplicates from repeat contacts by the same individual with primary and secondary care services. This is an essential requirement for epidemiological purposes, screening and vaccination services, in service planning and evaluation and in the management of waiting lists etc
> ▸ Support the tracking and recall of patients or products if necessary, e.g. for vaccines, medical devices and blood products
> ▸ Reduce wastage of resources, e.g. by reducing the number of repeated diagnostic tests.

## 11.3 Requirements for unique identification

Eliciting information in the health sector to identify individuals uniquely can, at times, be difficult. Unlike other state services, the required healthcare services must be provided without delay in all the following circumstances:

> ▸ Where contact is often unplanned
> ▸ Where clients/patients may be very unwell and require emergency care and are not in the position to provide personal information, e.g. following trauma or if severely confused
> ▸ Where information may have to be solicited from third parties e.g. neighbours, friends, ambulance personnel
> ▸ Where official and commonly used names may be different and where surnames change
> ▸ Where the client/patient comes from another administrative area within the sector.

The success of a unique identifier will greatly depend upon its functionality for frontline healthcare staff. There are a number of essential requirements to ensure its successful implementation in the health sector including:

> ▸ A comprehensive legislative basis for use of the unique identifier throughout the health sector that enables appropriate access while ensuring privacy, confidentiality and security
> ▸ Full implementation of the framework for information governance to ensure the protection and appropriate use of health information (chapter 12)
> ▸ Access to the unique identifier index to all frontline healthcare providers throughout the health sector – including both public and private domains (such as general practitioners and private hospitals)
> ▸ Maintenance of a complete, accurate and up-to-date core client and service provider index and a tracing service for the allocation and determination of unique identifiers on a national basis

- Full utilisation of all available searching techniques of the core index (such as common or known aliases, address histories, name changes) for all frontline healthcare providers on an online 24-hour, 7-day basis
- Assignment of unique identifier immediately at the time of birth. This is a period when many health professionals in primary and secondary care are involved in the shared care of the mother and child. Unique identification is highly important in delivering, for example, vaccination programmes
- Appropriate arrangements for issuing the number to clients/patients on a 24-hour, 7-day basis to satisfy healthcare requirements
- The linkage to the necessary information to determine current eligibility for public health services
- Ability to issue numbers on a temporary basis, pending a subsequent match
- Robust 'notification' arrangements must exist between sectors for changes to the core index data
- Access to audit trails of changes and additions to core index data
- The identification number is permanent and never reassigned
- The ability to issue numbers to non-residents in the State (tourists, asylum seekers etc).

### 11.3.1 Options for unique identification

Given the need for the identifier to be permanent and unique to the person and given the degree of population mobility and client/patient transfers across administrative boundaries, regional health identifiers are not considered a practical way forward. A national approach to unique identification is therefore essential and the two main approaches are:

- Utilisation of the Personal Public Services Number (PPS Number) together with its supporting inter-sectoral infrastructure
- Development of an entirely separate national identifier that is specific to the health sector and uses its own supporting infrastructure.

The PPS Number is managed by the Department of Social and Family Affairs and use of the PPS Number within the Reach/eBroker framework is in line with the general policy of Government in encouraging its use. Already the PPS Number is in use by the GMS (Payments) Board for Medical Cards and the Drugs Payments Scheme. The PPS Number has the potential to meet many of the key requirements of the health sector including:

- A robust means for unique identification
- A robust means of authentication
- A comprehensive core client index through continual updating by all sectors
- A means for providing linkages to the wider public service for a variety of purposes ranging from determining eligibility for public health services to epidemiological studies
- Provision of a high level of protection and security.

However, initiatives to incorporate the PPS Number as a common key in the process of migrating towards a unique identifier within the public sector has proven to be a challenging task, especially with regard to the incorporation of unique identification within existing databases.

Use of the PPS Number is currently confined to specified agencies within the public sector, and any further extension of its use requires legislative provision and consultation with the Department

of Social and Family Affairs (chapter 12).  A key consideration in this area is to recognise the marked interplay between the public and private health sectors.  For example a patient may attend a general practitioner privately, receive healthcare in a public ward or clinic in a hospital and later undergo surgery in a private hospital.  To support the quality and continuity of care, it is essential that unique identification enables health information to 'follow the patient' as appropriate, especially with regard to bridging the hospital (primarily public) and primary care (primarily private) domains.

Resources from both the health agencies and from within REACH will need to be set aside to facilitate the allocation of the PPS Number at birth.  Without this capability it will be impossible to fully develop the electronic healthcare record, and its benefits in terms of enhancing the safety and quality of care and providing information for service planning and evaluation will be lost.

To enable the PPS Number and its supporting infrastructure to meet the special functional requirements of the health sector, the use of a health service number which is unique to the sector but which also has a direct correspondence with the PPS Number may convey some advantages but would considerably add to the complexity of the process.

Given the scale and complexity of developing and maintaining a comprehensive and up-to-date client/patient database, the use of an entirely separate national identifier specific to the health sector with its own supporting infrastructure would convey few if any advantages.  Disadvantages would include poorer data quality in terms of narrower coverage and slower updating of information, as well as the cost of duplicating the effort being expended by other sectors.  For these reasons, such an approach is considered impractical.

# Action

## Action 16 A system for unique identification within the health sector using the PPS Number, will be introduced

The Health Information and Quality Authority, in cooperation with the Department of Health and Children, relevant health agencies, the Department of Social and Family Affairs, the Reach/eBroker initiative and other groups as appropriate will prepare a plan for a unique identification system that meets the functional requirements of the sector and which is based upon the PPS Number and its supportive infrastructure.  Special attention will be given to enabling the identifier to enhance the safety of personal care (such as through the use of the electronic healthcare record) and to promote the quality of service delivery, whilst safeguarding the privacy, confidentiality and security of personal information in line with a robust information governance framework provided for in legislation (chapter 12).

The experience to date of health agencies in attempting unique identification will be taken into account, and consultation with stakeholders will be included as part of the overall process.  It is recognised that unique identification must bridge the primary and secondary care domains, including the public and private sectors, and can effectively support the shared care of clients/patients irrespective of the location of service.  A successful outcome demands considerable enthusiasm and unity of purpose on an ongoing basis.

Unique identification of individual service providers/agencies for reasons such as resource allocation and usage monitoring, clinical audit, human resource planning and policy development

will also be required. The Health Information and Quality Authority in conjunction with the Department of Health and Children, and working in partnership with health agencies, will have responsibility for setting the standards to be used in this area and how they will be implemented. The following will be considered in particular:

▸ The range of health service staff/agencies where unique identification is required
▸ Whether identification will be at institutional or individual level or both
▸ Which identifiers will be used
▸ Who will be the custodians of the central indexes of identifiers
▸ The essential characteristics of these indexes
▸ The arrangements for access to these indexes.

# Part 3

## Supporting Health Information

# 12 Information Governance and Legislation

The primary objective of the health service is to ensure that the highest levels of health and social well-being are achieved for individuals and for the whole population.  This Strategy proposes to exploit information to the fullest in pursuit of this objective (see Vision, chapter 2). In doing so, it recognises that there is a need for a set of 'rules' to ensure full and proper use of information while fully protecting the privacy of the individual.

Information governance refers to a strategic framework that brings coherence and transparency to information initiatives and which is responsive to the spectrum of issues and concerns of those involved.  It is of central importance to this Strategy.  Information governance provides the stakeholders with a clear and practical basis for the appropriate use of health information. Issues such as information sharing, health surveillance, quality assurance, confidentiality, privacy, records management, freedom of information and data protection are included.

*Quality and Fairness: A Health System for You (2001)* specifies that the Department of Health and Children will publish a Health Information Bill.  The bill will aim to put health information governance on a sound and robust footing and provide a clear legislative context for supporting health service processes while recognising the rights and duties of clients/patients, health professionals and health agencies.  Above all, the bill should foster and support a culture that ensures and safeguards the appropriate and best use of health information.

Any proposal concerning the role of health information legislation in safeguarding privacy should take account of the positive framework for health information supported through data protection legislation, given its international human rights background and Constitutional foundation which arise from privacy being recognised by the Supreme Court as one of the unenumerated rights of citizens.  Any proposed use of the PPS Number in relation to health information must address, in consultation with the Data Protection Commissioner, the current legal position that this number is for public service use only and factors which could unintentionally result in the PPS Number, de facto, becoming a national identifier.

The Data Protection Commissioner has referred to this matter in his 2002 Annual Report presented to both Houses of the Oireachtas on 30 April 2003.

## 12.1 Assessment of the current position

The current legal environment for health-related information is dominated by Data Protection and Freedom of Information legislation.  While these measures will determine many governance issues, there is a range of other Acts which require the collection and notification of specific information (e.g. infectious disease regulations) or provide for certain information agencies to be established and operated (e.g. the National Cancer Registry).  However, there is no system-wide framework for governance of health information.  In the context of this Strategy, the legal environment is not sufficiently supportive of some key activities or the protection of the interests of those involved.  The safeguards for individual privacy may not always be sufficient.

Records management is the foundation layer of all information systems, yet there is no coordinated policy for the archiving of personal health records or for the maintenance of

organisational memory in health agencies. The National Archives Act does not apply to health service providers, and there is a growing need to revitalise the policies and processes for the management of health records throughout the sector.

