HEALTH INFORMATION STRATEGY FOR THE YEAR 2000

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Minister of Health

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Foreword from the Minister of Health

New Zealand's health information systems are in much better shape than they were five years ago, when a national health information strategy was first developed as a collaborative effort by the health sector.

Back then, the strategy was designed to address the lack of relevant, timely, and accurate information. A national framework and systems were proposed to provide the foundations for future development.

Much of what was envisaged in the original strategy has now been achieved, and significant improvements have been made. However, five years on it is worthwhile to once again take stock, and develop a new strategy for the management of health and disability information which will provide a blueprint for the next five years. The new strategy seeks to build on previous improvements, and foster new successes. Good information management is vital for the health sector and is relevant to everyone who deals with health information. It is clear that improvements in technology have resulted in corresponding improvements in information management.

The *Health Information Strategy for the Year 2000* recognises a number of trends that have become apparent in the last few years. These include the move towards a more patient-focused approach, evidence-based care and better co-ordination and integration of services (seamless care).

Above all, the strategy is intended to provide a strong base for the ongoing development of the health and disability sector by helping to ensure that accurate and relevant information is available to the appropriate people at the right time, but with appropriate means for protecting the privacy and confidentiality of information.

I am pleased that the sector has worked together to identify the issues, agree to a framework to guide development, and produce a plan for future action. While much work still needs to be done, this strategy will help show the way.

As with any plan, this strategy will need to be reviewed and revised to meet changing requirements. Implementing the strategy remains a significant challenge. The benefits from doing so are clear and I am confident the health and disability sector will work to build on the successes to date.

The establishment of a Health Information Council, as proposed in the strategy, will help provide leadership to ensure the health sector has the information it needs when it needs it, to help us all move to a healthier New Zealand.

Hon Jenny Shipley
Minister of Health

Executive Summary

Background

The *Health Information Strategy for the Year 2000* represents the culmination of nearly 12 months' work by the health and disability sector, led by a small project team within the Ministry of Health, and supported by local and international health information management specialists. While the strategy is the culmination of the effort to date, it is not the end point. A plan of action has been formulated, and now needs to be acted upon. This plan will be subject to continuous review and adjustment, but it indicates how the health and disability sector in New Zealand can substantially improve its management of information, and puts a number of fundamental building blocks in place.

This report

This document is in four parts.

The initial section outlines the background to the strategy, including summaries of earlier initiatives, the findings of a stocktake survey completed in November 1995, the conclusions of the working groups established as part of the project, and the analysis of gaps, overlaps and issues completed in March 1996.

The second section establishes some of the strategic building blocks. It deals with the strategic vision and its ongoing relevance, as well as outlining some key principles and areas of activity covered by the strategy.

The third part deals with implementation of the strategy. It outlines the basic framework and the role of the Ministry of Health, and proposes the establishment of a Health Information Council to oversee the ongoing implementation and development of the strategy. Issues covered include the costs of development and implementation, intellectual property rights, and the first phase of the work programme required to implement the strategy.

The fourth and last section is written as a view of the future and the ways in which some of the plans will be implemented. It deals with aspects of the technology, systems architecture, design considerations and other issues related to making the vision more concrete. It addresses a number of requirements and proposes a "system of systems" approach, not unlike the Internet.

Health information strategy project

The project to develop a health information strategy was initiated in August 1995. Because of the significance of health and disability information, the project was one of eight key result areas (KRAs) to be addressed as part of the Ministry of Health's 1995/96 work programme. The project aimed to achieve a consensus on the future co-ordinated management of health information by the sector. It was also seen as timely to review the previous health information strategy, developed in 1991, three years after its initial implementation alongside the health reforms.

The goals of the project, which were supported by the publication of a more detailed strategic direction for the sector in late 1995, suggested a consumer-focused approach to health and disability information management emphasising flexibility, choice, self-determination as well as continuity and integrity of care across all providers. It is clear that there is a need for more and better information to support the ongoing improvement in the health status of all New Zealanders, and to obtain the best quality healthcare for the dollars available.

The resulting strategy would need to be relevant to the whole of the health and disability sector. All users of health information, including funders, purchasers, providers, consumers, as well as researchers and others, would need to benefit from the strategy. It would also need to be equally applicable to large and small providers, whether they are public, private or voluntary organisations, and irrespective of whether the systems used were manual or automated. Furthermore, the strategy would need to be facilitative, rather than prescriptive, and help the sector form the kinds of collaborative relationships needed for effective, consumer-focused health information management.

It was also recognised that the use of personally identifying health and disability information would need to be within the context of strong protection of privacy and confidentiality.

Issues

The first phase of the project involved a stocktake of the current position. This work identified a number of areas of concern to the sector, including the fragmented nature of many initiatives and health information systems, the lack of agreed standards and definitions in many areas, and the lack of agreement about access to information by a variety of other parties. Concern was also expressed about the protection of privacy, particularly with increasingly sophisticated use of technology.

Further work indicated the need to consider developments within the sector, particularly the interest being shown in managed care, and the need for better integration between primary and secondary care, an issue that has also been identified in the "Green and White Paper" *Your Health and the Public Health* which heralded the health reforms in 1991. It was apparent from the stocktake survey that levels of system integration within the sector were low, and the barriers to more appropriate access to information to support co-ordinated and seamless care high.

It was also apparent that a stronger health information emphasis on preventive care and on health promotion was necessary. The need for a consumer focus on these issues was also identified, supported by the development of the *Code of Rights for Consumers of Health and Disability Services*.

An analysis of these issues led to the publication in April 1996 of a *Gaps, Overlaps and Issues* report which looked at the issues affecting health information management in the sector, and which were likely to need to be addressed by the strategy.

Operational issues of particular significance that were identified included:

- privacy, confidentiality and security
- ownership of medical records and health information

- costs associated with information collection and provision
- availability of and access to health information
- storage and retrieval of health information
- information quality
- standardisation
- classification and coding.

The *Gaps, Overlaps and Issues* report also put forward a number of suggested steps for change. These included:

- *Rewards* – identifying appropriate financial incentives and disincentives
- *Legislation* – reviewing the current legislative framework and identifying opportunities to promote changes consistent with the strategy
- *Consumer empowerment* – examining ways in which consumers are able to access appropriate information which enables them to make informed choices and empowers them to play a greater role in decisions relating to their use of healthcare services
- *Infrastructure* – encouraging adoption of appropriate standards, guidelines and measures
- *Education* – promoting educational and research initiatives which reflect an understanding of health and disability services information management issues
- *Tools* – developing appropriate casemix and other tools for understanding health and disability sector outputs.

At the same time as the *Gaps, Overlaps and Issues* report was being prepared, the various working groups that had been established to provide input from the different perspectives of funders, purchasers, providers, education and research, and information technology, provided reports on the issues and suggested mechanisms to bring about changes. To a large extent there was agreement about the issues faced, and a degree of consensus about the approaches available to deal with them.

In recognition of the significance that providing health information has for the consumer, the Ministry of Health also facilitated the establishment of a consumer health information focus group. This group provided a number of recommendations, which are currently being pursued in parallel to the health information strategy. Some of the issues identified by the focus group are included in this report to provide balance to the general emphasis on health information arising from the interaction between a healthcare or disability services provider and consumers.

In summary, this phase of the project identified and agreed a number of issues that the strategy must address, as well as some mechanisms for doing so. It was recognised that it is inherently difficult to deal with complex information issues within a devolved health and disability sector, particularly where the systems, tools, skills and understanding are sometimes not as developed or comprehensive as they could and should be.

Strategic vision

The next phase of the project was to identify an appropriate vision for the future of health and disability information management, and from that to identify appropriate strategic building blocks.

The health and disability information strategy is seen as being primarily facilitative, rather than prescriptive. Its success will depend to a large extent on the willingness of individuals and organisations to subscribe to its general aims, and implement its specifics. Therefore the vision proposed for information management in the year 2000 is:

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

The primary purpose of health and disability support services information is to support individual consumer/patient care and treatment, and to bring about general improvement in health status and outcomes, in a context where people are at the centre of service delivery, and where value for money is recognised. Supporting decision-making by both providers and patients and fostering patient self-determination are priorities.

Context

The current health and disability sector is characterised by a large number of separate service organisations (eg, primary, secondary, tertiary, and community care providers) who are commercially separate but functionally dependent in providing an integrated service to individuals. Care is provided within an overall framework largely determined by funders and purchasers, who have a duty to meet the health needs of their community with services of the best possible quality and fitness for purpose.

Without agreement on how individual organisations relate and communicate, the current devolved approach could lead to fragmentation. Collaboration and integration will avoid this, and will provide appropriate access to seamless or co-ordinated care. Effective, fast and efficient communication between providers and others in the sector is important to achieving continuity, integrity and co-ordination of preventive, screening and curative care, and this is where the strategy is seen as essential.

The emphasis of the strategy is not on technology *per se*, but on building a conceptual understanding of how to achieve effective management of information, and on the information requirements and standards that must underpin this, no matter the scale of the service provider or the level of computerisation.

A key issue for the success of the strategy is the need to engage and involve the whole of the health and disability sector in the implementation and ongoing maintenance and development of the direction. This is essential in order to maximise the potential benefits of the approach suggested.

The building blocks envisaged by the strategy are:

- ensure leadership is provided on health and disability information issues
- greater certainty about the future directions for the development of health information management, about the infrastructure and functionality likely to be required
- a strong and relevant legislative framework
- an appropriate conceptual technical framework
- use of appropriate standards, guidelines and measures creating a relatively stable information infrastructure
- agreement about who can access what information, and under what conditions
- development of information management and technology skills in the sector
- involvement of health and disability professionals in the development and implementation of appropriate systems
- an evolutionary and incremental approach which builds on what is already available and preserves the investment in legacy systems, where necessary
- health and disability information systems that are seen as enabling, and build trust and confidence
- appropriate technology assessment guidelines, as well as strategic planning, development and methodologies developed to support smaller providers
- ongoing support for the infrastructure
- development of co-ordinated access to reliable consumer health information
- a framework for continued improvements to the accuracy, coverage, relevance, and timeliness of health and disability information
- support for exemplars and demonstration projects, and foster research which demonstrates an understanding of health information management issues.

Implementation

Part three of the report deals with implementation of the strategy. The strategy provides a framework for the ongoing development and maintenance of a sectorwide approach to health information management. This means that implementation will evolve over time, and changes in direction and emphasis in both the purchase and delivery of health and disability support services are inevitable as experience develops, as evidence relating to outcomes grows, and as new demands emerge and new response options are developed. The strategy is designed to anticipate and respond to this process of sector development, and ensure that information becomes recognised as a valuable asset.

The strategy recognises the dynamic nature of the sector by encompassing a two-phased implementation process. In the first phase, which will extend over the first 12 months, the priority areas will be addressed. These include:

- completion of a high-level integrated data model from a patient-focused approach
- development of an accompanying set of standard data definitions
- review of access agreements and arrangements to protect and reinforce the security, integrity, availability and confidentiality of data, including data encryption
- review of technical standards and provisions for personal authentication
- agreements about data exchange protocols and formats and arrangement relating to the electronic transmission of data
- review and adjustment of core information requirements needed to enable the monitoring of purchase and service delivery policies and to meet local, regional and international reporting obligations.

Once these priority areas have been addressed there will be a continuing process to maintain and develop the strategy. This will require mechanisms to provide focus, and to ensure agreement on various standards and protocols.

It is proposed that two separate bodies will guide, monitor and oversee these developments. A Health Information Council will provide leadership and focus, while a reconstituted Health Information Advisory Board will continue to act as the authority for standards, data definitions and quality.

The role of the Ministry of Health will be central to the implementation of the strategy. One of its primary roles will be to provide advice on the intended direction of new policy initiatives with sufficient notice to enable the information management implications to be identified and addressed.

The Ministry will retain a significant role, directly or indirectly, in identifying the range of information which should be made available nationally to promote the development of health and disability support services options, and to contribute to international benchmarking of the performance of the sector. The Ministry will also act as the facilitator and will adopt a leadership role in carrying forward the proposed developments.

Funding the development

The Ministry of Health will directly fund the activities of the Health Information Council. Once the various component parts of the strategy have been identified, the sharing of implementation costs will be a matter for the sector to resolve. It is anticipated that to a large extent this could be achieved through efficiency gains in current health information management, or through re-prioritising a small proportion of the existing expenditure on health information management, thought to total over $200 million per annum.