Without a statutory framework for the recognition, support and protection of necessary information sharing initiatives, including quality assurance, accreditation, health surveillance and disease registration, individual health professionals and health agencies can be reluctant to fully participate in such processes. Furthermore, in the absence of a legislative basis for access to complementary information from the private sector and for the use of unique identification throughout the health sector (chapter 11), the potential of public health and quality initiatives is constrained.

While the range of legislation is currently limited, the position on guidance is changing rapidly. Professional practice is delivered within the context of the ethical guidelines of the Medical Council and other professional bodies that deal with issues of consent, confidentiality and privacy. The health boards have published recommendations on health record retention. The Order of St. John of God has published a framework for the ethical use of electronic record systems. The computerised infectious disease reporting (CIDR) project of the National Disease Surveillance Centre is developing frameworks for collection, transfer and use of data. The Health Research Board report *Genetic Research and Human Biological Samples: the Legal and Ethical Considerations (2002)* also addresses the issues of confidentiality and security.

Internationally, there is a growing body of expertise on health information governance. Areas include access to health records, confidentiality, models of health information governance, standards for records management and the appropriate use of statistical data.

## 12.2 The way ahead

### Information governance framework

Information governance requires recognition of the value of information to the health service and the loss of value where ad hoc systems, contents and structures invalidate comparison and reuse of data. It also requires a culture which respects the sensitivity of personal health information. This respect will be evident in the fair obtaining of such information, its secure processing and the ready access by the subject who will be informed as to its purpose and authorised use.

In order to ensure the protection and appropriate use of health information, a framework for information governance will be put in place at the national, regional and local levels. This will involve each agency planning, developing, implementing and maintaining an enterprise-wide programme to protect personal information and the interests of the individuals to whom it relates. Clear plans and allocation of responsibility should form the basis of sets of business rules governing how information should be collected, held, handled and made available. The rules should cover the possibility of unintended inference of identity and should ensure that access to information is role-based, i.e. that it is driven primarily by the need to have it for carrying out one's duties. These duties relate both to the care and treatment of clients/patients by health professionals and to the secondary uses of information, such as for health surveillance and disease registration processes. The Health Information Bill will include the necessary provisions to give effect to the information governance framework.

To support the overall process, an independent advisory forum will be established and a digest of relevant and up-to-date legislation will be compiled and made widely accessible.

## Privacy, confidentiality and information sharing

Health professionals have an ethical and legal obligation to ensure the privacy and confidentiality of information received in their professional capacity.  Such an obligation may be seen to arise from express or implied contracts, from equity, or from the fiduciary relationship that exists with the client or patient.  Regardless of jurisdiction, the policy of the courts has been to protect such confidences.  It is recognised that health professionals and agencies may retain such information for legitimate purposes related to the implied contract, such as evidence of care provided, and that they have a duty to protect information with which they are entrusted.  It is also recognised that confidential information may be disclosed:

▸   With the express consent of the subject
▸   With the implied consent of the subject, for the purposes for which the information was provided
▸   To avoid substantial harm to the patient or a third party
▸   Where required to do so by statute or court order
▸   Where the public interest clearly requires it.

It is essential that the privacy of an individual's information is respected and that, at the same time, health professionals who share health information as a necessary part of their duties are also protected.  Both these requirements must be achieved in a way that supports high-quality care of individuals while also allowing essential service functions to be carried out, such as health surveillance and disease registration and the quality assurance of health services.

**Apart from the Data Protection Act (1988) and its amending legislation enacted in 2003, compared to other jurisdictions we lack a comprehensive statutory framework within which to require, permit, or prohibit the sharing of personal health information for purposes beyond the context of treatment or personal services provided by the health professional.**  While ethical guidelines for professional groups set out the principles, in many contexts there are legal uncertainties arising from the sharing of health information.  To address these with consistency in making everyday decisions, explicit guidelines are required for health service staff.  Clear legal authority is also needed for the secure transfer of information to and between health agencies.  The Health Information Bill will address these issues and provide authority for requiring the collection and communication of important sets of data, including personally identifiable information where essential, while protecting individual rights.

## Freedom of information and data protection

Transparency is the core value of freedom of information while privacy is the core value of data protection.  Both support access to personal information by the individual and have common features, but there are also significant differences in areas such as timescales, procedures, exemptions, protection of the individual and appeal mechanisms.

**The Freedom of Information Act (1997)** is a significant driver of equity and other strategic goals. Publication and subject access are powerful incentives.  They bring information issues into focus and draw attention to the quality of information management within an organisation.  The

anticipation of disclosure creates an everyday pressure to create records that have a clear context and content. The phased implementation of the Act to date has been based on equity of access, so that rights of access to information should not depend on the service provider. It is important, therefore, that future contracts for service address information requirements including arrangements for access to information.

Within the application of the Freedom of Information Act (1997), several policy issues of active concern have arisen. These include access to quality assurance records held in the context of clinical audit, peer group review and accreditation processes.

The extension of Freedom of Information to the remaining statutory bodies in the health sector and the routine inclusion of new agencies or administrative structures is significant in terms of accountability and in delivering equity in access to information. Changes in data protection legislation will require health agencies to review records management and access practices and this offers an opportunity to complete these processes in tandem with the extension of Freedom of Information.

**The requirements of the Freedom of Information Action (1997) for public bodies are to:**

‣ Publish descriptions of their organisation, functions, records and services
‣ Publish policies, procedures, and rules relating to access to services
‣ Provide access to records in accordance with the provisions of the Act
‣ Provide for correction of records containing personal information
‣ Provide findings of fact and reasons for decisions affecting an individual
‣ Where required to do so by statute or court order.

**Data protection** applies to all personal information regardless of the holder. It combines the three concepts of privacy, confidentiality and security. The Data Protection (Amendment) Act (2003), brought in to ensure compliance with EU Data Protection Directive (95/46/EC), strengthens and makes explicit almost every aspect of the existing protections under the Data Protection Act (1988). It also extends protection to certain manual records. Although this legislation reflects the common concerns of all professions in relation to privacy and confidentiality, the impact of its implementation will be extensive and profound throughout the health sector. It will affect everyday practice and systems standards, maintaining confidentiality from initial collection to secure disposal, including:

‣ Communications with the individual patient, to ensure 'fair obtaining'
‣ The security of records
‣ The management and disposal of records
‣ The communication of personal information to third parties.

There is growing demand for advice and support on data protection issues, together with a greater awareness of the issues surrounding the processing of personal data in electronic form. Most of the concern relates to the sharing or transfer of personally identifiable data and the necessary authority to do this, together with the interaction of data protection and freedom of information access. This harmonisation of freedom of information and data protection access will be addressed through appropriate administrative and legislative measures.

The eight principles of data protection are that data should be:

‣   Fairly and lawfully processed
‣   Processed for limited purposes
‣   Adequate, relevant and not excessive
‣   Accurate
‣   Not kept longer than necessary
‣   Processed in accordance with the data subject's rights
‣   Secure
‣   Not transferred to other countries without adequate protection.

### Code of practice

To assist health service staff in the everyday collection and management of personal health information a handbook of good practice will be prepared.  The health board FOI liaison group have already commenced work on this project. The handbook will include developing a Code of Practice under the Data Protection Act (1988) which provides for the approval of sectoral and professional codes of practice by the Data Protection Commissioner.  Such a code will support shared policy and practice and provide guidance on good practice in the collection, protection, use, disclosure and disposal of personal information in the context of the health sector.  On its approval by the Data Protection Commissioner this code will have statutory authority under the Act.  It will draw on emerging international practice and it may be that more than one version of the code will be required for different groups, and be updated as required.  The Code would put the statutory requirements within a context of good practice and professional ethics, offer practical advice on everyday situations, recognise the range of contexts in which access may be required, and reassure health professionals that practice within the guidelines would be in accord with requirements.

### Statistical data

The EU Data Directive applies to the processing of personal data (i.e. relating to a living individual who can be identified directly from the data itself or in conjunction with other data).  It does not apply to statistical data processed in a form that does not allow for the identification of individuals.  Statistical data can be generated through the use of a number of sophisticated techniques including:

‣   Anonymisation of data by the removal, aggregation, or conversion of information items which would identify the individual
‣   Pseudonymisation of data on transfer to specific parties so as to protect privacy but allow connection back to the individual where such reference becomes necessary
‣   Restriction of disclosure by aggregation or manipulation of data so that the recipient would be unable to restore the information to an identifiable form.

There is a need for information systems to separate the identifiable from the non-identifiable data and, in response to the Data Directive, to rely where possible on the latter.  Health professionals need guidance on the appropriate statistical practices to safeguard privacy and confidentiality together with a common approach to be adopted, for example in relation to record linkage and the avoidance of re-identification of individuals.  These issues will be addressed in the business rules and information governance arrangements of health agencies.

## Ownership

Uncertainties over the ownership of health information can arise.  The philosophical basis of access to personal health information is that it should be seen as belonging to the individual to whom it relates, and that the health professional/agency is the custodian of that information.  This principle is central to information governance and its enshrinement in legislation will be sought.

## Supporting health service functions

Individuals in receipt of care presume on a health system that maintains and grows its expertise and ability to protect the public by virtue of its access to the health information of the population.  While legislation must protect the individual, it must also enable the maintenance of information systems to support necessary health service functions in the common good.