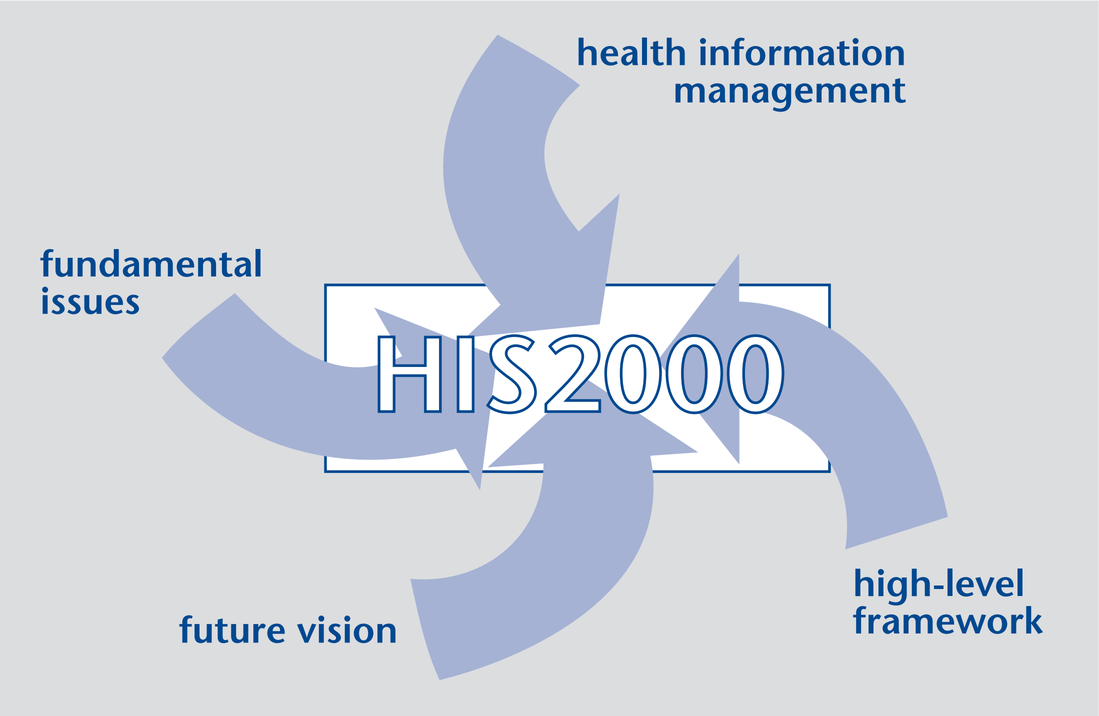
As a general preference, the strategy is predicated on the belief that the cost/benefit ratio relating to each area of proposed activity should be sufficiently attractive to elicit a level of commercial interest and/or to generate its own funding through savings achieved without recourse to other start-up funding arrangements.

The strategy is designed to deliver the framework necessary for this to happen, particularly in the area of co-ordination, fostering collaborative relationships, and developing and/or adopting appropriate standards, guidelines and protocols.

Vision for the future

The final part of the report provides a description of what the implementation of the strategy may mean. It is based on widely used standards and technologies to facilitate communication between various systems and people who interact, or need to interact, within the sector. This concept has the chance to evolve through the judicious selection of appropriate technical and other standards, many of which will be based on the de facto standards and environment established through the Internet and World-Wide Web (WWW). The system would capitalise on the investment already made by the health and disability sector, and by other sectors, to facilitate the bringing together a large number of currently fragmented components in a way which is relatively low cost. Overall, the aim of the system would be to support the vision articulated for the strategy as a whole.

HEALTH INFORMATION STRATEGY



Conclusion

The development of the *Health Information Strategy for the Year 2000* has seen many people in the sector willingly participate and contribute. While the strategy does not necessarily represent any individual views, it does represent a broad consensus of those views about the future of health information management.

The process has identified a wide range of information needs as well as a large number of perceived obstacles and concerns. Health information systems and services must expand to meet these needs, and an outline is presented of how it is planned that this should be done and how the expanded systems will bring benefits to the stakeholders.

It has been encouraging to note the level of involvement of a wide range of people in this process, and their willingness to tackle the difficult issues. The continuation of this willing participation will be necessary to ensure that the strategy is successful as it tackles the challenges which lie ahead.

Part 1: Background to Developing the Strategy

Scope of the strategy

The *Health Information Strategy for the Year 2000* includes disability information and is intended to have a very broad scope. It is a plan which has been designed to be relevant to all parties in the health and disability sector, regardless of whether they are public, private or voluntary, funders, purchasers, providers, or researchers, whether they are large or small organisations, and irrespective of their degree of computerisation, either now or in the future. Some of it will also be relevant to the technology and education sectors. Above all, it also needs to be relevant to consumers, and cognisant of their needs.

The other key consideration for the strategy is its relevance over time and sustainability. The strategy is for the year 2000, but it must be relevant for the next five years or more, irrespective of future changes to the way in which services are purchased or delivered.

What is health information?

At its broadest, health information covered by the strategy includes health and disability information derived from the following:

- routine sources, such as those related to clinical events (eg, hospital discharges), including information about service quality and episode of care outcomes
- special and non-routine sources of information on health status and epidemiology, including research, national and regional health and disability surveys, census data and specialised monitoring
- library and literature resources on health and disability, and especially published material constituting evidence for and against the use of specific approaches or services in the context of identified problems or conditions.

A time of change for the sector

The role of information management in the New Zealand health and disability sector, including the associated operational policies and processes, is in a constant state of change as it adapts to emerging demands from users, consumers and patients. New forms of intervention, new technologies and changes in consumer expectations all act as catalysts for this ongoing process.

In spite of this continuing process of review and modification, it is appropriate to occasionally step back and take a more in-depth look at where the existing policies and emerging changes are leading and to ascertain whether this direction is consistent with the wider goals of the sector. To do otherwise runs the risk that the very platform for the incremental changes may itself be inappropriate and require modification to achieve those goals.

1991 health information strategy

The most recent comprehensive review of information management in the New Zealand health sector was concluded in 1991. The result was a policy framework for achieving a consistent approach to the development and maintenance of a number of nation-wide services and facilities and a mechanism for maintaining the currency and relevance of those decisions.

Since the development of the original strategy there have been many significant changes made or foreshadowed for the future of health and disability service information management. These include the emergence of comprehensive or managed care as way of purchasing services, the addition of the Accident Compensation Insurance and Rehabilitation Corporation (ACC) to the range of health purchaser agencies, the clear shift to a patient or client focus, greater integrity of care across various organisations, the development of telemedicine and the push for paperless offices.

At the same time there has been a continuing drive for improvements in the quality and cost-effectiveness of health and disability support services, to which information management is poised to make a major contribution. These emerging priorities run in parallel with an increasingly stable and mature sector where purchasers are developing a much clearer view of what they can and should be able to achieve and when.

Strategic view for the sector

Late in 1995 the Minister of Health, the Hon Jenny Shipley, published *Advancing Health in New Zealand*[1], which set out the context for changes in the health and disability sector over the next 10 years. The document also articulated some of the new themes and messages culminating from policy and service development in the preceding three years. This document, together with the “Green and White Paper” *Your Health and the Public Health* published by Hon Simon Upton in 1991, provides the overarching strategic framework for development of the health and disability sector.

Advancing Health in New Zealand outlines three key goals that are also central to an information strategy. These are:

Goal 1: To improve the health of people in New Zealand

Information will not only be fundamental to achieving this goal, but it will also be needed to measure its achievement. Appropriate specific information will be required to identify population groups that have lower health or continuity of care status, set targets, and develop and agree suitable measures.

Goal 2: To put people at the centre of service delivery

The information strategy project recognised early in the process the need for a view of information that was consumer/patient focused. This reflects a fundamental shift

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[1] Minister of Health (1995): *Advancing Health in New Zealand*, Wellington: Ministry of Health.

that is already happening internationally, and has a profound impact on information requirements, particularly the need for integration, standards, and a high level of co-operation between providers. To achieve this goal, importance must be placed on the protection of consumers' rights and the appropriate protection of privacy.

Goal 3: To get the greatest amount of health and disability support services for the dollars available

Good health and disability information will be fundamental to achieving this goal, especially in areas such as research, purchasing strategies and the development of best-practice guidelines, and will also be needed to measure whether this goal is being achieved.

Time to update the 1991 strategy

In early 1995 it became apparent that the shifts in emphasis and direction that were being discussed on both a formal and informal basis throughout the sector were potentially so significant that it was timely to again review the information strategy so as to ensure it could continue to support the sector throughout the remainder of the decade.

Such a review was considered to be fundamental to the progress on those other possible initiatives. In recognition of that important position it was classed as a *key result area* (KRA) for the Ministry of Health. This meant that it was to be regarded as one of the eight priority issues to be addressed in the 1995/96 work programme.

The terms of reference for the project outlined the following goal for the strategy:

> To co-ordinate national, regional and local health information initiatives and activities in the context of an overall strategic direction for the health and disability sector that promotes the ready availability of and access to health information to support the continuity and integrity of healthcare services to consumers across the sector.

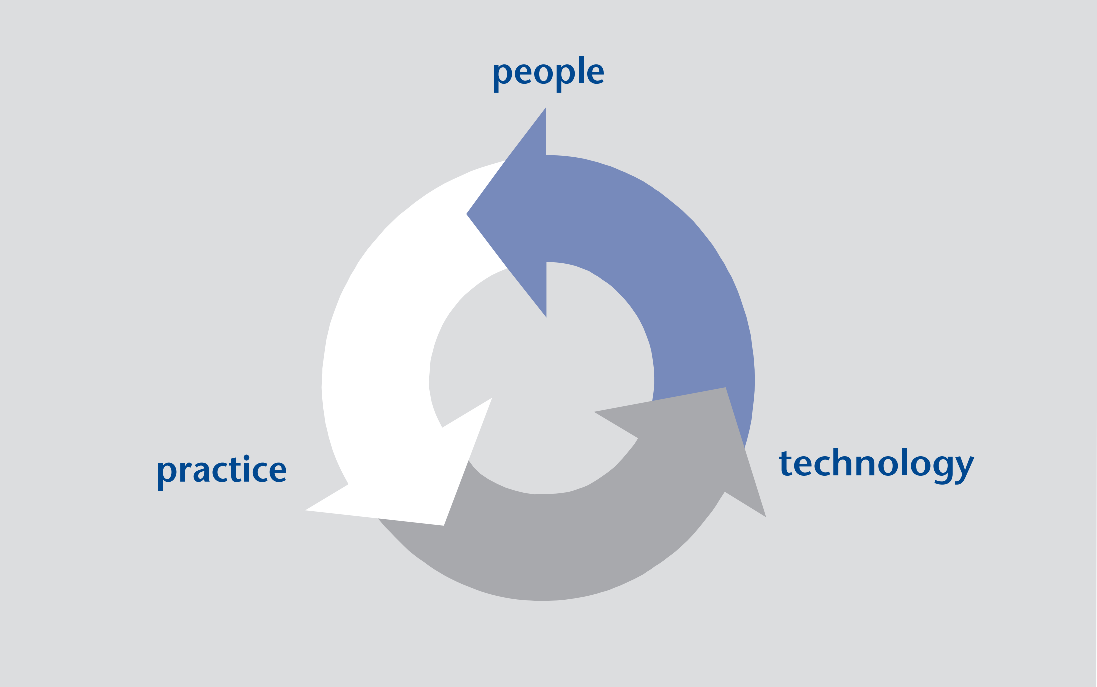
The terms of reference for the project also emphasised the importance of ensuring the widest possible participation in, and ownership of, the resultant strategic framework, standards and guidelines. The aim was to achieve a consensus to which all would want to subscribe because they understood and supported the outcome resulting from their participation.

The strategy does not cover issues such as the current structure of the sector or the funding mechanisms, nor is it intended to comment on the organisational structure of any of the organisations. These matters are outside the scope of the terms of reference for the project.

To obtain input in the development of the strategy, a number of working groups were established. These covered the perspectives of funders, providers, information technology, education and research. A focus group to look at issues relating to consumer health information was also convened.

The KRA project was initiated in October 1995 and was concluded on 30 June 1996. However, after this date mechanisms are being established to maintain, refine and further develop the strategy for information management in the sector.

SOLUTION



Phase one of the review

The first phase of the project was a stocktake to ascertain the issues and opportunities as identified by those involved in the delivery and use of health and disability support services. The results of this initial exercise were the subject of the first report published in December 1995[2]. Information from the stocktake survey was augmented by material drawn from equivalent sectors overseas, and from the experience and views of those involved in the management of the current service.

Stocktake report

In November 1995 a stocktake survey was undertaken to establish the high level requirements relating to information which needed to be reflected in the subsequent delivery of a strategic framework for the management of health and disability information. It was by no means a comprehensive review of the issues, nor a detailed inventory of different parties' information requirements, but sought to establish a starting point by reviewing:

- the current situation with the development of health and disability information systems in New Zealand
- where the various organisations and individuals surveyed expected development to occur
- what some of the barriers to this development were perceived to be.

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[2] New Zealand Health Information Service (1995): *Health Information Strategy for the Year 2000: Stocktake of Current Position and Future Plans*, Wellington: Ministry of Health.

The results of the stocktake questionnaire conveyed a number of very positive messages, while at the same time reinforcing the need for a strategic framework to be agreed and implemented. There was strong endorsement for the concept of consumer/patient-focused care. Most respondents believed that health and disability information should be readily accessible for all authorised users. They also indicated that they thought information should be captured once only, with automatic update of linked records. Therefore, the developing role of information technology in the support of clinical service provision was rated the most significant development likely to affect providers and patients over the next five years.

While in conceptual terms the future direction appeared relatively clear, the sense of direction was not matched by the reality of the respondents' indicated plans for information technology development. Few identified a firm commitment to initiatives that would lead to the electronic sharing of information, and the situation changed little when the numbers planning to explore such options were included. By contrast, perceived impediments such as cost, securing third party co-operation, and data security and confidentiality issues were readily identified as reasons for not proceeding.

In summary, the responses indicated that the sector was looking for leadership, that the focus for information management was on business management, rather than the support of consumer or patient-focused service delivery, and that the development and implementation of any strategy was likely to be time consuming and involve significant investment in skill enhancement and technology. Equally, it was probable that in the absence of such leadership the true potential of information-related initiatives to contribute fully to the delivery of high-quality cost-effective health and disability support services would not be realised.

Follow-up interviews

As part of the stocktake questionnaire, respondents were asked if they would be willing to discuss the planning assumptions used in developing their information systems strategy with a representative of the project team. A sample of those who indicated a willingness to participate were asked a further set of focused questions in February 1996.

The follow-up questions indicated that there was a wide range of views about what "strategic" meant, from a relatively narrow focus to a much broader "blue skies" approach.

All organisations participating in this phase listed a range of impediments to the development of the strategy, with few enablers. For most, it was too early for them to determine "what had worked and what had failed", and too early for post-implementation review. Many had projects that had yet to be completed.

All organisations interviewed used some form of user needs recognition as part of their strategic development. However, it was also clear that many did not use a formal methodology for the development of their strategic information systems plans and, in some cases, the process was led by an influential individual. As with the stocktake survey itself, the follow-up interviews found, in many cases, the organisation's strategic information systems plan reflected immediate needs, often based on the historical situation and technology legacies, rather than being firmly based on a clear vision of future direction.

Phase two of the review

Following the analysis of the stocktake findings, the project team sought to further refine the key issues which would need to be addressed in the strategy. A consultative process was used which endeavoured to maximise the opportunity for contributions from the sector. This process was complemented by information from information management advisers active in the health and disability sector, information on comparable overseas experience and literature sources. The result was a report released to the sector in April 1996[3].

Gaps, Overlaps and Issues report

The *Gaps, Overlaps and Issues* report covered the issues, gaps and overlaps that had been identified by various working groups and the project team. This report identified a number of generic requirements for health information from the points of view of different perspectives of stakeholder interests.

Consumer information

Consumers need information about health and disability support services, who these services are available from, when, where and with what audited quality and outcomes. In the context of a specific health issue, they need to know what the problem is, what investigation and treatment options there are, what are the recommended best practices and protocols (where they exist), and what the risks and benefits of each option are.

Individuals also need access to materials that can help them play a more active role in their own health maintenance and care, including general health knowledge, information about the rights they have, and what to expect from providers and others in the health and disability sector.

An analysis of the issues regarding consumer health information is available in the reports “Providing Consumer Health Information: Key Issues” and “Providing Consumer Health Information: Recommendations” which are both accessible via the Ministry of Health’s WWW home page <http://www.health.govt.nz>.

Provider information

Providers need information about best-care practices, guidelines and protocols and information to better manage relationships with their clients, including knowing where to go for consumer health information. Providers will need information to help them manage their own business better, including information about their own and other’s performance, and will need to review and audit their own

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[3] New Zealand Health Information Service (1996): *Health Information Strategy 2000: Gaps, Overlaps and Issues Report*, Wellington: Ministry of Health.

performance on an ongoing basis. Better data will be required by purchasers and other quality standards bodies for audit and to support bids for contracts based on their past performance, experience, demonstrated skills and expertise.

Purchaser information

Purchasers need information to manage relationships with their clients, providers, and funders.

They will need, in conjunction with their contracted providers, and within the context of national policies, to develop recommended care guidelines and protocols, and best quality practices, based on data gathered from many care encounters, and reviewed continuously in the light of new research, both local and overseas. They need to be able to assure their clients of the best possible health and disability support services, to eliminate waste and to adopt the most effective and efficient methods for preserving their health and well-being.

Purchasers need to know which clients they are responsible for, and will need to interact with their clients (either directly or through third parties) in order to achieve the best possible health risk reduction, status and illness outcomes for them.

A more detailed analysis of purchasers' information requirements can be found in "Information for Informed Purchasing: Key Issues" which is accessible via the Ministry of Health's WWW home page <http://www.health.govt.nz>.

Funder information

Funders need to maintain oversight of the health and disability sector in order to ensure gaps in services are identified and addressed. They should also monitor performance against appropriate benchmark indicators, such as care costs and outcomes, with particular reference to data derived from similar overseas environments. Funders need to be able to take measures of the health of the nation, to make decisions on how best to deploy funds in order to achieve health gains and benefits, and to take early and effective action to manage emergent problems and epidemics.

The full analysis of Funders' information requirements is contained in the report entitled "Strategic Issues Affecting Information: Supplementary Report from the Funders' Working Group for the Health Information KRA", also available from the Ministry's WWW server.

Issues to be addressed

The *Gaps, Overlaps and Issues* report identified or confirmed a number of operational issues needing to be addressed by the strategy. These included:

- overriding concerns about privacy, confidentiality and security
- issues relating to the ownership of medical records, and access to them
- costs associated with information collection and provision and how these would be managed equitably, especially when information was being transferred from one provider to another

- availability of and access to health information
- formats for storage of health information and issues surrounding retrieval of it
- the need for monitoring and improvement of information quality
- the need for standardisation, and for adherence to standards that have been adopted
- the need for a unified, flexible and user-friendly approach to the classification and coding of health data.

Challenges to improved information management

A number of challenges to improved information management were also identified in the *Gaps, Overlaps and Issues* report. These included environmental and infrastructure issues, information gaps, timeframe, potential funding and legislative issues, gaps in the current education and research area, and workplace and change management issues. Some of the more important challenges noted were:

- lack of "big picture" vision
- no generally endorsed plan for moving forward
- uncertainty caused by the rapid rate of change associated with the health reforms
- lack of clearly defined roles and responsibilities
- lack of appropriate technology and guidance for choosing best available technology
- difficulty in making use of communications in everyday practice
- lack of integration within organisations and between organisations
- lack of information resources to support changes
- differences of opinion about what information should be, or can be, shared
- lack of comprehensive coverage
- lack of quality assurance of data collected
- little agreement on standards and classifications
- inadequate specific performance measures and indicators for outcomes
- limited up-to-date information about providers and services
- short-term view of investments in health and information
- legislation lagging behind current practice in areas such as electronic signatures, assignment of professional responsibility, accreditation of non-locally registered health professionals
- uncertainty about "ownership" and rights of access to medical records
- few relevant initiatives in the education and research area
- lack of medical informatics skills and training

- lack of use of information technology by clinicians and healthcare professionals in general
- lack of commitment to change in some areas
- lack of understanding about the appropriate application of information technology in healthcare
- lack of funding for technological change
- genuine concerns about confidentiality
- lack of demonstration projects to show what information technology can achieve.

Steps forward for change

A number of suggestions for the successful implementation of the health information strategy were identified in the *Gaps Overlaps and Issues* report. These included:

- looking at options for funders and purchasers to promote specific directions by using financial incentives and disincentives
- investigating the current legal framework and identifying opportunities to promote changes to policies and procedures that are consistent with the strategy
- examining ways in which consumers are able to access information which enables them to make choices and exercise rights appropriately
- investigating opportunities to encourage providers to subscribe to appropriate standards (eg, outcome measures), and to publish information about their compliance with such standards
- developing mechanisms to encourage the use of appropriate information management processes and technology by providers
- looking at ways to ensure compliance with the strategy by Crown-owned agencies;
- promoting educational and research initiatives that reflect an understanding of health and disability support services information management issues
- developing appropriate casemix and other tools for understanding health and disability sector outputs.

Issues identified by the working groups

In parallel with the development of the *Gaps, Overlaps and Issues* report, a number of working groups were established to obtain input about the issues to be addressed and recommendations on likely key features of the information strategy, from the perspective of the interests that they represented. Comprehensive reports were provided by the Funder, Purchaser, and Education and Research Working Groups, and from the Consumer Health Information Focus Group. Less formal input was obtained from the Provider and the Information Technology Working Groups. The various reports can be found on the Ministry of Health's WWW home page at <http://www.health.govt.nz>.

While several of these groups identified the same or similar issues, there was also some divergence of opinion, depending on the perspective of the group.

Nearly all of the groups saw the need for accessible information and the need for common data definitions, standards and agreed protocols. A number of current information gaps were also commonly identified, particularly in the areas of primary care, community-based services and consumer information. However, approaches suggested to resolve these issues were sometimes different, particularly when it came to discussing the current and prospective roles of the various agencies, including funders and purchasers, in information management activities at both the policy and operational level.

Further input, perspectives on the issues, and insights were obtained in discussions with recognised experts in the field of health informatics, information management, and information technology, both locally and internationally.

Issues identified by the Consumer Health Information Focus Group

The initial report of the Consumer Health Information Focus Group identified the following key issues:

- the need to impress on everyone involved in the provision of health and disability support services that satisfactory access to consumer health information can improve health, save money, and is a basic right
- uncertainty and hence concern about the quality and consistency of consumer health information, and the services which provide it
- the need to put together a picture of the extent to which consumer health information is already being provided to the New Zealand public, and how effectively it is being provided, as a precursor to any further action
- the difficulty which the average health consumer faces when trying to obtain reliable information from a vast range and number of sources in many different places
- the impact of new ways of creating, disseminating and retrieving information and access to consumer information over the next five years
- the need to set realistic and achievable goals for improving access to consumer information, including how this might be funded.

Issues identified by the Education and Research Working Group

The Education and Research Working Group produced a discussion paper in April 1996. This paper focused on issues the Group believed needed to be addressed by the strategy. These included:

- the need to establish a set of mechanisms and procedures designed to provide, at the national level, information required for policy development, planning, management and evaluation of health and disability support services, that is readily available to consumers, policy makers, purchasers and providers

- the importance of the concept of a national minimum dataset (including demographic information on the population as well as health status, resource and services utilisation, and outcomes)
- the integration of information from a variety of sources (both routine and non-routine) in order to provide ready access to comprehensive information for consumers, providers, purchasers, and policy makers.

Areas for policy development and operational guidelines identified by the Group included the following suggestions:

- Formulate and implement a national information policy, including national datasets, data definitions, standards for data quality, privacy and confidentiality, priorities for new information sets, and the respective roles of each agency with respect to provision of data.
- Identify, organise and co-ordinate all relevant data sources, having regard to the needs of users of information derived from such data.
- Establish national datasets which bring together all relevant data and which are accessible, timely and relevant to all users of information.
- Provide guidelines for regional health authorities (RHAs), Crown health enterprises (CHEs), independant practioner associations (IPAs) and other service providers on the development of regional and local information systems policies, regional or local databases, and standards for technological development, and training of staff.
- Advise and assist in the undertaking of surveys and other activities needed to develop new information sets.
- Promote the wide use of the National Health Index (NHI) as a national resource, vital for the aggregation of information from various sources within the health and disability sector.
- Decentralise data management to the operational or service level to ensure user involvement and data entry compliance, checking quality control and utilisation.
- Formulate and implement a national research and development strategy, to ensure that health research resources are, as far as possible, targeted to achieve health gains.

Features identified by the Purchaser Working Group

The Purchaser Working Group, consisting of the four RHAs and the ACC, proposed that the following features be incorporated in any sectorwide strategy for information management:

- development of a national information resource
- standard data definitions
- standards for information and information exchange
- establishment of a national provider index
- focus on cost/benefit.

The emphasis of the recommendations of the Purchaser Working Group is on the establishment of an appropriate conceptual framework within which the strategy should be developed.

The Purchaser Working Group was unanimous in endorsing the following:

- common data definitions for the collection and interchange of health-related information
- use of the NHI as the common unique identifier, and the use of the NHI instead of personally identifying information such as name and address when recording or exchanging health information
- establishment of a unique provider identifier
- inclusion of Community Service Card (CSC) information as part of the NHI
- progressive replacement of all non-electronic information exchanges with electronic equivalents.

Issues identified by the Funder Working Group

The initial Funder Working Group report identified a number of information related issues and gaps, mainly from the point of view of the Ministry of Health. A second report was completed after consultation with the Department of Labour, Treasury, the Department of Prime Minister and Cabinet, Statistics New Zealand and the Ministry of Education.

The main information issues identified included:

- the need for common data definitions
- a requirement to be able to obtain information relating to health and disability support services provided by the private sector
- the need for improved timeliness of data collection and provision
- the ability to obtain cost information at a disaggregate level, so that policies targeting specific demographic, diagnostic or treatment groups can be costed
- better linkages between various data collections.

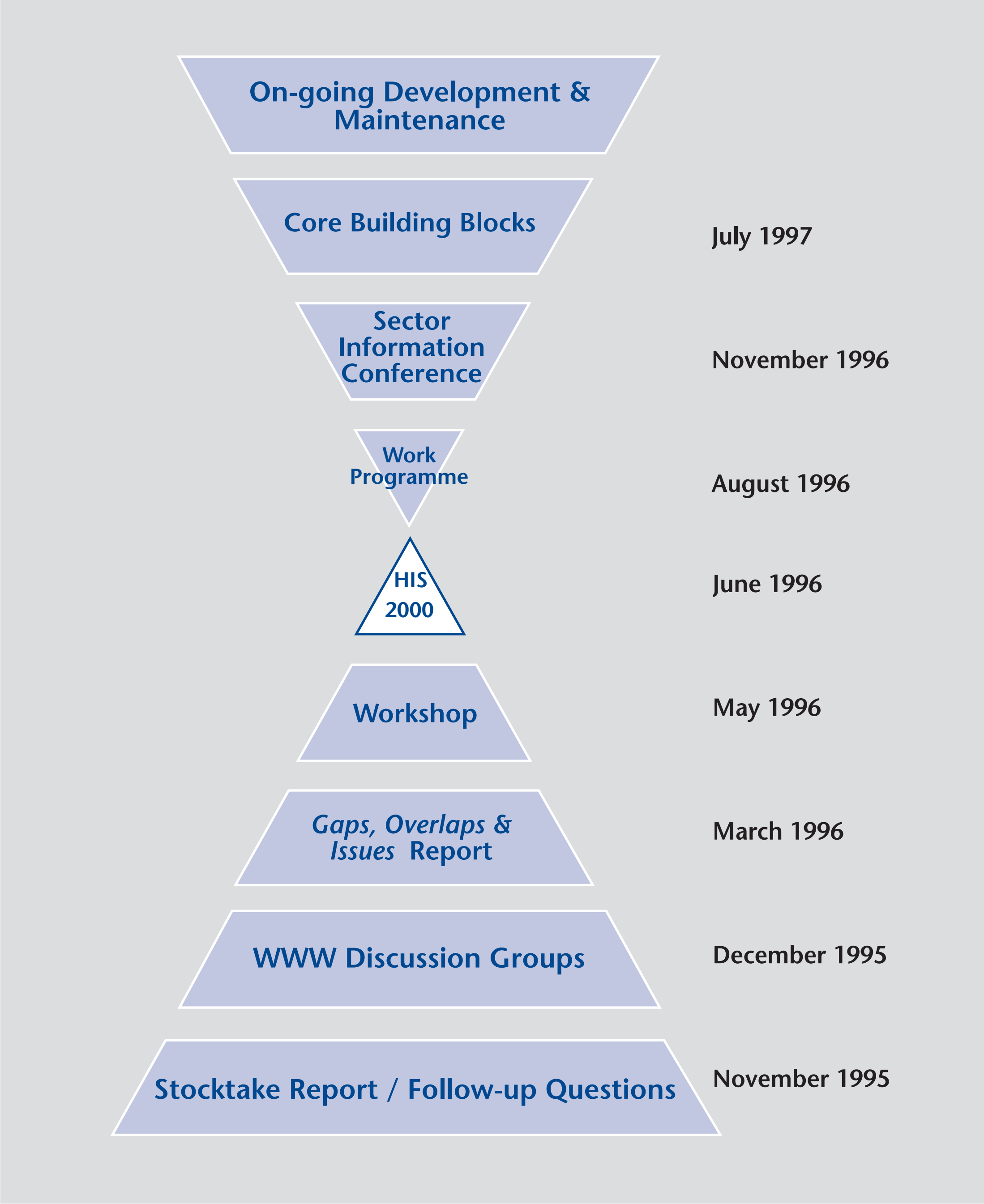
An analysis of current information gaps identified the following areas where consistent or comprehensive information is lacking or deficient:

- information about primary healthcare service volumes and reasons for attendance
- information about the population with disabilities, and the disability support services being provided and used
- information on the provision and utilisation of community mental health services
- cost information on secondary and tertiary-level health services
- information on ambulatory healthcare
- specific information to assist with unbundling accident related and other health and disability service costs.