The collection of information for quality assurance purposes, including professional audit mechanisms, disease and procedure specific registers, risk management and adverse incident reporting systems and performance measurement systems, is an essential requirement if the actions set out in this Strategy are to be implemented.  The standardisation of health information (chapter 13) will support quality assurance.

The dissemination of information about quality assurance activities and their outcomes is important in building public confidence in the health system while accelerating improvements in the quality of care.  Sensitive processes, such as clinical audit, peer group review and accreditation depend upon the confidence of both the public and health service staff if they are to achieve their goals.  The former requires openness about the operation and effectiveness of quality assurance procedures; the latter requires measures to ensure participation.

In order that the appropriate balance be maintained, a legislative framework for the support of quality assurance initiatives is required.  This will enable the dissemination of information while defining circumstances in which a degree of privilege is warranted to protect necessary confidentiality.  Such a framework will prevent misrepresentation and the inappropriate or unwarranted use of information arising from these processes.

Quality assurance requirements (to be set out by the Health Information and Quality Authority from the perspective of their quality remit) may include performance appraisal of individual health professionals and agencies.  Information identifying professionals and agencies will have to be available for such appraisal.  In general, this will require non-identifiable aggregate information about the clients/patients using the services, but the sensitivity of the processes will need to be recognised within the wider quality assurance arrangements and their legislative basis.

Current legislation requires notification of infectious disease by attending physicians on the basis of the potential threat to public health.  However, while this process was provided for in law at a time when infectious disease was one of the greatest threats to public health, there are now a number of additional major public health issues for which legislation should enable the provision of information, e.g. health surveillance and service planning and evaluation.  To support these processes, the registration and monitoring of certain diseases is of paramount importance, e.g. cancer, cardiovascular disease and congenital anomalies.  These conditions represent such a threat to the health of the population that a strong argument exists to support their ongoing surveillance and registration on a national basis in order to observe trends in their occurrence and

to determine the impact of prevention programmes and the outcomes of treatment services.  It is clearly essential to protect the process of information sharing by the health professionals who provide the necessary information.  A legislative solution will be sought that provides appropriate safeguards for the health professional and the individual client/patient.

In addition, there is a need to give power to the Minister for Health and Children to make certain diseases notifiable from time to time according to their importance to public health.  This will be actively explored in the drafting of the Health Information Bill and will help to ensure that the health system can obtain the necessary information to tackle the most significant threats to the health of the population.

The orderly development of health information standards is an important aspect of governance (chapter 13).  Consistency of content and structure is required within all health systems to enable connectivity and to provide reliable and comparable information throughout the sector.  Unique identification (chapter 11) and use of the electronic healthcare record (chapter 10) will support the delivery of high-quality care and will reduce the need for more identifiable information (such as name and address) being provided for health surveillance and disease registration processes.

Health research plays a crucial role in the ongoing development and provision of quality healthcare that best meets the needs of individuals and the population.  It is essential that there is a robust legislative basis to support appropriate research activities, together with inbuilt safeguards to protect privacy and confidentiality.

The Irish health service is a mixed private/public system.  It includes both public and private facilities, clients/patients and staff.  Just as clients/patients have the right to consistent healthcare practice regardless of context, they equally have a right to consistent information practices. These practices include those in the delivery of care, in providing information to the client/patient and in ensuring quality of care.

Without information from both sectors, it is impossible to build up a comprehensive picture of healthcare needs of populations or sub-groups.  Furthermore, the inability to access information from a private healthcare setting would prevent the full introduction of an electronic healthcare record which would have significant implications for the delivery of high-quality and safe healthcare.  The requirements for the health system to be seen as one whole system covering both sectors from an information point of view will be considered in the formulation of the Health Information Bill and in full consultation with the Data Commissioner.

# Actions

## Action 17 A legislative framework to support the National Health Information Strategy will be developed

The publication of a Health Information Bill will provide a framework for regulations and for the information dimensions of other health legislation.  It will provide or enable a set of primary and secondary legislation that will cover:

‣   The establishment of the legislative basis for the **Health Information and Quality Authority** (chapters 6 and 15)

- The creation of an **information governance framework** which reflects the principles that personal health information belongs to the individual to whom it relates, that the health professional/agency is the custodian of that information with legal responsibility and that access to such information be role-based including the role of Information Guardian (Action 18 below)
- Establishing the **Personal Health Information Advisory Group** (see below).
- Underpinning the **assessment process** undertaken by the Health Information and Quality Authority in the development and enhancement of information systems and sources (chapter 6)
- The development and regulation of **health information standards** in terms of data, technical and quality requirements (chapter 13)
- The mandating of **standard flows of health information** whilst protecting individual rights. The information flows include the voluntary or mandatory provision of identifiable information required by the Department of Health and Children, the Health Information and Quality Authority and the health agencies to carry out their roles.
- The specification of the appropriate use of the **electronic healthcare record,** for example in supporting shared care and the integration of health data from different sources (chapter 10), including the appropriate sharing of information across the public and private domains in the interests of client/patient care
- Support and regulation of the use of **unique identification** within the health sector, especially in realising the full potential of the electronic healthcare record in promoting the safety of client/patient care  (chapter 11)
- Authorising, supporting and protecting the use of information for **quality assurance** processes.  Quality assurance structures and processes will be supported by legislation that will balance concerns about accountability and confidentiality
- Supporting the collection and management of information for health **research purposes.**  The Health Information Bill will recognise the importance of health research and provide for the legitimate use of personal health data in support of this function

Other legislative initiatives may include:

- Extending the National Archives Act to the health sector with the establishment of a national health archive to ensure the proper retention of health records and the preservation of important historical records
- Harmonising of freedom of information and data protection regulations.  Ready access to one's own personal health record is central to this Strategy.  Access to data will be made as seamless as possible for members of the public.  Common access procedures will be adopted where feasible and provide for indirect access via a nominated health professional where appropriate
- Extending the Freedom of Information Act (1997) to those statutory bodies not currently scheduled

## Action 18 A framework for information governance will be developed

An information governance framework will be put in place that sets out how information is to be processed in the context of new health information legislation.

A specialist function for information governance will be established within the Health Information and Quality Authority.  This work will involve close liaison with the Department of Health and Children, the Data Protection Commissioner, the Health Research Board, the Central Statistics

Office, the Personal Health Information Advisory Group (see below) and other parties as appropriate.  The specialist functions will include:

- ▸ Providing advice to the Department of Health and Children and the health agencies on information governance issues, especially in relation to Freedom of Information, data protection and records management.  Specialist advice would be provided, for example, in relation to policies for sharing or transferring personally identifiable data and the necessary authority to do so
- ▸ Specifying the pertinent information requirements including access arrangements within service agreements.
- ▸ In consultation with the Central Statistics Office, setting statistical practice standards for the anonymisation, pseudonymisation and restriction of disclosure of data to safeguard privacy and confidentiality and publish guidance for use by research and system design teams.
- ▸ Assisting in the development of educational and training programmes on information governance
- ▸ Monitoring the implementation of information governance requirements, such as auditing the compliance with client/patient consent practices and systems security processes and procedures.

An independent Personal Health Information Advisory Group will be established on a statutory basis.  The Advisory Group will be a forum for the expert consideration of client/patient information issues and will be a valuable source of independent advice to the Minister for Health and Children, especially in areas of sensitivity such as balancing the need to safeguard privacy and confidentiality within the wider requirements of achieving the common good.  The Advisory Group will liaise with the Department of Health and Children, the Office of the Data Protection Commissioner, the Health Information and Quality Authority and other agencies and groups as appropriate.

The chief executive officer (or equivalent), or a named delegate in each health agency, will be designated as the Information Guardian for that agency and will be responsible in law for ensuring that agreed processes and procedures are in place for the implementation, operation and evaluation of the information governance framework and that responsibilities have been assigned to appropriately resourced and competent individuals.  The processes and procedures will be documented and they will list those who have access to information, the type of information that such people can access, the circumstances in which they can access it and the manner in which the information will be provided.  The availability of appropriately trained staff to support the implementation of the governance framework will be required.  The Information Guardian will oversee the following:

- ▸ A programme of staff training and education on information governance.  To ensure the health system and its professions respect privacy and set considerable store by it.
- ▸ Systems compliance.  There is a need for an ongoing review of systems, procedures and physical arrangements to ensure full and ongoing compliance in light of information governance requirements, especially with regard to fair obtaining and consent.
- ▸ Security arrangements.  The EU Data Directive emphasises the importance of explicit and comprehensive security including physical barriers and storage arrangements, secure electronic systems and data encryption.

# 13 Information Standards and Quality

Information standards are necessary to allow for the sharing of health data, for example sharing data between primary and secondary care settings, the pooling of data from a number of sources to reveal the bigger picture and allowing the comparison of like with like across the health sector. The adoption of standards is an essential requirement for improving the quality and usefulness of information for all stakeholder groups, and is of crucial importance in the use of the electronic healthcare record (chapter 10).

## 13.1 Assessment of the current position

The bulk of information systems operated by hospitals and other service providers do not conform to the same standards, making inter-operation and information sharing impossible. This clearly has implications for operational efficiency and effectiveness. In the absence of a national mechanism for the selection and adoption of information standards, health agencies record and process the same data in a great variety of ways. A number of the major health information systems, such as Vital Statistics, the Hospital In-Patient Enquiry and the National Cancer Registry, do use internationally recognised information standards. Consequently, the information can be used to facilitate local, regional, national and international comparisons thus illustrating some of the benefits of information standards.