Future challenges to information management were identified in the following areas:

- the development and implementation of managed care and co-ordinated care environments
- greater focus on outcome monitoring and outcome-related purchasing
- greater use of technology for medical care, information collection and communication
- increasing use of community care and mixed service delivery settings.

HIS 2000 DEVELOPMENT



Other issues to be addressed

Dealing with complexity

The health and disability sector in New Zealand is relatively devolved, with purchasing contracts being the main mechanisms to drive sector wide change at the provider level. Currently much of the information that is needed for this process is unavailable in the form needed, or at the time that it would have the greatest impact. This is in part because of gaps in the conceptual understanding of service delivery, which in this sector is a very complex business spanning what has been an extensive range of relatively autonomous functional areas. But it is also due to a lack of reliable information about outcomes, effectiveness and actual costs on which improvements can be based. Because of this lack of empirical data, the tools for dealing with this complexity, and understanding what happens and why, are deficient. New Zealand is not alone in this: it is an international problem.

The major aim of the *Health Information Strategy for the Year 2000* will be to ensure that health information drives, enables and facilitates sector changes that meet the overall strategic objectives of the Government, rather than the currently perceived lack of information impeding desirable change and innovation.

Improving health information management skills

Expertise in health information management and systems is limited. Currently few health and disability sector personnel have the knowledge and skills to understand the issues or to make informed judgements about the validity of the advice they obtain. The absence of knowledgeable users of health information is a potentially serious drawback to the implementation of any future plans and will need to be addressed by a process of education and in-service training, and making use of distance learning technology.

Part 2: Strategic Building Blocks

Introduction

The consultation undertaken through this project indicates that there is general agreement about the range and nature of the issues the strategy must address. In the preceding section, a vision for future information management within the health and disability sector has been formulated. In order to support it, a number of specific building blocks and approaches have been identified. This section deals with these aspects of the strategy.

Strategic vision

The *Health Information Strategy for the Year 2000* is seen as being primarily facilitative, rather than prescriptive. Its success will depend to a large extent on the willingness of individuals and organisations to subscribe to its general aims, and implement its specifics. Because of this, the vision proposed for information management for the year 2000 is:

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

It should also be clearly understood that the primary purpose of health and disability information is to support individual consumer/patient care and treatment, and to bring about general improvement in outcomes, in a context where people are at the centre of service delivery, and where value for money is recognised. This follows from the strategic goals articulated in *Advancing Health in New Zealand*.

Context for the strategy

The strategy must be consistent with the context within which it must operate. The current health and disability sector is characterised by a large number of structurally separate service organisations (eg, primary, secondary, tertiary, and community care providers) who are functionally interdependent in providing an integrated health and disability support service to individuals. Care is provided within an overall framework where the patterns of care services delivered are largely determined by funders and purchasers, who have a duty to meet the needs of the populations they represent in the most effective and efficient ways possible.

Without agreement on how individual organisations relate and communicate, the current devolved approach could lead to fragmentation. Collaboration and integration is needed to avoid this, and to provide appropriate access to “seamless” or co-ordinated care. Communication between providers and with others in the sector is also important to achieving co-ordinated care, and this is where the strategy will be critical.

The context is complicated by the fact that funding is unlikely ever to be enough to meet all the demands for services, particularly as new technologies make possible interventions which were previously impossible. Consumer expectations will continue to rise, and an ageing population is likely to continue to put pressure on resources. Limiting supply of services is an unsatisfactory approach to the issue, although elimination of services that are either not appropriate or not effective will help.

While the sector's continuing research into improved methods of caring for patients has clear benefits in expanding the effectiveness of interventions available, mechanisms for evaluating relative effectiveness need to be robust, and potential risks need to be clearly identified. All of these requirements are dependent on robust and timely information.

The solution to the potential imbalance between supply and demand for services lies in addressing the demand side of the equation, giving consumers better information about costs, risks and benefits of health and disability support services, encouraging them to take better care of their own health, promoting healthy lifestyles, proactively addressing issues of health risk reduction, and so on. Where access to health and disability support services must be prioritised because of resource constraints, priorities have to be established transparently and consistently. This process will need to balance clinical and social criteria against the resources available, as well as the needs of individuals. Again, good information is key to the process.

In summary, the health and disability sector represents a complex set of interactions amongst individual consumers and different providers and other organisations. Excellence in communications will improve the service able to be offered to consumers, and assist in demonstrating that co-ordinated care, and continuity of care, can be provided.

Information is central to understanding the complexity of the provision of health and disability support services and minimising risk, uncertainty and anxiety.

Strategy relevance

This strategy is presented at a conceptual level which is intended to be equally relevant to the private sector as it is to the public sector. Whether the consumer pays for services directly or via the tax system should make no difference to the need for a sector wide agreed approach to defining events or sharing information.

The health and disability sector embraces a wide range of service configurations and providers, each of whom is looking at how best to expand their information gathering and adopt appropriate technology. Care is needed to ensure that the information strategy is relevant to both big and small organisations as well as to sole practitioners, to those who make extensive use of technology as well as to those who may not computerise their practices in the foreseeable future. For this reason much of the emphasis of the strategy is not on technology *per se,* but on building a conceptual understanding of how to achieve effective management of information, and on the information requirements and standards that are relevant, no matter the scale of the service provider or the level of computerisation.

A key issue for the success of the *Health Information Strategy for the Year 2000* is the need to engage and involve the whole of the health and disability sector in the implementation, ongoing maintenance and development of the strategy in order to maximise the potential benefits of the approach suggested.

Strategic building blocks

Developing and implementing the strategy will be an ongoing process. This reflects the fact that the sector is engaged in a constant process of refining and developing the contracting for and provision of services. Information management must therefore anticipate and adapt to these new ways of operating if it is to add value to the search for excellence.

Notwithstanding the certainty of a constant state of evolution, there are several areas where current policies and guidelines can be endorsed as relevant for the immediate future or initiatives can be taken to establish a foundation for the future. These areas are termed building blocks and are described in the next part of this section.

Legislative framework

Legislation is required to support and facilitate the secure exchange of information between providers supplying services to an individual. Further work is needed to identify current gaps, and where relevant legislation is perhaps now out-of-date because it does not recognise technological advances (eg, acceptance of electronic records as evidence, acceptance of electronic signatures).

Other issues to be considered include the storage and retention of health information, international data flows, particularly where health and disability support services are provided offshore, or where the privacy of information may be less well or differently protected to the situation that pertains in New Zealand. It may be that patients should be apprised of the issues and be required to give their permission (or not) for the use of offshore services in the knowledge of the nature of the potential risks (eg, loss of control) and benefits (eg, better care).

Mechanisms to ensure the continued protection of personally identifying information, as required by the Health Information Privacy Code, taking into account changes in technology, and altered threats to data integrity and security, must also be included in the infrastructure which is developed to support the strategy.

The legal framework will need to reflect the socio-cultural perspective and the balance of society’s views on issues relating to the management of health information.

Certainty

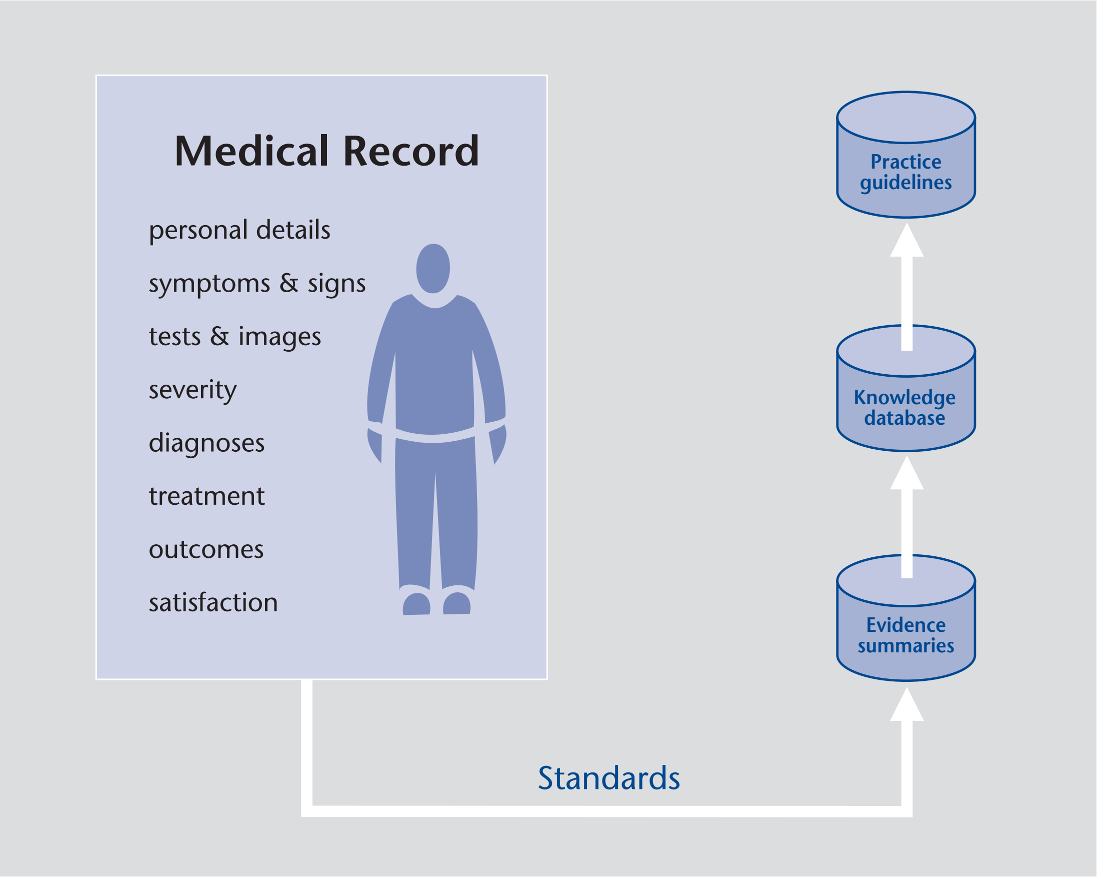
The establishment and maintenance of a relatively stable framework for the management of information will provide a measure of certainty about the future direction and will thereby enable organisations to identify more readily the appropriate information management and technology solutions to meet their business and clinical needs. This will obviate the need to second guess the likely future development priorities, as is the case at present. To be successful the strategy will need to demonstrate a significant degree of foresight and flexibility in order to remain current for five or more years, without the need for major intermittent review, as has historically been the case. In order to remain relevant, the strategic framework will need to be continually monitored and fine tuned, with that process balanced against the need to maintain a level of future certainty for the sector.

Conceptual technical framework

The need to develop a conceptual technical framework, consisting of suitable data models, dictionaries and definitions, is seen as being necessary for the development and maintenance of a consistent approach to information management in the health and disability sector.

Generally, the conceptual model will need to be predicated on a consumer/patient-focused approach. However, the model must take into account the likely requirement to integrate other sources of knowledge, particularly clinical guidelines and protocols, evidence-based medicine and medical knowledge, as well as to place increased emphasis on the measurement of outcomes and the building of a knowledge base about effectiveness and costs of care in different clinical situations. Quality assurance data will be a high priority in the immediate future.

CONCEPTUAL MODEL



Standards

Following from the development of a conceptual framework, the identification and application of appropriate information standards and nomenclatures will help to enable improved access to information, which will assist understanding of services delivery to individuals as well as the public in general. The need for increased levels of standardisation was also consistently identified by participants as an issue. While some work in this area has already been done, the identification or development of many more appropriate standards will be one of the first major challenges for the sector in the implementation of the strategy.

Areas requiring early attention relate to the development of suitable, secure standards for electronic medical records and patient retained records, and for the likely introduction of intermittently connected devices, which may carry summary patient information relating to individuals, indices of past care encounters and the location or reference where an abstract of the care provided can be obtained.