## 13.2 The way ahead

The successful implementation of this Strategy is heavily dependent upon the general adoption of information standards that are appropriate to the specific healthcare domains. The task will pose a significant cultural and technical challenge, requiring intensive training and ongoing support, within a framework of change management. Standards will be fully incorporated into the development and enhancement of information systems, building upon the available expertise and progress already made in this area.

### Data standards

A key requirement for health information systems is to have consistent coding and classification systems for the data items, ranging from the most objective and quantitative (e.g. sex, date of a visit) to the more subjective and descriptive (e.g. symptoms). Standards are essential for clinical terminology since a 'day case', an 'in-patient' or 'waiting times' must each mean exactly the same thing in two hospitals; otherwise comparisons of their activity rates may be meaningless. It is important that data content, e.g. name and address, is recorded in the same format by different systems.

### Common indicator sets

Common approaches to the use of information depend on the availability of national data standards. The Public Health Information System is an example of an application that provides added value and insight by bringing together data from diverse sources in a common indicator-based format. The approach of Common Indicator Sets (CISs) will be extended across the full health information spectrum. In many ways, the process of applying standards will be guided by common indicator requirements. CISs are required in a range of areas including baseline demographic indicators, financial and human resource indicators, indicators of health

determinants and health inequalities, performance indicators, health status indicators and other indicators to inform prevention, protection and promotion activities.  CISs need to meet a number of important criteria:

> ‣ Be well-specified to meet required purposes but limited in number to maximise quality and usefulness
> ‣ Be based on existing, comparable data sets where possible; the identification of indicator requirements will also assist in highlighting areas where information is deficient
> ‣ Meet appropriate standards of quality, validity, sensitivity and timeliness
> ‣ Offer a high degree of flexibility to meet evolving policy and service requirements. The current capabilities of electronic database systems will help to facilitate this
> ‣ Take account of earlier and ongoing work in the area at international (WHO, OECD) and EU (Health Monitoring Programme, EUROSTAT) levels so as to avoid duplication of effort and promote cooperation.

In order to facilitate the flexibility of future information systems, the emphasis on data collection should be on item level data (e.g. individual client/patient) and on collecting primary rather than derived data (e.g. 'admission date' and 'discharge date' rather than 'length of stay' or 'weekend admission').

### Technical standards

Technical standards are required in a number of areas, including messaging, connectivity and security.  Messaging is the process of exchanging specified health data (agreed datasets) between individual users or agencies using the same language, conventions and coding system in accordance with strict rules; for example the exchange of test results between primary and secondary care information systems.  Connectivity is the ability to connect computers and information systems so that they can exchange data in a transparent way.

Data containing personal and sensitive information are confidential and ensuring their security is of paramount importance.  There are a number of approaches to security standards, all of which can be deployed together including:

> ‣ **Physical security** which ensures that only authorised personnel can physically access information through PCs, terminals, printouts or other areas where information is stored
> ‣ **Authentication** of users, for example through password, PIN numbers or biometrics, required to gain access to information electronically
> ‣ **Restriction of access** to information to groups on a 'need to know' basis, e.g. hospital front desk staff cannot access clinical information and clinical staff cannot access billing information
> ‣ **Audit trails** of access attempts which help to identify attempts at unauthorised access
> ‣ **Encryption,** an added layer of security that is usually used for messages being exchanged between agencies, but is used at a local level if required, including storage media (such as disks).

### Quality standards

The quality of health information is closely related to the issue of data standards described above. There is little point in the use of standards where the quality of the data undermines its

usefulness.  Data quality includes coverage in terms of the capture of all relevant records, comprehensiveness with respect to the information collected and accuracy of coding and data entry.  The concept of quality can be extended to include timeliness of data and well-specified procedures for its use and dissemination.

Poor information quality in any of these respects can lead to mistakes and be harmful for patients and clients of the system. It also erodes confidence in the data which in turn results in its under-utilisation and further deterioration in quality.  The objective for all health information systems must be to create a reinforcing cycle where improved data quality results in benefits to end-users and positive feedback to data providers.  The usefulness of the information system to the providers themselves and their involvement in decisions related to its improvement are key aspects to developing and maintaining data quality.  The important components of quality assurance in information systems include:

▸ Ensuring use and usefulness of the data to data providers
▸ Regular audits of data to assess quality with respect to coverage, comprehensiveness, accuracy and adequacy of validation procedures and the timeliness, use and dissemination of information
▸ Personal involvement of data providers in the system
▸ Application of internationally recognised quality standards wherever relevant.

As discussed in chapter 9, health information made available to the public by the health sector can be of highly variable quality and relevance.  Standards are therefore required for the format and contents of information intended for the general public, including hardcopy and electronic media such as websites, for example in relation to presentation, authorship, language, timeliness and reading-age.

# Actions

## Action 19 A national health information standards framework will be developed

The Health Information and Quality Authority, in cooperation with health service agencies and others as appropriate, will put in place a framework for adopting and implementing data, technical and quality information standards and common indicators throughout the health sector. The standards will be decided on a priority basis by the Health Information and Quality Authority on the advice of standing committees of appropriate stakeholders appointed by the Authority. Wherever possible, international or pre-existing standards will be adopted.  National and international expertise will be used so as to build upon the progress made in this area.
The role of the Health Information and Quality Authority in the implementation of the multi-annual information and ICT action plan will include assessment of conformity with the national health information standards framework (see Action 2).  Responsibility for overseeing the process of standardisation will rest with the Health Information and Quality Authority and will be supported by legislation as indicated in *Quality and Fairness: A Health System for You (2001).*

## Action 20 Common indicator sets will be developed

Where the Health Information and Quality Authority identifies the need for information to be available in common forms, it will work on behalf of the Department of Health and Children and the Health Services Executive to ensure the development of agreed Common Indicator Sets (CISs). These will be developed by standing committees of appropriate stakeholders convened by the Health Information and Quality Authority.  The Health Information and Quality Authority, through the service planning process with health agencies, will ensure that health information systems support agreed CISs requirements.

## Action 21 Information services provided to the public will be quality assured

Information quality standards for health agencies providing information to the public, for example through the Health Information Portal, will be set by the Health Information and Quality Authority in terms of the minimum data, format and content of the information, authorship, timeliness, reading-age and language versions (chapter 9).  This will ensure that comparable information is provided in an intuitive, relevant and user-friendly way.  The information quality standards will be implemented and monitored through service agreements, especially with regard to keeping the information up-to-date.

# 14 Information and Communications Technology

Information and communications technology (ICT) includes hardware and software for the support of health information.  It covers the telephone, personal computers, mobile devices, computer networks as well as voice, data and picture storage and transmission using internet-based technology and landline, wireless and satellite links.

ICT offers many ways to make the health service more people-centred, improve the quality and safety of care, help staff to make better use of their time and expertise and promote greater efficiency.  The range and quality of ICT solutions has vastly improved over time and it can revolutionise the way information is shared between health service staff.  Mobile communication technologies have the potential to develop new service delivery models for accessing and maintaining clinical and administrative databases.  Such models are especially relevant for staff working in the field such as public health nurses, out-of-hours services and emergency services.  Telemedicine and telecare systems can bring images and other clinical data rather than the client/patient to the service provider (remote consultation) and by limiting the need to travel this technology has the potential to increase the accessibility and efficiency of some services.

ICT is a tool to facilitate the collection, analysis, dissemination and use of health information.  It is not an end in itself and it is essential that strategic ICT developments are determined by the information requirements they are designed to serve, not the reverse.  Looking to the future, the recommendations under this Strategy will facilitate standardisation and enhance the information capabilities arising from ICT.

## 14.1 Assessment of the current position

There have been ICT systems implementations and usage within the health services for many years and it is important to note that there is considerable knowledge and experience in relation to ICT in the health services.

However, as pointed out in *Audit of the Irish Health System for Value for Money (2001),* it is hard to conceive of an operation of such complexity, and involving such a level of commitment, being managed effectively with the current level of funding of information systems.  The legacy of under-investment in ICT is an inadequate infrastructure to support the complex information requirements of a modern health service.  However, an increase of around 100% in information systems funding has been agreed for the 2004 Estimates.  This is a very significant development and underlines a commitment to make the necessary decisions to prioritise information as the very foundation of a high quality and responsive healthcare system.

In some areas, ICT provision is significant and provides sophisticated support for complex processes, while in other areas ICT provision is very limited.  There is an urgent need for a mechanism to determine and enforce data standards on a health services wide basis so as to ensure ICT conformity and connectivity and the availability of health information across the healthcare spectrum.

The current implementation of single enterprise-wide ICT developments for Personnel and Financial Management through adoption and roll-out of single best practice takes into account the need to reduce the level of fragmentation of systems developments and to improve the collection and flow of information.  In this regard, funding for ICT investment is now being made in the context of national solutions for systems that have applicability across a range of agencies.

## 14.2 The way ahead

As ICT opens up new horizons for its use in healthcare, such as the electronic healthcare record or telehealth/care/medicine solutions, it is also becoming increasingly complex, sophisticated and costly to implement and support.  At the same time, the need for better information sharing between clients/patients and their service providers, and within and between agencies is ever more apparent.  It is recognised that ICT is also a powerful enabler and catalyst for organisational change but for the purposes of this Strategy the focus is on information.  To ensure value for money, spending on ICT must be complemented by major change management programmes and supported by comprehensive business cases.

### National ICT framework

There is a need for a national, cohesive and integrated approach to the implementation of modern ICT solutions in response to priority health information requirements.

National ICT developments will take account of eGovernment initiatives such as Reach/eBroker and OASIS.  eBroker services enable the appropriate exchange of information within each public service sector, such as access to client index databases and the provision of robust user authentication services.  As the eBroker for all Government services may not hold information specific to any sector (such as health, education, local government), a dedicated eBroker function may be required, holding more detailed information relevant to health, for example pointers to where relevant information might be held or to key health data held in summary format.

### Operational systems

First class ICT support for operational systems is essential for the delivery of first class health services.  It is also essential for the collection of a very large proportion of the information underpinning this Strategy.  Collection of information at the operational level ensures its fullest use and highest quality.

A very wide range of operational systems is required to support the entirety of the health service. The range includes all areas of service provision, primary and secondary, as well as the great number of community services and services for special care groups.  Significant progress has already been made in some areas, notably in the administrative and financial areas where many larger health agencies are now migrating to their third generation of financial systems.

Work will be started by the Health Information and Quality Authority as soon as possible on developing the scope and specifications for the electronic healthcare record as a frontline operational information system (chapter 10).  There are already innovative examples of the use of electronic patient records in the primary and secondary care domains, and significant progress is being made with the supporting technologies such as test ordering and reporting.  The introduction of unique identification is of crucial importance in this regard (chapter 11).  It is recognised that introducing the electronic record throughout the health sector will be a vastly more challenging undertaking than any that has occurred in the past.

### Fast and secure communications infrastructure

The appropriate sharing of health information between health service staff and their clients/patients is a prerequisite for good-quality care. The development and implementation of a fast, robust, reliable, scaleable and secure communications infrastructure for carrying all health service communications traffic within the sector on a national basis is of central importance to this Strategy. The Government Virtual Private Network (VPN) will provide the basic voice and data communications networking infrastructure for health and other public sectors. The health services are actively participating in the VPN project. The VPN will facilitate the creation of smaller networks within it (e.g. a region, a health agency or hospital, a team within primary care) to serve specific groups of authorised users who are given a portfolio of access appropriate to their needs, such as access to specific hospital databases from primary care. The VPN will provide the underlying technology to enable the real time and secure exchange of information, for example between primary and secondary care. It is a key requirement for supporting the functionality of the electronic healthcare record and for providing immediate and secure access to scheduling/booking services, waiting lists, the Health Information Portal and the world knowledge databases through the Internet (chapter 9).

# Action

## Action 22 ICT actions will form part of the multi-annual ICT action plan to be developed by the Health Information and Quality Authority

The Health Information and Quality Authority's multi-annual information and ICT action plan will set out national ICT priorities. The Health Information and Quality Authority will undertake this work as a high priority.

The plan will take *Quality and Fairness: A Health System for You (2001), Primary Care: A New Direction (2001)* and this Strategy as its framework and, in developing the plan, will review available relevant strategic reports in the area of ICT. It will include a national implementation plan that builds upon the existing ICT infrastructure where appropriate. The plan will ensure that the process of identifying and remedying strategic health information deficiencies is fully supported.

The plan will also ensure that a standardised approach to systems is taken on a national basis and that value for money is achieved. The process may involve commissioning centres of excellence to pilot developments where there is a commitment to national roll-out following a successful pilot. The Action Plan will be broad-ranging and, in addition to the phased implementation of the electronic healthcare record (chapter 10) and eHealth Services, other specific areas to be included are outlined below.

The human resource requirements of the Action Plan will be addressed in the context of workforce planning processes under *Quality and Fairness: A Health System for You (2001).*

The Action Plan will incorporate ongoing national projects such as SAP Financials/Materials Management and Personnel Management Projects. To ensure the ongoing inter-operability of systems, processes and procedures for migration to newer generations of ICT will be defined.

A national data model will be included in the Action Plan (see Action 6) which will be at a strategic level and will consider the major elements of health information and their locations. It will define the major information flows and the level of integration required between databases. The model will define the location of major databases, such as the database to support the national unique identifier, and who will have responsibility for their maintenance.  Additionally, it will define how the model will interact with the public service broker and how these databases will be accessed by the various levels of users.  The model will also address how the electronic healthcare record will assimilate data and how user access will be provided.

The information and ICT action plan will, inter alia, deal with the following:

▸   A national secure communications infrastructure
▸   Electronic broker services
▸   ICT support for primary care
▸   A national ICT inventory
▸   Relevant universal access to email/Internet services
▸   A national waiting list database
▸   Telehealth solutions.

# Part 4

## Implementation

# 15 Implementation and Monitoring

This Strategy is an integral part of the overall Health Service Reform Programme.  Its implementation will require a complex range of developments and changes in legislation, organisation, management and culture.  This will present significant challenges throughout the sector, and effective change management processes will be of particular importance.  Success of this Strategy is dependent upon the presence of ongoing strategic direction, a strong central driving force and regional and local mechanisms that ensure its consistent, effective and timely implementation.  As described below, major investment in human resources, capital projects, new technology and change management is required.  The Health Boards Executive will set down the levels of investment required in implementing major health information systems.

There are potential opportunities for cooperation on an all-Ireland basis with regard to information and ICT.  The implementation of this Strategy will explore possibilities for joint working with Northern Ireland in ways that would be beneficial to both jurisdictions.

## 15.1 Infrastructural requirements

A number of infrastructural developments are required to support the implementation of this Strategy, as it is essential that a clear mechanism exists for implementing all of its dimensions.  An effective process for monitoring and enabling its progress over time in line with the targets and deliverables as set out in the Action Plan (chapter 17) is essential.  The Action Plan also specifies the lead responsibility and timeframe for each element.

The Health Information and Quality Authority will play the lead role in the whole process, and its empowerment as the central driving force for implementation of this Strategy is of critical importance.  The Authority will work in partnership with the Department of Health and Children and the health agencies as appropriate (chapter 6).

## 15.2 Human resource and change management requirements

The availability of appropriately skilled and trained staff to support the potential of information within health agencies, together with providing the skills-base and training programmes to support the roll-out and full use of major ICT solutions throughout the sector, are critical for the implementation of this Strategy.

Developing the capacity of the health system to deliver on the actions set out in this Strategy requires significant and sustained investment in human resources.  *Quality and Fairness: A Health System for You (2001)* sets out a series of actions relating to human resources as one of the six frameworks for change.  The development of staff to support the implementation of the Strategy will be carried out in the context of the actions in *Quality and Fairness: A Health System for You (2001),* particularly as they relate to improved workforce and action planning for people management.

Using ICT and information effectively requires an understanding of its potential together with imagination, innovation and an appreciation of the way people currently work and how they can be enabled to work differently.  This goes far beyond new skills training and requires fundamental changes to the ways in which people interact with each other and use information.  The most immediate effect is often felt by those closest to the operational systems while those in positions of management must modify their management style to exploit the benefits of the newly available information.  While using ICT to optimise service delivery requires that technology be designed around the needs of the people using and providing those services, the migration towards a set of common systems for similar functions throughout the health service and the need for standardised information will force some standardisation of procedures.  The implications of a transition from a mainly paper-based health system to a digital environment should not be underestimated as such a transition will be a significant cultural challenge to health service staff.  Considerable effort will be required to manage the necessary changes in procedures and practices.

In respect of ICT, innovative programmes are required in structured project management methodologies, business process reengineering, process mapping, benefits realisation and new and emerging technologies and applications.  In respect of information management, the same innovative approach is required, with particular emphasis being placed upon developing skills in information science, information management, data quality, business intelligence tools and a broad appreciation and understanding of the complementary role that ICT has in information management.  The training brief, however, extends beyond the traditional information management function.  Information authors, information providers, information consumers and those who form part of the knowledge management and information society value chain also need relevant training.  The training requirements will be different for the various information constituents and careful consideration is essential for the development of such programmes.

## 15.3 Information governance requirements

Effective healthcare demands close cooperation and teamwork.  Better communication and information sharing can be of great benefit to the individual and to the service overall, but there are also risks to privacy and confidentiality.  Harnessing the power of modern ICT systems within the health service increases benefits and risks.  There is a need for a cultural change regarding the use and sharing of health information throughout the health service if the benefits are to be reaped while the risks are minimised.  It is essential that a clear and supportive legislative and information governance framework be established for the appropriate use of health information throughout the sector, while safeguarding privacy and confidentiality (chapter 10).

## 15.4 Information system requirements

As pointed out in *Audit of the Irish Health System for Value for Money (2001),* major and sustained investment in information systems is required.  Otherwise it will not be possible to provide the necessary scope and depth of information that is necessary to meet the complex requirements of the health sector.  Major investment in systems is required so as to provide a basis for coherent and consistent appraisal of effectiveness, efficiency and economy, and to determine the value for money being delivered in return for increased levels of investment in the system generally or in its component parts.  This Strategy requires investment in the phased adoption of modern enabling technologies of proven value.  It will take advantage of the developing health information infrastructure and the new opportunities that arise in the ever-evolving field of ICT (chapter 14).