Development of information and technology skills

It is apparent from the work done to date that many organisations and providers are not currently equipped for the tasks ahead, and feel there is lack of access to the required levels of health informatics and information technology skills. The *Health Information Strategy for the Year 2000* offers a vehicle for raising the profile of these issues and supporting and encouraging the development of appropriate courses and materials for developing skills at the training and operational levels. This will involve introducing appropriate course material into undergraduate and diploma courses, developing of in-service and distance education modules, and appropriately recognising the achievements of those who have successfully completed such courses.

Provide appropriate guidelines and methodologies

It is clear that many agencies, especially smaller providers, do not have access to suitable models for the development of their own strategic plans, or for systems development and procurement. The provision of best-practice guidelines or methodologies would be of benefit to these organisations, and also foster a more consistent and professional approach by the sector in these areas. The provision of expert guidance on strategic information management and technology planning could be of considerable benefit to many classes of provider.

An extension of this kind of service would be for independent information to be available about mainstream health and disability information systems, including the functionality provided, ease of use, as well as performance against other criteria used to evaluate systems. Such an approach should do much to reduce the level of duplicated effort investigating the same issue many times over that undoubtedly occurs at the present time, and would provide clear guidance to systems developers as to what are the features that users are expecting in their practice software systems.

Ongoing support for the infrastructure

Currently there is a lack of easily accessed, low-cost support for some aspects of the information infrastructure needed within the health and disability sector, particularly in the area of communications. Mechanisms to encourage the provision of such support will need to be identified as part of the development of the implementation plan if the strategy is going to be successful.

Access to reliable consumer health information

Along with an increasing consumer/patient-focused approach, mechanisms that enable access to reliable consumer health and disability information need to be developed. Recommendations from the Consumer Health Information Focus Group on how this might be achieved are currently being considered.

It may be appropriate to develop these recommendations in parallel with the strategy rather than as an integral part of the process. This would ensure they are not overlooked in the quest for answers to what may be perceived as more pressing operational issues affecting purchasers and providers. Such an approach would need to be developed in consultation with the Health and Disability Commissioner, given many of the needs that have been identified are directly related to the Code of Patient Rights. Even if pursued in parallel, the clear connection with the objectives of the health information strategy means the processes would need to remain closely linked to avoid duplication and overlap, and to capitalise on the synergies which may exist.

Improvements to accuracy and completeness of information

It is envisaged that the strategy will provide a framework for ongoing improvement in the completeness and accuracy (as well as timeliness) of health information, including incorporation of encounter/event reports relating to the following:

- ethnicity, particularly Māori health status
- mental health information
- primary care information
- ambulatory care
- screening care and selected other preventive care services
- community (and individual) risk profiling
- outcome and other measures of quality
- measures of health status.

Exemplars and demonstration projects

In several areas appropriate systems may already be being used that support the approach envisaged by the *Health Information Strategy for the Year 2000*. It would be beneficial if these were identified as exemplar systems, so that others could learn from the approach or technology used. In areas where such systems do not currently exist, consideration should be given to the establishment of low-cost demonstration projects, to show what is possible, and to aid the subsequent development of similar systems by others in the sector. It is expected that a small investment in research and development is often likely to have considerable benefit, provided that the project is suitably evaluated and documented, and relevant material shared widely.

Facilitating the developments

The final section of this part of the report identifies some of the approaches and styles that are important for the successful management of this developmental project.

Leadership

In an environment consisting of many autonomous or semi-autonomous entities there is a great deal of potential for fragmentation. This is particularly true where some of the benefits from a particular course of action may accrue to another party, and not be recognised in the financial transactions associated with the action. In many cases this will not matter, but where it does, leadership will be essential.

The need for leadership in the health and disability information area was one of the most consistent themes identified by those involved in the development of the *Health Information Strategy for the Year 2000*. At the same time there was some concern that the leadership should not be unduly influenced from any particular perspective. The strategy envisages the establishment of a ministerially appointed Health Information Council, to provide leadership as well as a mechanism to help broker agreement on an implementation plan. The Council is seen as the logical “holder of the vision” for the ongoing development and implementation of the health information strategy. Members will be persons of standing from within the sector, selected to ensure as representative a perspective as possible but appointed in their own right.

It is also proposed to reconfigure the Ministry of Health’s current Health Information Advisory Board. The Health Information Advisory Board was initially established to oversee the implementation of the 1991 Health Information Strategy, and subsequently filled an advisory role to the Ministry of Health on health information issues, particularly consultation on standards and extensions to the National Minimum Dataset (NMDS). Refocusing its role will involve extending the brief to include all aspects of health and disability support service purchase and delivery while retaining the role of brokering standards and guidelines in respect of the priorities recommended by the Council and agreed by the Minister.

Agreements about access to records

Communication of health and disability information and the provision of integrated care will not happen unless there is clear agreement about who can have access to what information, in what circumstances, and for what purposes. In order to promote the collection and sharing of quality data, it may be necessary to explore issues relating to how these activities, which cost money to undertake properly, should be funded and reimbursed. Agreements about access will need to be developed in the context of the current privacy legislation and the Health Information Privacy Code

1994[4], as well as being aware of changing consumer expectations in this area.

There is at present a lack of agreement about access to records, as well as lack of clarity about the purposes for which information solicited in the context of providing care will be used. Explicit default agreement will be necessary in order to at least provide a starting point, and this will be vital to the development of a collaborative, integrated environment.

Involvement of service provider professionals

There is currently a lack of involvement of care provider professionals in information systems developments. The recent focus of systems development has been on business and management priorities, but many of the gains to be made lie in the area of clinical and case management information systems and the better integration and management of such information. If successful information systems are to be developed, health professionals must be involved, and must have a conceptual understanding of information management and technology issues.

It should be recognised, however, that health professionals may need some incentives, including financial incentives, if they are to be involved more significantly.

Evolutionary approach

The approach suggested for the strategy is evolutionary, building on standards, technologies and systems already available and making use of natural re-investment cycles. This should avoid the need for high levels of short-term investment, while at the same time delivering performance and value-for-money improvements relatively quickly.

A number of the key building blocks already exist, albeit that they may require further refinement and development in the medium term. The National Health Index (NHI), which provides unique identifiers for healthcare users, is an example of such a building block. Ongoing roll-out and improvements to such systems within the context of an overarching strategic direction is seen as being of significant benefit to all parties in the sector.

An enabling approach

Above all, the *Health Information Strategy for the Year 2000* is seen as enabling. This applies equally to consumers as well as to providers, purchasers, funders, researchers and others. The strategy will, however, only be enabling if it is owned by the right people, and is not seen as something remote and unresponsive. The strategy must demonstrate that it can deliver benefits, and that it has the explicit support of those that lead opinion in order to achieve the level of buy-in that is essential for its success. Already some of this commitment has been demonstrated during the development of the strategy itself. It will be crucial for the future success of the strategy to capitalise on that support as quickly as possible.

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[4] Privacy Commissioner (1994): *Health Information Privacy Code 1994*, Auckland: Office of the Privacy Commissioner.

Part 3: Implementation Involvement: People and organisations

Introduction

The *Health Information Strategy for the Year 2000* provides a framework for the ongoing development and maintenance of a sectorwide approach to information management. This means that implementation will be in a constant state of evolution; and changes in direction and emphasis in both the purchase and delivery of health and disability support services are inevitable as we learn from experience, as new demands emerge and new response options are developed. The strategy is designed to anticipate and respond to this process of sector development and thus ensure that information becomes a valuable asset rather than a burdensome cost.

The proposed strategy recognises the dynamic nature of the sector by encompassing a two phase implementation process. In the first phase, which will extend over the next 12 months, the priority areas identified for attention will be addressed. This will provide the basic framework within which future developments can proceed.

Initiatives will include the completion of a high level data model and accompanying set of standard data definitions. These will be presented in a readily accessible format that will ensure future information system developments within the sector can take place with a sound appreciation of the broader interests of patients, consumers, providers and purchasers.

An agreed set of access and data exchange protocols will ensure that privacy and confidentiality obligations are consistently maintained, that information is shared only in accordance with the governing principles regarding security and the right/need to know that information and that there is a clear and agreed understanding on ownership and sale of data.

Technical standards will be ratified to enable the continued and extended use of information technology to receive and transmit data in a secure environment.

The essential minimum data requirements for meeting international reporting obligations and to enable monitoring of purchase and delivery policies will be reviewed and, where necessary, adjusted to meet the changing focus of service delivery from large organisations to health and disability support providers who operate within the community.

Once these priority areas have been addressed there will be a continuing process to maintain and develop the strategy as necessary and appropriate. The experience with the previous information strategy for the sector indicates this will involve a significant ongoing commitment from all participants. It will also need mechanisms to provide focus to the process and to agree the various standards and protocols which may be proposed.

The plan is to use two separate bodies to oversee and endorse these developments. A Health Information Management Council will provide the focus while a reconstituted Health Information Advisory Board will continue to act as the decision making authority with respect to standards and protocols.

The basic framework

Implementation of the strategy will be an ongoing process. It is therefore important there be a clear and agreed framework for this process from the outset. It is proposed to adopt an approach which will enable the sector to take as much "ownership" of the process and outcome as possible. It is envisaged that this will be achieved by ensuring that the sector has a major role in advising on the priority for addressing the issues identified and in agreeing the proposed response.

Role of the Ministry of Health

The role of the Ministry of Health will be to facilitate the implementation process by offering guidance on the likely direction of new policy initiatives with sufficient notice to enable the information management implications to be identified and addressed, and through the provision of advice on strategic options for information management. The Ministry will not be the decision making authority for information management standards and protocols. The Ministry will, however, retain a significant role in determining the range and detail of information which is required to be made available nationally to promote the development of health and disability support service options and to contribute to international benchmarking of the performance of the sector.

The Ministry will also have a significant role in determining how to best advance the consumer information needs which have been identified by the Consumer Health Information Working Group. As noted in Part 2 of this report, it may be appropriate to examine these interests in parallel with the strategy development rather than as an integral part. A decision on the preferred approach will be made within the context of developing the work programme for the next 12 months.

Health Information Council

A Health Information Council will be appointed by the Minister of Health to provide advice on the priority for addressing the issues identified. The Council may also offer advice on how the process of implementation might be facilitated. There will be nine or ten people appointed to the Council. They will be individuals of standing within the sector invited to participate because of the particular skills and knowledge they possess.

Every effort will be made to ensure the span of interest and experience the members collectively provide is as extensive as possible.

The role of the Council will be to maintain effective linkages with the sector and use these to identify areas of concern and possible new initiatives. It will not be a decision making authority in respect of standards and policies for the sector. The Council will operate in accordance with terms of reference approved by the Minister. It will have a three year term of office after which a decision will be taken on the merits of continuing with such an arrangement or adopting a fresh approach.

Health Information Advisory Board

The 1991 Health Information Strategy introduced the Health Information Advisory Board as a body representing the interests of the sector and deciding on policies and standards for information management. The approach has been largely successful. The New Zealand health and disability sector has available a range of standards and protocols that is seldom seen elsewhere. Standards for information exchange and a range of agreements on data definitions and minimum dataset specifications have been developed or brokered through the Board and successfully implemented within the sector.

However, the sector has developed significantly since the Board was established. In 1991/92 the focus was mainly on secondary care services and the emerging role of the purchaser. Today the purchase and delivery of disability support services are an integral part of the broad spectrum of activities and the relationship between health and accident compensation related activities has been developed in such a way that there are large areas of common interest. Also new initiatives such as evidence based medicine, telemedicine and managed care have evolved to the point where the current information strategy must also evolve to address the new demands these changes present or run the risk of becoming an impediment rather than a facilitative tool.

It is proposed to retain the original concept but revise the terms of reference and membership to ensure that the Board is able to operate effectively in the new environment. The Health Information Advisory Board will continue to act as the decision making authority in respect of standards and protocols for information management. However, it will not necessarily perform this function directly. Where there are relevant and technically competent existing authorities which could provide the necessary authoritative standard or protocol these may be used. The New Zealand Health Informatics Foundation and arrangements with Standards New Zealand provide useful examples of the approach envisaged.

Members of the Board will be appointed by the Director-General of Health. Membership will be structured so as to ensure the wider interests of the sector are represented. Members will be appointed in their own right and expected to be in a position to contribute to the decision making process without the need to refer back to any other organisation for authority to act. They will, however, be expected to make all reasonable endeavours to ensure the position they represent is in the best interests of the consumer and the sector as a whole.

Appointments will be for an initial term of two years with the option of further extensions where both parties agree. It is proposed to adopt the practice of reviewing half the appointments each year so that any change does not adversely effect the continuity of the work programme or the collective experience level of the Board.

Determinations from the Board will primarily represent recommended best practice. Unless specifically required to be implemented by some other mandate, the sector has the discretion to use some other alternative approach if that is considered more appropriate in a given situation. However, where such a decision has a potential impact on the wider sector then the cost of negating that impact will be for the individual or organisation which chooses to stand alone to bear.

Thus if an organisation elects not to use, say, an electronic information exchange protocol recommended by the board, and this involves conversion costs at the point of interface with the wider sector, then those costs must be borne by that organisation.

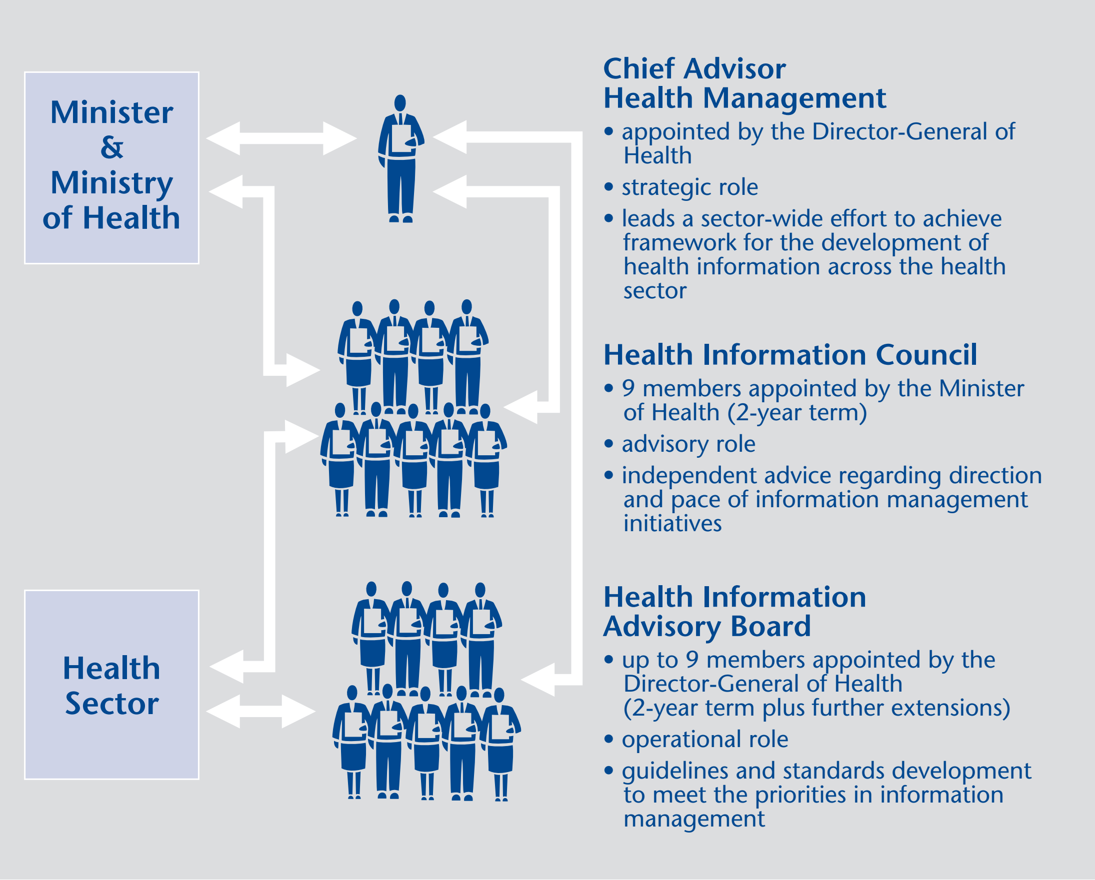
Standards that are likely to be mandated by other organisations could include data definitions for use in the purchasing process and use of the national unique identifier for providers and consumers who use the publicly funded services.

Chief Advisor Health Information

The Ministry of Health has established a chief advisor position to provide leadership and focus for the ongoing development and implementation of the strategy. The chief advisor will work with the Council and the Board to agree on the detailed work plan. The chief advisor will then be responsible for co-ordinating the collective efforts of the sector to develop and implement the decisions taken. To this end they will need to be supported by a range of ad hoc working groups drawn from the sector and by appropriate technical advisors in respect of particular tasks.

The chief advisor will also have a wider responsibility to remain informed about international developments in health information management and to take appropriate action to ensure any such developments which could be of benefit or relevance to the New Zealand context are considered within the context of this strategy.

IMPLEMENTATION



Chief Advisor Health Management

- appointed by the Director-General of Health
- strategic role
- leads a sector-wide effort to achieve framework for the development of health information across the health sector

Health Information Council

- 9 members appointed by the Minister of Health (2-year term)
- advisory role
- independent advice regarding direction and pace of information management initiatives

Health Information Advisory Board

- up to 9 members appointed by the Director-General of Health (2-year term plus further extensions)
- operational role
- guidelines and standards development to meet the priorities in information management

Indicative initial work programme

The development of this strategy has lead to the identification of a wide range of issues that need to be incorporated into the initial work programme.

There is an urgent need for agreement on the minimum set of data which must be retained for national monitoring and reporting purposes. The current collection is largely silent in the key areas of primary care, disability support services, outpatient services and mental health services, yet these are all significant areas of expenditure, contracting and delivery development. The purchasers wish to extend the use of the national unique identifier to all state funded transactions and to use a similar mechanism in respect of providers from whom they purchase services: private providers should be encouraged to make similar use of the National Health Index (NHI) in the interests of integrity and continuity of care delivery to the patient.

There is also the need to provide a measure of certainty in respect of the standards and protocols that are currently in use. An early decision on their continued use must be a high priority.

It is proposed to address both these needs in parallel. By October a review of the current standards will have been undertaken and the results advised to the sector. It is envisaged that the outcome will classify existing standards into three groups. Those for which no immediate change is in prospect; those which are likely to be changed within the next 12 months; and those where the continued relevance is in doubt and which will be finally decided within a specified time period.

Also by October a detailed work programme for the next 12 months will be advised to the sector. This will be prepared by the chief advisor working with the Council and Board and with other interested parties from the sector. The programme will seek to prioritise the plan in terms of potential impact on purchase and delivery activity and the capacity of the sector to contribute time and expertise to the process so as to ensure the relevance of the end result. The selection criteria will be developed in further detail and form part of the advice to the sector.

There are a number of information management initiatives currently in train. These address issues such as the extended use of the National Health Index, the introduction of a national provider index, and the promulgation of minimum datasets for primary care and community mental health. These initiatives will continue, but where appropriate, the recommended course of action will be subject to review by the Health Information Advisory Board before implementation proceeds.

The work programme can be expected to give priority to initiatives which promote a consumer/patient-focused approach to service delivery, facilitate the co-ordination of services delivery, and enable more effective forms of purchasing to be developed and implemented.

Costs of development and implementation

The existing baseline

The management of information is one of the most important and costly activities within the health and disability sector. It is important because the effective purchase and provision of services is totally reliant on ready access to good-quality information.

It is costly because of the sheer volume of information generated within the sector and the need to be able to refer to historical records from any point in the future.

Various estimates have been made about the current costs of this activity. A recent survey suggested that the direct cost of information management would be in excess of $200 million a year. This would cover the purchase and maintenance of information management systems and services including staff. International studies reveal much higher expenditure to revenue percentage ratios. Indeed, the UK Audit Commission 1995 study “For Your Information” indicated that the figure was 20 percent of total acute care sector costs.

If the cost of collecting, retrieving and applying the information is taken into account the role of information becomes far more significant. For example, it has been suggested that the average consultation is around 25–40 percent reliant on previously gathered information. If a value were to be placed on the time involved in gathering, storing, accessing and applying the information according to this assessment then information management is at the heart of 25–40 percent, or between $1 billion and $2 billion each year.

In this context, information management is not to be confused with information technology. Information management is, and will likely remain, a people-focused activity. Information technology, where applied, simply serves to provide a more cost-effective means of storage, sorting, transfer and retrieval.

Against this admittedly superficial analysis, the cost of implementing the proposed strategy becomes a minor investment. It also has the potential to provide significant benefits to the sector as a whole. These benefits will be both tangible and intangible, but must be demonstrated and realised in some part early in the process.

The application of agreed standards for the electronic exchange of data eliminates the need for often expensive interface arrangements or the serial development of different solutions for the same problem.

The use of electronic data exchange standards opens the way to new and innovative ways of service delivery which can be more consumer focused, thus producing fewer tangible benefits such as increased confidence in access arrangements or reduced travel requirements. For example, with an agreed standard for exchanging diagnostic image information it is possible for a consultation to take place at a location remote from the centre of expertise.

This strategy does not seek to quantify the potential benefits implementation could provide the sector and consumers. That will be an issue for those who consider implementing the component parts. However, it is apparent from the foregoing analysis that the magnitude of information use within the sector is such that even a minor gain can deliver substantial benefits.

Funding the development

It is proposed to fund the strategy development through a mix of direct financial contributions and by capitalising on the experience and skills that are available throughout the sector.

The Ministry of Health will meet the costs of servicing the Council and the Board. This will include travel, facilities for meetings and any daily allowances where appropriate. The Ministry will also contribute to the cost of developing a response to the various issues identified. The exact amount of that contribution will be dependent on the scale of the proposed work programme and the extent to which the sector is willing and able to continue to make contributions in terms of finance and access to staff with appropriate expertise.

The experience to date in the development of the strategy has been very positive. Individuals and organisations have demonstrated a willingness to be involved in the project and this has been particularly noticeable in the activities of the purchaser, consumer, and education and research working groups. If the evident goodwill continues, the direct cost should be relatively modest.

If there is any shortfall that must be met by purchasing advice and expertise, then the intention is to seek contributions from the sector. These could be by way of grants towards the development costs or through the use of licence agreements to more directly relate the benefits to the ongoing activities of the sector. Advice will be sought from the Council on the relative merits of each of these options and any others which may be identified.

Implementation costs

Once the various component parts of the strategy have been developed, the costs of implementation will be a matter for the sector to resolve. The current view is that information management is an integral part of the purchase and delivery of services and as such the cost is “bundled” into the price paid by the funder or purchaser. In that situation, any variance in cost which might have an impact on price is a matter for negotiation between the parties involved in the purchase relationship. Such variances can be both positive and negative. For example, streamlining the content of the national minimum dataset should reduce costs to those who supply the data, whereas adding new components to that collection may involve additional costs.

During the course of developing the strategy, some people have suggested that the price of collecting and supplying information, particularly to the national collection, should be made more transparent by separating it from the cost of the services purchased. There are a number of compelling arguments against such an approach. For example, the supply of such information is usually an integral part of the contract for the provision of the service and as such the interrelationship between the two activities may be very difficult to separate. Associated with this view is the likely overhead cost of managing the purchase of two separate components versus the likely benefits.

Notwithstanding these observations, it is likely that the Council will be asked to express a view on the merits of maintaining the status quo with respect to the provision of information or moving to some other arrangement.

Intellectual property rights

At least some of the protocols and standards developed as part of the strategy could have a value in the wider market, including overseas. If this is realisable, the plan is to maintain Crown copyright interests in all elements of the strategy and only allow third party use with express permission. Such authorisations may be subject to licensing or other payment arrangements to reflect the cost of development and the potential benefits to the user.

Depending on the level of financial support that may be available from the sector, it is possible that similar licensing arrangements may be used in respect of the New Zealand health and disability sector. This is not a preferred arrangement given the overheads associated with maintaining such a service, including ensuring unauthorised use is detected and addressed. However, if the use bestows a benefit it may be appropriate to offset that if no other contribution to the cost of development and maintenance can be secured.

The place for seeding and transitional investments

Some interest has been expressed in the provision of seed monies or transitional funding to provide momentum to the strategy implementation, especially in areas where it might otherwise be difficult to establish the necessary critical mass for an expensive roll out.

As a general preference, this strategy is predicated on the belief that the cost/benefit ratio from any investment in implementation should be sufficiently attractive to enable the necessary level of interest to be established without recourse to other start-up funding arrangements. That said, it is possible that situations could arise where the necessary infrastructure costs are greater than the immediate level of interest could sustain but the down stream benefits are clear and merit some initial support.

The emerging role of telemedicine has been cited as a case in point. Remote access to clinical expertise during the course of a diagnostic imaging session can have substantial benefits for the patient in terms of ease of access and the timeliness of the intervention. It also reduces the risk of diagnostic error and increases the prospects for commencing a treatment programme with the minimum of delay.

The strategy can deliver the necessary technical standards for the safe and accurate transmission of the large quantities of data involved in an imaging session. However, the infrastructure requirement of a data transmission network capable of handling such volumes is another matter.

Any proposal to use telemedicine for such purposes should clearly demonstrate that the benefits will be equal to or greater than the likely costs. However, for the network service provider there is likely to be a need for greater certainty of demand before they would invest in the infrastructure changes needed to carry the data loading. If that certainty could not be achieved in the short run, yet the potential benefits were clearly established, it may be appropriate to consider some form of venture capital funding to facilitate the uptake. But the funding/purchasing arrangements need to be flexible enough to pay appropriately, given the savings that this can generate.

There is a precedent for the use of such transitional funding to facilitate change with the 1994 programme of funding support to enable the introduction of a range of changes in the way primary services are delivered. The Ministry of Health must give further consideration to the use of such an approach and seek a view from the Council before making any recommendation to the Minister.

The first phase of implementation

Establishing the framework

It is clear that the sector is looking for leadership in the area of information management. Time is therefore important if that interest is to make a positive force. Accordingly, the plan is to have the basic framework for the strategy in place and operational by September. This will include appointing the members of the Council and the Board and preparing the work plan for the first 12 months.

As part of that process, the various initiatives currently under way will be encouraged to ensure they reflect the wider interests of the sector. To assist this process, a check list will be developed which seeks to alert the various working groups to the key principles underpinning this strategy, such as the consumer/patient focus, the need to be as technology independent as possible, the use of facilitative rather than prescriptive approaches and the maintainence of sufficient flexibility to enable new approaches to purchase and delivery to evolve.

Developing the work programme

A considerable amount of information has been gathered about the current activities and perceived information management needs of the sector. This will now be developed into a draft work programme for review by the Council and Board. Prior to this a process of consultation will be followed to seek and incorporate views from the sector about the relative priority of the issues identified.

This review process will largely focus on the existing consultative options such as sector interest groups, individuals and organisations. It will also make extensive use of the Ministry of Health Internet facility to encourage comment and feedback from a far wider potential audience, including the views of those with an interest in such matters who live and work overseas.

Introducing the work programme

Given the level of interest in information management issues there may be merit in convening a sectorwide forum to launch the work programme, garner support and feedback and to register interest in the ongoing development process.