## 15.5 Funding requirements

*Quality and Fairness: A Health System for You (2001)* and *Primary Care: A New Direction (2001)* identify the need to greatly improve the availability of high-quality information. Indeed, the achievement of the objectives of these strategies is largely dependent upon the availability and proper use of information. Similarly, the report by Deloitte and Touche, *Audit of the Irish Health System for Value for Money (2001),* found a general absence of information to both drive and demonstrate efficiency, effectiveness and economy throughout the sector and concluded that significantly increased and sustained investment in human resources and in the overall health information infrastructure is urgently required.

It is recognised that we have examples of good health information systems and that there is a growing body of expertise in using information and in implementing sophisticated ICT solutions. However, it is clear that the level of investment in health information in general and ICT in particular (although it has increased in recent years) is central to our difficulties in meeting the complex information requirements of a modern health service.

It is absolutely necessary to implement personnel and financial systems, whether under current structures or those emanating from the reform process. Also, to meet the objectives set out in the Brennan report for example, the personnel, financial and acute hospital systems must be implemented as soon as possible. The implementation of financial systems will help health agencies in the management of their non-pay budgets. This has been seen to be effective where agencies have already implemented SAP financial systems. In regard to PPARS, this will be of considerable help to the system in controlling areas like rosters of health staff where staffing norms can be implemented. In other areas, for example the hospital system, it will not be possible to have budgets by individual clinicians without significant systems investments.

However, the full extent of what is needed across the health service in terms of properly integrated and comprehensive systems, including at the level of individual clinicians, will be worked through by the Information and ICT Action Plan. This means that the Department of Health and Children, in the context of the annual Estimates, will make an explicit commitment to information development so that the information base will once and for all fully support evidence-based decision making at all levels in the health services. The management and continuation of this programme of investment will be contingent upon evidence of value achieved from the investment.

Initially, the vast majority of these costs relate to major ICT programmes. A number of options will be explored in funding the investment programme in order to maximise its effectiveness in terms of cost, system delivery and performance. These include outsourcing, strategic alliances with the private sector and value for money (VFM) programmes. The benefits of shared services across agencies for common functions and for agencies providing similar types of services will be considered. In some areas it may prove beneficial to outsource elements or all of a particular service. A range of options is now commercially available in this area, from externally managed services and facilities management to outsourcing of an entire service, and the range is constantly developing. Each option will need to be assessed on its own merits, taking into account the cost-effectiveness that can be achieved through economies of scale and critical mass. A major part of the Information and ICT action plan will be the identification of the most cost-effective delivery method. In this regard, full account will be taken of guidelines on procurement and capital appraisal and the National Development Finance Agency will be consulted where appropriate.

The implementation of this Strategy is divided into three broad phases (chapter 16), but in the knowledge that the whole process is closely interdependent and will be influenced by factors outside the health sector itself. In addition to the new initiatives, the cycle of ICT upgrading and replacement will continue, but it will be carried out in the context of the Information and ICT action plan and in light of the policy of a common approach to ICT investment and deployment set down by the Department of Health and Children.

It is recognised that there must be ongoing investment in a change management process to accompany the implementation of this Strategy. No matter what decisions are taken on future methods of resourcing and implementing the Strategy, a change management programme is essential if we are to grasp the opportunity presented to transform the way the health system responds to community and individual needs. This will entail a radical analysis of the organisation of work throughout the system and a determination to follow through with the necessary changes. An information-based culture amongst all personnel is fundamental to any modern health system. The costs of this change, including appropriate facilities, development of new procedures and training staff in their use, should be an integral part of any systems implementation.

# Actions

### Action 23 Appropriate administrative arrangements to support health information at health agency level will be established

In line with any administrative reforms as required under *Quality and Fairness: A Health System for You (2001),* the administrative capacity required to support the implementation of this Strategy at health agency level will be strengthened so as to ensure that there is a major emphasis on the health information function at senior level in the planning, development, evaluation and implementation of agreed policy. The information function will include:

- Supporting the functions of the Health Information and Quality Authority
- Leading the implementation of the Strategy at health agency level and on a national basis
- Advising on development of health agency implementation and service plans to ensure that they meet the requirements set out in the Strategy
- Information governance in health agency areas
- Supporting other health agency functions through the provision of appropriate information
- A research and development function as set out in the Health Research Strategy, *Making Knowledge Work for Health (2001)*
- Health agency library services, both electronic and non-electronic.

### Action 24 A system to evaluate and monitor the implementation of the National Health Information Strategy will be established

#### National system of monitoring and evaluation

A dedicated monitoring and evaluation function will be established in the Health Information and Quality Authority to support the implementation of this Strategy in line with the Monitoring and Evaluation requirements set out in *Quality and Fairness: A Health System for You (2001).* The results of this monitoring will be reported to the Department of Health and Children. The Health

Information and Quality Authority will work with the Department of Health and Children to develop a set of performance indicators to be used in the evaluation and monitoring of the implementation of this Strategy.

Health agency system of monitoring and evaluation
A dedicated monitoring and evaluation function will be established in the Health Service Executive to facilitate the implementation of the National Health Information Strategy at the regional and local level, and will complement and support the national overview, for example by employing performance indicators that are consistent with those used at the national level.

## Action 25 Human resource development will support the delivery of the National Health Information Strategy

The availability of sufficient specialist analytical, interpretive and information services expertise is essential for exploiting the potential of available health information.  The Health Information and Quality Authority, in partnership with other agencies and relevant groups, will review human resource needs for implementing this Strategy in line with the Health Service Reform Programme and in support of *Quality and Fairness: A Health System for You (2001)* and *Primary Care: A New Direction (2001),* with a view to optimising the essential information-related competencies and staffing levels at national, regional and local levels.  Human resource developments to support the implementation of this Strategy will then be set out in the context of:

▸   Integrated workforce planning
▸   Assignment of appropriate numbers of knowledge managers, information specialists including librarians, public health specialists, ICT staff, epidemiologists, health economists, risk managers, information guardians and others.

It will be important to ensure the availability of a critical mass of these disciplines throughout the health agencies, including the Health Information and Quality Authority, hospitals, health and health information agencies.

## Action 26 Relevant training programmes will be provided

Human resource development to support the Strategy will focus on the education, training and skills maintenance requirements of all staff.  Each agency will be required, through improved people management, to identify the information training requirements of staff and ensure that these are provided for in continuous personal and professional development processes.  The development of a culture of information use requires training at all stages of the information and knowledge production process so that high-quality information and information technology are used to the benefit of clients/patients, healthcare professionals, managers and the health system generally.

In recognition of the importance of delivering an appropriate spectrum of skills to meet the requirements of the information constituents, training programmes, in line with a policy framework developed by the Health Information and Quality Authority in cooperation with the health, educational and other relevant agencies, will be offered through a variety of media. Options will include distance learning, e-learning, part-time or day release, through formal academic institutions (with accreditation offered as an incentive) or other means, special graduate training programmes, in-service and/or rotational programmes, mentoring opportunities and top-up courses as required.

## Action 27 The Health Information and Quality Authority will review and update the National Health Information Strategy every year and submit it to the Minister for Health and Children for approval.

Given the dynamic nature of the requirements for health information and the ongoing evolution in ICT, it is likely that new opportunities and challenges will arise for which this Strategy may not provide an adequate policy context. Modifications to elements of the Strategy may therefore be important for its successful implementation and to ensure that it remains harmonised with the implementation of the Health Service Reform Programme and *Quality and Fairness: A Health System for You (2001)* particularly in light of its ongoing review and evolving priorities.

The Health Information and Quality Authority will review progress on a yearly basis and submit the updated Strategy to the Minister for Health and Children for approval. The information and ICT action plan will then be updated in line with the updated Strategy.

# 16 Implementation Phases

This Strategy will be implemented on an incremental basis, and the overall process is divided into three broad and overlapping phases.  These are divided into phase 1 (years 1-2), phase 2 (years 3-5) and phase 3 (year 6 onwards) following the publication of the Strategy.  At the outset, emphasis is placed on getting the essential building blocks into place at the earliest opportunity.  Given the scale and scope of the Strategy and the resource requirements, many of which will only be identified over time, a precise timetable is not described.

## 16.1 The pace of progress

It is important to note that most of the steps in implementing the Strategy are closely interrelated, such as information governance, unique identification and the electronic healthcare record.  Difficulties and delays in one area will impact elsewhere.  The timetable of the Action Plan is used, therefore, for illustrative purposes to highlight the priority areas over time.  Furthermore, many factors outside the health domain will markedly influence progress, such as the roll-out of the REACH and other eGovernment initiatives, including the virtual private network for state services.  The successful establishment of the Health Information and Quality Authority at the very outset is of critical importance to the entire Strategy.

The pace of implementation of the Strategy will also be greatly influenced by the general economic climate in which the health system operates.  However, given the crucial role that it plays in implementing the Health Service Reform Programme, considerable priority will be afforded to this Strategy.

It is important to note that many of the critical actions in the Strategy will be achievable through relatively modest new investment.  Examples include actions relating to improving the use of information (e.g. in service planning and evaluation), improving the accessibility of information (e.g. the Health Information Portal), and introducing an information governance framework underpinned by the Health Information Bill.  What is required in these cases is a clear commitment to change management processes on the part of the stakeholders and sufficient priority being afforded to their achievement.

Other initiatives are more heavily dependent upon investment decisions and the overall pace of new developments in the wider health system, together with international influences.  These include investment in major ICT solutions such as financial accounting and human resource systems and the general deployment of the electronic healthcare record.

Furthermore, the ongoing capacity of the sector to respond to the challenges involved will greatly influence the process, as will the overall implementation of the Health Service Reform Programme.  However, it is clear that ongoing consultation and partnership with all stakeholders will be of central importance to the implementation process throughout.

### Phase 1: short-term priorities (years 1-2)

Priority will be given to developing the necessary information infrastructure and processes during this phase.  Emphasis will also be placed on improving access to and making better use of available information.  It is recognised that the developments will require additional human

resources, especially in specialised health information fields, but must also adhere to Government decisions on overall personnel numbers in the public sector. The Department of Health and Children and its agencies must prioritise the information area so that it is not adversely affected by decisions on appropriate staffing numbers.

The development of standards in the area of clinical terms and clinical coding and classification systems is an essential prerequisite to much of the implementation of the National Health Information Strategy. It is, therefore, essential that the Health Information and Quality Authority be established on an interim basis as early as possible in order to advance this work. The information governance framework which will underpin the overall implementation of the Strategy will be put in place with a legislative basis provided by the Health Information Bill.

A number of 'quick wins' are achievable within this timeframe. The Health Information Portal will be developed to meet many of the priority health information requirements of all stakeholder groups, including the public and clients/patients (chapter 9). Features of the Health Information Portal will include eHealth services such as online eligibility applications. The national eHealth library will provide a window on to the world's knowledge databases and it will be a vital resource for health service staff. The electronic payment of primary care providers will be progressed.

The Health Information and Quality Authority will initiate a process for identifying the major information deficiencies, and the process of approving solutions will begin (chapter 6). The standards framework established by the Authority will support the development and enhancement of new and existing information sources and systems (chapter 13).

Developments in the service planning and implementation process will become increasingly evidence-based as better health information becomes more accessible. Other initiatives will include building upon and making better use of available health information, such as performance indicators, the Integrated Management Returns and the evolution of the Public Health Information System to become a comprehensive National Health Atlas.

The Health Information and Quality Authority will complete a detailed plan for information early during this phase. To support the process, the data model, the specification of the electronic healthcare record, an inventory holding a description of the contents of health information databases and an ICT hardware/software inventory, will be progressed.

Emphasis will be placed on developing the necessary ICT infrastructure, including the roll-out of a secure communications system throughout the sector, and the deployment of unique identification infrastructure and procedures. The ongoing roll-out of key functional systems such as for financial accounting (SAP) and human resources (PPARS) will continue during this phase within available resources. This will also apply to other major areas such as hospital and primary care information systems.

## Phase 2: medium-term priorities (years 3-5)

During this phase, health information initiatives will be prioritised by the Health Information and Quality Authority, working in partnership with the health agencies. The process will involve a structured approach to identifying information deficiencies (chapter 6), together with the outcome of the information and ICT action plan (chapter 14). New information services will be developed, such as the public health observatory or the development of information functions in existing

information agencies, for example in relation to health impact assessment or narrowing inequalities in health.

The secure communications system will be rolled out throughout the sector, and the infrastructure for unique identification will be deployed.  In addition, the ongoing roll-out of key functional systems such as SAP and PPARS will be completed during this phase.

### Phase 3: longer- term priorities (year 6 onwards)

The implementation of initiatives during this phase will be greatly dependent upon the rate of progress achieved in the earlier phases of the Strategy.  However, the implementation and roll-out of the electronic healthcare record and the supporting infrastructure across the primary and secondary care domains will be the dominant undertaking.  It will build upon the primary care ICT developments from phase 1 and the overall electronic healthcare model as addressed in the multi-annual information and ICT action plan.  The electronic record is a central plank of the overall Strategy and it is recognised that its complexity and scope poses one of the greatest ICT and change management challenges ever faced by the sector.

# 17 Action Plan

As indicated in Chapter 16, timing for the completion of implementation phases will depend on the pace at which the necessary structural reforms and improved levels of resourcing are achieved. Where interdependencies exist, the timing of some actions will be dependent on the successful completion of the preceding actions.

With the exception of those elements of the Action Plan which will be ongoing for the whole term of this Strategy, the actions are each allocated to a particular phase. The phases are described in Chapter 16 with phase 1 referring to those particular actions that will be addressed in years 1-2 of the implementation process, phase 2 being years 3-5 while phase 3 will commence in year 6 for the remainder of the term.

| No. | Action | Deliverable | Phase | Responsibility |
|-----|--------|-------------|-------|----------------|
| **Chapter 6 The Information Role of the Health Information and Quality Authority** | | | | |
| 1 | The Health Information and Quality Authority will be given a central role in implementing the National Health Information Strategy | Health Information and Quality Authority set up and given appropriate responsibility | 1 | Department of Health and Children, Health Information and Quality Authority |
| 2 | The Health Information and Quality Authority will assess and advise on major developments in information and information technology | All major developments assessed by Health Information and Quality Authority | 1 | Health Information and Quality Authority, Department of Health and Children |
| 3 | The Health Information and Quality Authority will draw up a multi-annual information and ICT action plan. | Multi-annual plan in place | Ongoing | Health Information and Quality Authority, Health Services Executive, Department of Health and Children |
| 4 | The Health Information and Quality Authority will assess information databases of all agencies which provide key health service information on an ongoing basis and enter into service agreements as appropriate for the supply of information. | Relevant business plans regularly assessed | Ongoing | Health Information and Quality Authority, Health Agencies |

| No. | Action | Deliverable | Phase | Responsibility |
|-----|--------|-------------|-------|----------------|
| **Chapter 6 The Information Role of the Health Information and Quality Authority** | | | | |
| 5 | An annual report will be published by the Health Information and Quality Authority | Annual report of the Health Information and Quality Authority | Annual | Health Information and Quality Authority |
| 6 | A health services data model will be developed and maintained by the Health Information and Quality Authority | Data model available | 2 | Health Information and Quality Authority |
| 7 | A national health information database will be developed and maintained | Database established | 2 | Health Information and Quality Authority |
| **Chapter 7 Information and the Service Planning Process** | | | | |
| 8 | Health agencies will be required to demonstrate the appropriate use of information in implementation and service plans | Planning processes underpinned by specific reference to best available evidence | Ongoing | Health Agencies |
| 9 | Health information requirements will be a specific dimension within implementation and service plans | Implementation and service plans specify information requirements for all proposed services | Ongoing | Health Agencies |
| 10 | Improved information on human resources will be made available | HR information solution operational in all health agencies | 1 | Health Agencies |
| | | Approval of service developments will be based on timely and accurate HR information being supplied by health agencies | 2 | Department of Health and Children |

| No. | Action | Deliverable | Phase | Responsibility |
|-----|--------|-------------|-------|----------------|
| **Chapter 8 Population Health** | | | | |
| 11 | A national population health observatory will be established | Observatory in place | 2 | Health Information and Quality Authority |
| 12 | Health information will contribute to the process of narrowing inequalities in health and other population health priorities | Attributes included in relevant health information systems | 3 | Health Information and Quality Authority, Health Agencies |
| 13 | Health information will be geo-coded by small area | Geo-coding system in place for key health information systems | 2 | Health Information and Quality Authority, Health Agencies |
| **Chapter 9 Access to Information – Health Information Portal** | | | | |
| 14 | A Health Information Portal will be developed | Portal up and running | 1-2 | Health Information and Quality Authority |
| **Chapter 10 The Electronics Healthcare Record** | | | | |
| 15 | The electronic healthcare record will be implemented on a phased basis | Definition adopted  Implementation sites in primary and secondary care in place  Roll-out takes place | 2-3 | Health Information and Quality Authority, Primary Care Task Force, Health Agencies |
| **Chapter 11 Unique Identification** | | | | |
| 16 | A system for unique identification within the health sector using the PPS Number will be introduced | Unique identifier available for use in the health sector | 1 | Department of Health and Children, Health Information and Quality Authority, Health Agencies |
| **Chapter 12 Information Governance and Legislation** | | | | |
| 17 | A legislative framework to support the National Health Information Strategy will be developed | Health Information Bill published | 1 | Department of Health and Children |
| 18 | A framework for information governance will be developed | Framework in place | 2 | Department of Health and Children, Health Information and Quality Authority |

| No. | Action | Deliverable | Phase | Responsibility |
|---|---|---|---|---|
| **Chapter 13 Information Standards and Quality** | | | | |
| 19 | A national health information standards framework will be developed | Framework in place | 1 | Department of Health and Children, Health Information and Quality Authority |
| 20 | Common indicator sets (CISs) will be developed | CIS structures/processes in place | Ongoing | Department of Health and Children, Health Information and Quality Authority |
| 21 | Information services provided to the public will be quality assured | Quality assurance system in place | 2 | Health Information and Quality Authority |
| **Chapter 14 Information and Communications Technology** | | | | |
| 22 | ICT actions will form part of the multi-annual information and ICT plan to be developed by the Health Information and Quality Authority | Action Plan published | 1 | Health Information and Quality Authority, Department of Health and Children, Health Agencies |
| **Chapter 15 Implementation and Monitoring** | | | | |
| 23 | Appropriate administrative arrangements to support health information at health agency level will be established | Information function in place | 1 | Health Agencies |
| 24 | A system to evaluate and monitor the implementation of the National Health Information Strategy will be established | System in place at national level | 1 | Department of Health and Children |
|  |  | System in place at local level | 2 | Health Agencies |
| 25 | Human resource development will support the delivery of the National Health Information Strategy | Information requirements included in integrated workforce plans for health staff under Q&F | Ongoing | Department of Health and Children, Health Service Employers Agency, Health Agencies, Health Information and Quality Authority |

| No. | Action | Deliverable | Phase | Responsibility |
|---|---|---|---|---|
| **Chapter 15 Implementation and Monitoring** | | | | |
| 26 | Relevant training programmes will be provided | Training standards and processes in place | 1 | Health Agencies |
| 27 | The Health Information and Quality Authority will review and update the National Health Information Strategy every year and submit it to the Minister for Health and Children for approval. | Review process completed | Ongoing | Department of Health and Children, Health Information and Quality Authority |