Detailed consideration of this option will take place in parallel with the development of the draft work plan due by October. If there is sufficient interest, a seminar could be convened in November or December.

Potential participants could range from purchasers and providers through to agencies which promote patient interest and technology providers.

Communicating with the sector

The success of the strategy is at least in part dependent on the level of understanding and support achieved within the sector. A significant and ongoing effort will be required to make sure the information on which such understandings are developed is readily available and that effective feedback mechanisms are maintained.

A key part of the communications process will involve utilising the established mechanisms for sharing information within the sector. It is likely that this will be the most frequently used method of information dissemination with the Ministry's WWW site providing the central repository for such communications.

Part 4: Looking Ahead:
Exploring elements of the proposed solution

Introduction

The purpose of this section is to describe the vision for health information management in simple terms and to explore the potential of certain elements of the solution being proposed. While the strategy adopts a broad approach, equally relevant to manual and computerised health information management, the changes that are required in the management of health information electronically are more difficult to conceptualise or understand without a baseline solution.

To help in this understanding, the concept of a "meta-system" has been developed which covers the set of all systems and people handling health information. The concept diagram represents our "meta-system" including all processes manual or otherwise (ie, as inputs or elements) and within which are the "objects" (ie, the systems and people) to be described and discussed. This section reviews the meta-system make-up, what needs to be in place for it to work, what component objects will be designed to do, and links these with what the meta-system will deliver for the sector and the consumer.

Given the pace of technological development and the degree to which technology direction is determined by the market, it is difficult to reliably predict exactly what technologies should be used at this stage. Therefore specific technologies are usually identified only where it is necessary to properly illustrate a particular approach.

The meta-system would most favourably be implemented in a number of incremental steps with roles and responsibilities for implementing each element of the system clearly defined and agreed as described in Part 3: Involvement of People and Organisations.

Architecture

The meta-system will evolve as the existing and new objects are increasingly brought together. Each object (system, person or organisation) will retain its own discrete purpose, function and systems. These systems can communicate via standard messages which will return packages of information, but the packages in isolation will not include any patient identifiable information nor have this information secured via encryption. This process will enable the consumer or their agent (people with suitable access rights) an ability to assemble, on an as-required basis, information about a healthcare user, provided the user has given their permission.

The key to the solution is that each patient's index points to their packages of information. The index could be held by the patient, or in some other distributed fashion. In addition, wherever the point of access is not continuously available in a standardised format, it must be known what protocols/standards need to be used, within what file structures the data is held and at what locations, and when they are likely next to be on-line.

Architecturally, this system resembles the World-Wide Web (WWW), where a set of discrete and autonomous systems interact to provide access to information. With appropriate modifications, this system can indeed be the WWW, and several pilot operations are already under way in Europe and North America to further the concept.

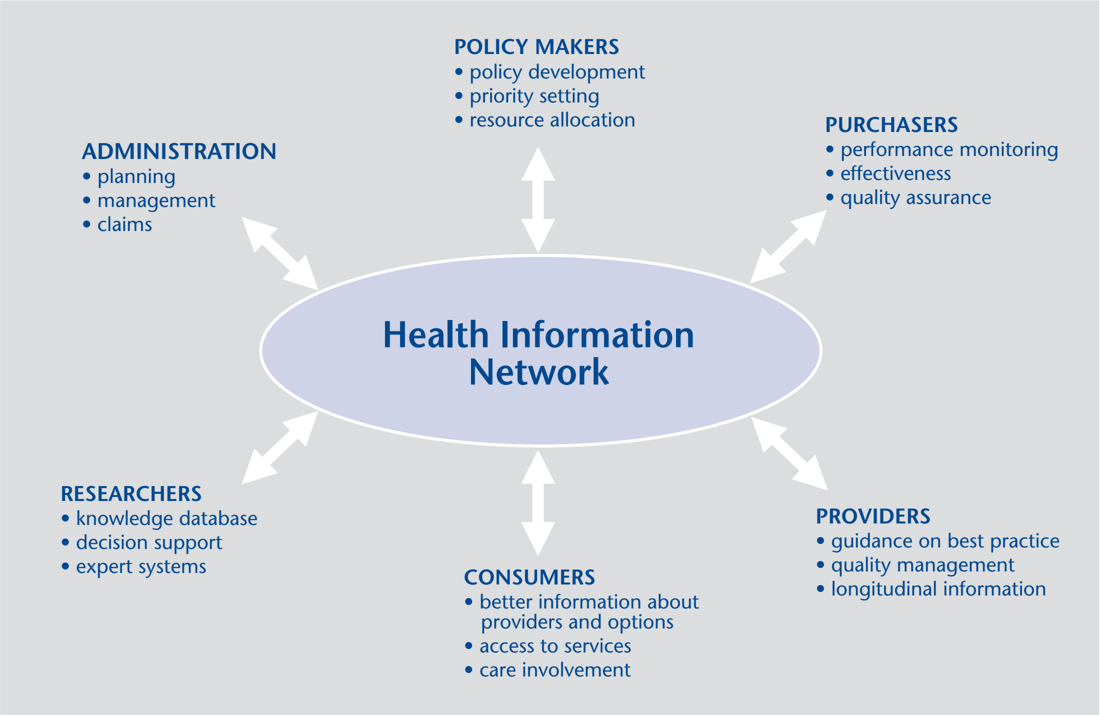
This approach can also be used within organisations or facilities themselves and/ or between allied organisations. This will allow any key applications used by consumers or clinicians a direct "window" to a comprehensive virtual store of information relating to themselves or their patients at any time. Interoperable frameworks such as these have at times been termed "intranets" and can enable healthcare organisations to transcend the limitations and redundancies created by islands of information centred around function or geography, the result being a more co-ordinated service to their patients.

The objective is to make all information that, in many cases, already exists in today's systems, readily available, in order to provide co-ordinated and integrated care and treatment for individuals.

The broad use of these open systems frameworks will soon evolve into acceptable means of inter-connection with the assurance of security, data consistency and integrity. These approaches will also reduce the effective cost of access to information and help organisations clarify their business processes.

The approach of encapsulating the objects will ensure that their internal operations remain opaque, that they can be developed and extended without regard to any impact they may have on others, and that they explicitly control what information and access they provide to other systems. In this way the messages act as an explicit application-level firewall.

HEALTH INFORMATION NETWORK



Design requirements

In determining how the meta-system should act, there are a number of practical considerations and design criteria that need to be taken into account. To ensure that data are captured once and used for many purposes, it will be important for people at the point of care to understand many of the broader purposes the information is likely to be used for (eg, research, administrative and other purposes).

Focus on the patient

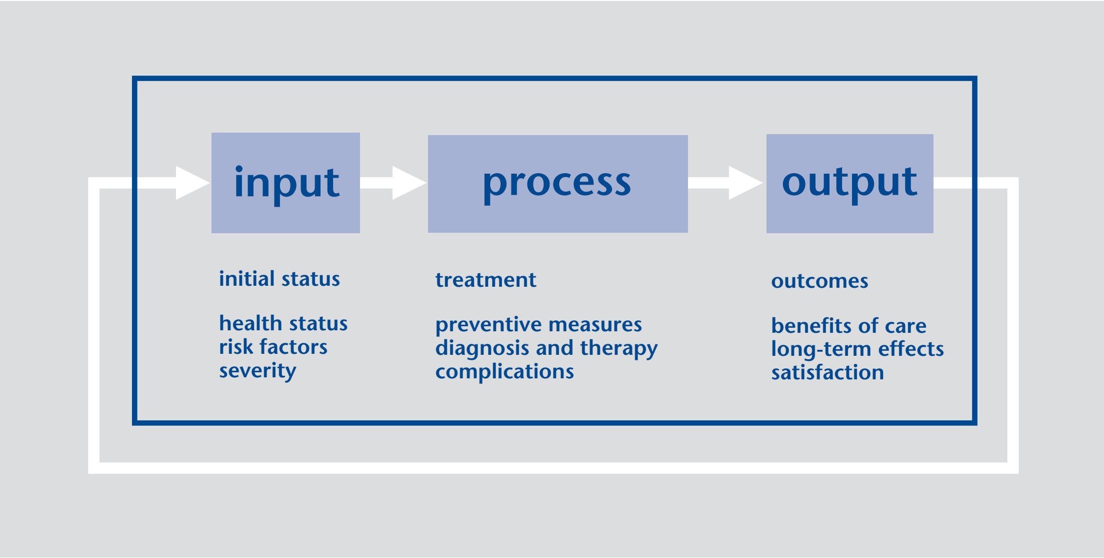
Managing patient care across the continuum requires information across the continuum. With an increasing move to services not based on centralised facilities (eg, outreach services) or a single provider, and with the advent of patient-centred technologies, it is reasonable to expect that the sector will be both more automated and more decentralised, and the logical centre of focus of information will become the consumer.

As health provision changes to place more focus on prevention, community and ambulatory care, and becomes based around a larger number of smaller or satellite facilities, it will become imperative that information is dealt with efficiently and consistently. The meta-system would enable services to be delivered in a broader range of settings than is the case today. Access to resources at local community, regional, national and international levels would help this to happen.

Support for evidence-based care

Feedback on treatment and outcome will be essential information for planning and research purposes. Many organisations will be aiming to measure effectiveness to provide the basis for ongoing improvements.

PROCESS IMPROVEMENT



Utilise bodies of knowledge for improving community and public health

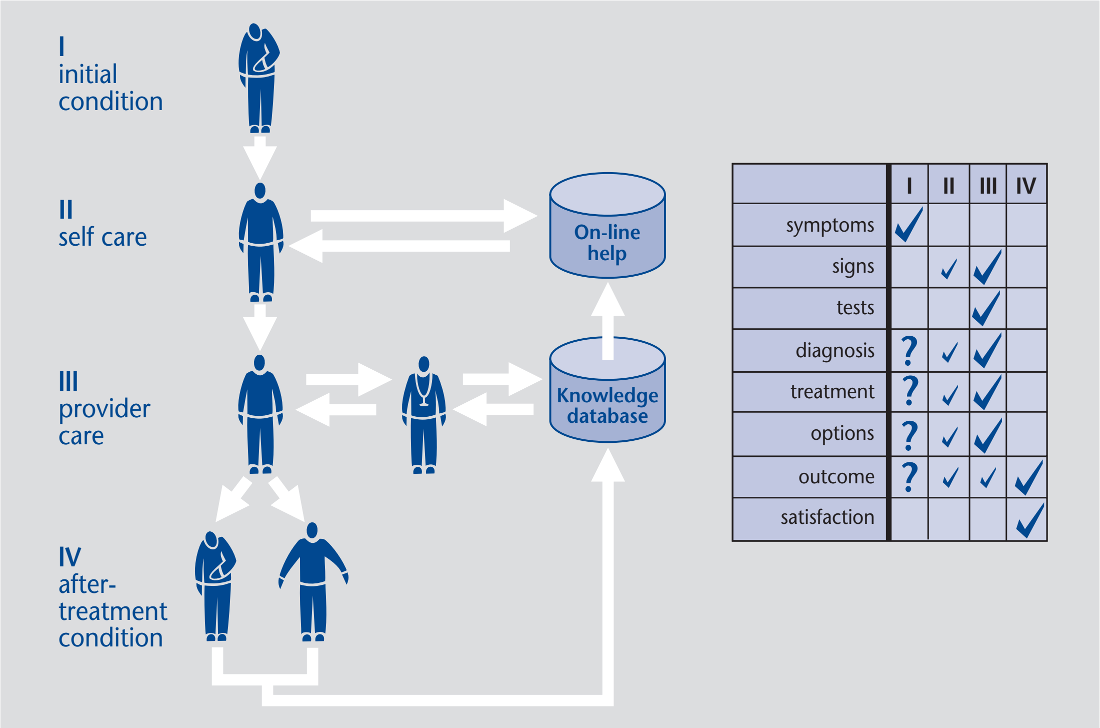
Information for disease prevention and policy development will also be required. It may be either collected as a by product of clinical or care transactions, or when the system is more developed; generated on an as-required basis by a set of queries on the systems which hold the core data. Closing the information loop (condition or initial status – treatment – outcome or concluding condition or status) and communicating this information will not only help to improve health knowledge generally, but will also support the development of longitudinal health records.

Empowering consumers with better information

The consumer will be provided with access to, or the means to access, all information held about their conditions and treatment. They will need to be able to discuss and seek counselling from people who can interpret the information.

It will be possible to determine who is allowed access to any information held about an individual, and explicitly track or monitor when access occurs. Access permissions would be able to be granted explicitly (by the individual concerned) rather than implicitly by the system.

CONSUMER HEALTH INFORMATION



	I	II	III	IV
symptoms	✔			
signs		✓	✔	
tests			✔	
diagnosis	?	✓	✔	
treatment	?	✓	✔	
options	?	✓	✔	
outcome	?	✓	✓	✔
satisfaction				✔

Promote innovation

It is essential that mechanisms and approaches aimed at sharing common information do not stifle new and innovative ways of viewing and using the data. The adoption of core technologies that are widely used and commonly understood, and which minimise the use of specialised technology standards will help ensure that barriers to entry are as low as possible.

Leverage on investments made for other sectors

Systems should be built on common (not sector specific) technology platforms where they exist. This will ensure that investments made by the technology sector as whole, as it moves to address the needs of all sectors, are capitalised on by using generic solutions to generic problems wherever possible (eg, encryption, messaging, mail, common user interfaces). This would avoid the need for expensive specialised expertise in sector specific standards that is available from a limited set of people. Using common technologies that people are already familiar with would help to avoid the risks associated with specialised development and poor user uptake.