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# Appendix 2 Terms of Reference

*Recognising the central importance of accurate, timely and relevant information for assessing population health, guiding service planning, measuring effectiveness and informing health policy, the National Health Information Strategy Committee will develop a strategic approach toward the achievement of a coordinated and integrated national health information system.  The Committee will consult widely and will make recommendations on the actions required to realise this aim.*

In particular, the National Health Information Strategy Committee will:

1. Review and assess present arrangements for the collection, reporting and use of health information, as broadly defined, in terms of requirements for both health service management and measurement of population health

2. Examine approaches to integrated health information systems adopted elsewhere.

3. Address issues of data quality, standardisation of definitions, integration of data and timeliness

4. Consider gaps in data and look at requirements for the development and use of performance indicators and outcome measures for monitoring and evaluating health and the effectiveness of health services

5. Examine issues of access to data including protocols for confidentiality and release of data to third parties

6. Investigate Information and Communications Technology (ICT) coordinated solutions for the improved storage, updating, collection, analysis dissemination and standardisation of health and health-related data in order to optimise data integration, management and delivery

7. Recommend the required steps and estimated technical manpower and hardware resources required to develop and implement a national integrated health information model in a working environment where suitable ICT and statistical expertise is at a premium.

# Appendix 3 Glossary of Terms

| Term | Definition |
| --- | --- |
| Capital funding | Money allocated for spending on assets, such as buildings or equipment, which will be used for more than one year (see also revenue funding) |
| Cascade system | An organised system that ensures that critical health information, such as health alerts, can rapidly reach all those for whom it is relevant |
| Casemix | A method of quantifying hospital workload by describing the complexity and resource intensity of the services provided. This differs from a simple count of total patients treated or total bed days used |
| Clinical audit | The systematic, critical analysis of the quality of care, including the procedures used for diagnosis and treatment, the use of resources and the resulting outcome and quality of life for the patient |
| Coding systems | Systems that code textual descriptions to numeric values for electronic storage. An example used in the coding of health information is the International Classification of Diseases (ICD) |
| Common Indicator Set (CIS) | In order for information from different sources to be compared, it is necessary to ensure that they have identical definitions. The use of common indicator sets ensures that like is being compared with like and avoids any need to further transform data to comparable formats. |
| eBroker | The eBroker initiative is being developed as the Public Service Broker by REACH with a view to providing a standard means of electronic access to all Government agencies |
| eGovernment | The concept of providing public service through electronic media |
| eHealth library | Library services provided through a computerised network rather than printed volumes with information made available over the internet or similar technologies with searching facilities |
| eJournals | Journals that are made available electronically, typically over the internet or similar technologies with searching facilities |

| Term | Definition |
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| Electronic healthcare record | The electronic healthcare record is the digital equivalent of the client/patient's paper chart and includes the electronic patient record (EPR) which is typically maintained by the individual healthcare provider as with today's paper record, and the more complex version which is referred to as the electronic health record (EHR) where individual EPRs are linked in part or in whole to build up a fuller health picture over time and to create a longitudinal record that could run from birth onwards. |
| Eligibility | Refers to whether or not a person qualifies to avail of services, either without charge (full eligibility) or subject to prescribed charges (limited eligibility) |
| eProcurement | The electronic linking of health services  purchasers with their suppliers to conduct any or all aspects of procurement |
| Evidence based practice | Practice which is based on the use of best available and appropriate evidence arising from research and other sources |
| General Medical Services (Payments) Board (GMSPB) | The board, on behalf of the health boards, calculates and makes payments to general practitioners, pharmacists and dentists under the GMS (Medical Card) Scheme. |
| Geocoding | A means of identifying geographic location, for example by district electoral division (DED) |
| Health Atlas | Health information presented in a geographical basis such as by county or small local area |
| Health Board Executive (HeBE) | The Executive comprises the chief executive officers of the seven health boards, the Eastern Regional Health Authority (ERHA) and its three area health boards.  The Executive was established to enable joint working between health boards. |
| Health determinants | Factors that can have an impact the health of an individual such as lifestyle choices, environmental conditions and individual susceptibility |
| Health impact assessment | An integrated study of health determinants that provides decision-makers with sound information on implications on health of any given policy. |
| Health observatory | An organisation or body with the function of monitoring the health status of a population |
| Health services directory | An element of the Health Information Portal that will provide details on the availability of local statutory, private and voluntary services on a national basis |

| Term | Definition |
|---|---|
| Hospital In-Patient Enquiry (HIPE) | A hospital based information system managed by the Economic and Social Research Institute on behalf of the Department of Health and Children that collates data about each in-patient and day case hospital discharge, including diagnostic and treatment information and length of stay. |
| Information and communications technology (ICT) | Includes hardware and software for the support of health information. It covers the telephone; personal computers; mobile devices; computer networks; voice, data and picture storage; and transmission using internet-based technology and landline, wireless and satellite links. |
| Integrated Management Returns (IMRs) | Make up a management information system within the Department of Health and Children based on data provided by the health service providers. |
| Internet portal | Internet concept of an access point that enables a user to navigate through many related sites by means of links |
| Medical Council | Protects the interests of the public when dealing with registered medical practitioners. The Council was established by the Medical Practitioners Act 1978 and commenced operation in April 1979. The Council has 25 members including elected and appointed members. The members represent the range of medical specialties and teaching bodies and include lay members appointed by the Minister for Health and Children |
| Multi-annual budgeting | A system of budgeting where money is allocated for a project for more than one year. In effect a budget is agreed for each year over the lifetime of a project and the agreed level of funding is guaranteed for this period. A multi-annual budget (MAB) is a budget for a project covering more than one year |
| National Anti-Poverty Strategy (NAPS) | The National Anti-Poverty Strategy, 1997 is a 10-year Government programme for reducing poverty through a range of targets focusing on global poverty, educational disadvantage, unemployment, income adequacy and rural/urban development. The Programme for Prosperity and Fairness (1999) committed the Government to setting targets in the area of health, housing and accommodation |
| National Development Plan 2000-2006 (1999) | The plan sets out a coherent strategy for development in the areas of infrastructure, education and training, the productive sector and the promotion of social inclusion. It includes a framework for the promotion of a more balanced regional development. It will involve an investment of €52 billion over the period 2000-2006 of public, EU and private funds. A total of €2.5 billion has been allocated to the health sector |

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| Term | Definition |
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| National psychiatric in-patient reporting system (NPIRS) | A database with details of all discharges from public in-patient units for persons with mental illness |
| National Perinatal Reporting System (NPRS) | An information system managed by the Economic and Social Research Institute on behalf of the Department of Health and Children that collects and analyses national perinatal data. |
| OASIS | An internet portal providing access to consumer information on public services |
| Personal Public Services Number (PPS Number) | A personal identification number to be utilised for recipients of public services |
| Primary care | An approach to care that includes a range of services designed to keep people well, from promotion of health and screening for disease to assessment, diagnosis, treatment and rehabilitation as well as personal social services.  The services provide first-level contact that is fully accessible by self referral and have a strong emphasis on working with communities and individuals to improve their health and social well-being |
| Personnel Payroll Attendance and Recruitment System (PPARS) | A health services-wide ICT programme covering the implementation of a modern integrated enterprise-level system for human resource management |
| Public Health Information System (PHIS) | An interactive application developed by the Department of Health and Children for presenting detailed health information and indicators |
| REACH | An independent agency established by Government to oversee the development of a set of facilities to support the effective and efficient interface between the citizen and the state.  Key components include the rollout of the Personal Public Services Number (PPS Number) as a common person identifier for all transactions with individual persons and state services.  At the heart of the concept lies a core index that provides the national reference source for unique identifier and related information necessary for secure client and provider identification. This will enable much greater efficiency and reliability in the provision of public services to the individual |
| Revenue funding | Money allocated for spending on day to day running costs, including pay, which is usually allocated on an annual basis (see also capital funding) |
| Secondary care | Medical care that is typically provided in a hospital setting |

| Term | Definition |
|---|---|
| Sentinel practices | Selected primary care practices which report data on, for example, infectious disease, which is intended to act as an early warning system |
| Telemedicine | Rapid access to shared and remote medical expertise by means of telecommunications and information technologies, no matter where the patient or relevant information is located |
| Value for money (VFM) | Examinations carried out by the Comptroller and Auditor General (C&AG) that aim to establish whether resources have been acquired, used or disposed of economically, efficiently and effectively. Examinations can also investigate whether public bodies have appropriate systems, practices and procedures for evaluating the effectiveness of their activities |

# Acknowledgements

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