Capitalise on existing systems investments

It will be important to avoid unnecessary replacement of systems just because they do not currently talk to each other or do not comply with a specific standard. Information brokers should be able to assist in reconciling information on a one-off basis or providing an ongoing service for these systems until they reach the end of their economic life.

It will be equally important to ensure that the functionality of any individual system (new or old) is not unnecessarily or adversely affected by the demands placed on it by the meta-system. It is also important to ensure that there is no need for everyone to converge to a common approach – diversity is important for evolution. Excessive standardisation acts as a barrier to development just as much as too little. With the use of WWW servers, for example, the rights of the organisation to use legacy and/or idiosyncratic systems behind them as best suits their specific needs is retained.

The use of WWW servers would also provide a level of parity for smaller organisations and alternative care providers so that they can effectively provide care in different ways without being off put by a system or structure that is difficult or expensive to comply with.

Capitalise on investments in equipment and expertise

To maximise the availability of care to people in remote locations and smaller centres and to enable optimal use of expensive items of equipment (eg, super computers) or the skills for the remote diagnosis and treatment, consumers in rural areas may be provided with services from centres of expertise within regional centres, and regional centres may be supported by national or international centres of expertise.

Significant improvements can be made using current technologies, systems and skills simply through better co-ordination and planning.

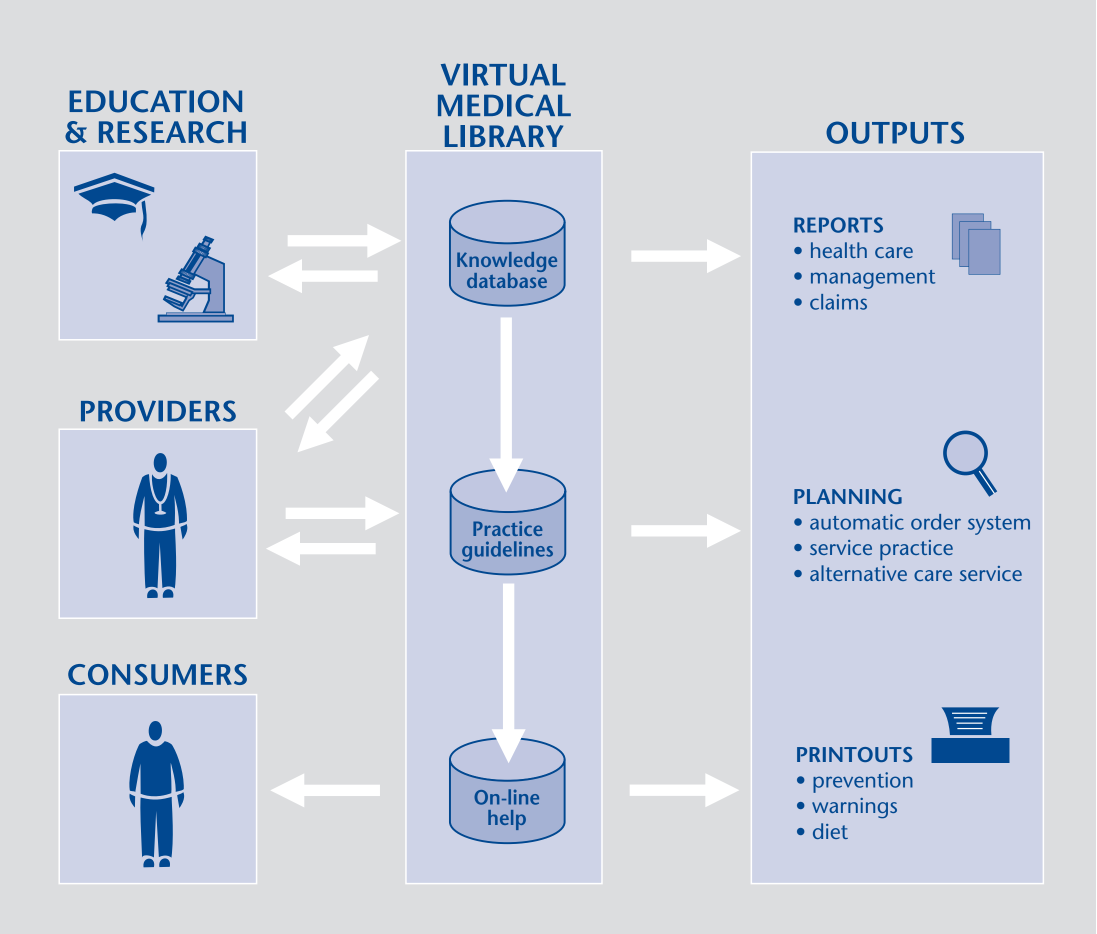
Foster new information services and value-added information services

New information services targeted at professional clinicians, administrators and the consumer will become available. These will include traditional providers of information, specialised information clearing houses, valued added agents and information brokers.

Technology enhancements, such as a “virtual” medical library, will allow the hospital to become an even more integral part of the community, as medical libraries and academic medical centres currently experimenting with intranet communications extend the range and value of services that they are able to offer.

Increasing numbers of value-added information services based on the Internet are likely. Many future developments will rely on the extension and expansion of common communication infrastructures, with associated reduction in the cost of using these services.

INFORMATION CLEARING HOUSE



Design considerations

To discuss what the system will look like it is important to clarify a number of underlying assumptions regarding technologies that will be available and in use.

Continual improvements will take in the human system interfaces and several expected improvements are outlined below. In general these improvements can be expected to enable significantly more information to be collected in a digital form at the point of care (document scanning, voice recognition, etc) and effectively communicated to people in local and remote locations (video conferencing, paging, inexpensive PC-based imaging).

Authorisation and access control

In many cases at present, any authorised person with access to a system can access the records of anyone entered in the system. New approaches would provide options for data to be encrypted so that regular access to a consumer's personal information would require consent in the form of their code or password (in the same way that a bank asks you to enter your PIN code), possibly along with the code of the facility or provider. For another facility to access information on the consumer, permission may be required from either the owning facility and the consumer, or just the consumer. In all cases "overrides" would be available for contingency conditions (eg, emergency care) together with appropriate mechanisms for monitoring and reviewing each use of an override, and for ensuring that the patient is made aware of that use.

A variety of encryption mechanisms may be applied depending on agreements among the sector, individual facilities and individual consumers. Some specific systems may also be required for sector wide or implicit authorisation processes.

One key design consideration is that with the patient index in place and the removal of all other identifiers from the data presented, the reliance on encryption as the prime security method can be reduced.

Authentication

The technical issues associated with authentication will be addressed by common inexpensive technologies embedded in common applications. The authentication information may be held on a number of systems depending on who is responsible for ensuring authentication and guaranteeing security.

Scalability

Increasing the number of systems and users by several orders of magnitude is not expected to have a material effect on the architecture as proposed, but there are safeguards to be considered to ensure scalability.

Reliable and secure communications

Reliability and security can be ensured by strategies employed in the underlying communications infrastructures (eg, multiple paths, encryption, etc) and service providers.

Contestable selection

The selection of systems, components, service providers, etc can remain fully contestable and there should be minimal reliance on proprietary skills and/or technology. Any sectorwide system needs to be built using standards and technologies that are simple and inexpensive to use, well proven, and widely adopted, easy to implement and supported by services and products available for multiple sources.

A system of systems

With the reducing costs of systems and technologies, expenditure for the same level of functionality will reduce, and additional features necessary for the meta-system will be able to be incorporated without major capital investment. By making these small improvements to each system, a multiplicative effect will be achieved at the level of the meta-system.

Intermittently connected devices will empower consumers

The architecture will make it possible for users to carry with them, or have in their home, forms of intermittently connected devices (eg, PCs), which will allow them to have the ability to review and update information about their health status and treatment history. These systems or devices will offer secure, robust and reliable systems, and technologies developed for commercial transactions will provide generic security capabilities suitable for applications requiring secure transmission.

This will provide consumers with new options for ensuring the security and integrity of their information. They will be able to assert their rights over their health data, for which they must also be able to authenticate that they are who they say they are. They may also carry portable data with them, and even receive care remotely (eg, blood sugar/ECG monitoring when at home), which will also serve to assure the service provider of their identity, even though the two may not be able to see one another.

Intermittently connected devices are likely to be relatively simple to adopt as they will be based on approaches used for other applications and in other industries, where consumers will already be familiar with them, such as EFTPOS, ATMs, entertainment and consumer electronics, and generic communications technologies.

In particular, card technologies are likely to interact with a range of systems and allow consumers to retain information regarding their treatment and history (including the results of examinations and prescriptions) and will provide options for storing diagnostic and examination results, medical histories and drug reaction information, as well as X-ray and CT imaging information.

Consumers are rapidly becoming accustomed to technologies that will enable them to participate in information management on an equal footing with professionals in the sector. However, at the same time consumers are likely to need increasing support in order to interpret the increasing amount of information to which they are likely to have access.

Generic communications networks to provide inexpensive access mechanisms

The Internet (and the products and protocols designed to be used over it) offers the potential to create new dimensions of applications and technologies to provide a standard approach for processing, sharing and exchanging health information. Using such technologies, information can be made available to authorised users from all stakeholder groups in a very cost-effective, user-friendly manner.

The Internet will offer secure standards for the transmission of a wide range of information between diverse groups of users. Standards will exist for conveying generic classes of information and these standards will be built into core technologies and may be passed to and from a wide range of business systems using standards such as HTML forms, MIME, etc.

Industry-wide initiatives, probably led by the banking and commercial sectors (such as supporting EDI over the Internet), will effectively remove any significant barriers to electronic claims processing and make the approach and systems accessible and understandable to consumers. This will lead to the development of applications that are able to securely transmit patient records over the Internet (in the same way, and with the level of consumer acceptance that they are transmitted by post or fax today).

Devices to enable legal execution of electronic documents over a network (eg, using a hand-written signature) will further assist in authentication, if necessary. For example, standards have been already developed for carrying out electronic commerce (banking and shopping) over the Internet. Electronic "cash" is now in use and standards for conveying generic personal information as a virtual business card are already being deployed.

The Internet is likely to quickly become a means of communication as common as mail and fax are today. It is reasonable to assume therefore that generic issues to do with security, access controls, and legislation to support or regulate electronic initiatives, will be dealt with on a broader basis than the health sector alone.

Generic remote communications and feedback technologies will support extended interaction

Inexpensive paging technologies will be able to remind patients when and how to take prescription medication, to encourage patient compliance (taking prescription medication properly and on time). Patients will be able to be advised of the name of the medication, the correct dosage, instructions for use and drug interaction warnings.

In addition to medication reminders, it will be possible to send patient and disease specific health messages from doctors directly to patients as they monitor treatment programmes. This ongoing communication support should motivate patients to comply with their treatment plans, reducing unnecessary consultations, diagnostic tests and hospitalisations by reducing the risk that conditions fail to improve, worsen or relapse.

Paging and messaging systems may also provide direct feedback loops confirming the drugs used and direct patient feedback on outcome or state of health.

The ability to remotely monitor a person's condition or safety (such as providing help when a person has fallen, or when their condition has changed) would enable more people to be cared for in their own homes, irrespective of the level of family or other support.

Low-cost medical imaging can allow broader participation and understanding

A growing portfolio of clinical visualisation products designed to build three-dimensional images on desktop computers to assist with medical education, diagnosis, treatment, surgical planning, and intraoperative navigation will be widely available.

These visualisation products will use output from CT scans and MRI images to create a three-dimensional rendering of anatomical structures. They may be the subject of conformal treatment programmes in radiation therapy planning, for assisting medical specialists in developing and providing treatment without needing to resort to more invasive techniques, or for providing consumers with a better understanding of the issues and treatment options available to them.

The three-dimensional images will be the nucleus of visual clinical diagnostic products available on PCs and accessible over distributed telemedicine networks. They will initially allow clinicians and eventually consumers (via the home PC, or WWW-based access) to understand the result of scans and make meaningful the option of the consumer having access to a copy of this element of their medical record (available on CD readable by home computers). Using multimedia techniques and providing access to information in this way would also enable providers to communicate treatment options or other information more effectively to consumers.

Generic digital capture and conversion tools

Information will be able to be transcribed directly via voice recognition technology that allows clinicians to dictate into their personal computers at their own natural pace, rate and rhythm of speaking. These systems will utilise context sensitive language models. The systems will be designed to accurately identify specific terminologies and remove barriers to electronic capture of key elements of the patient record.

Video, documents and associated images can already easily be captured and stored. The WWW is leading to a rapid increase in the general understanding by the public of the issues associated with images and their formats.

Broad-band networks will support telemedicine

Value-added broad-band networks will be developed to capitalise on advances in remote diagnostic technology and support the transfer of medical images between medical facilities. Medical information networks utilising communications (and eventually satellites) may be introduced in the future as medical care at home becomes more common.

These developments will leverage off the generic technologies being deployed today for general business communication and entertainment (eg, cable television).

Design summary

A developmental framework built on a message paradigm will support providers, purchasers and others to develop strategies for integrating their own systems into the larger community of systems. As a result, information users and their technology vendors will be able to develop systems with the confidence that their investments in information technology are consistent with others in the sector.

Such an approach would rely on individual organisations building and managing their own information solutions, with information systems and services vendors continuing to provide value-added communications and decision support services in an environment where standard definitions and approaches are used consistently and systems are able to communicate via simple message protocols.

This would parallel the traditional approach which has served well in the past where information is:

- held in a person's or organisation's files (by an object in whatever form best suits them)
- extracted and processed to form a letter or form (in an agreed format)
- written in a way that conveys concepts and quantities (ie, properties expressed based on agreed standards)
- prepared in letter and envelope – confirming address, provides security, confirms sending identity (authentication)
- carried via a generic information deliverer (ie, a value-added service provider)
- sent to a destination – secure or otherwise (ie, with appropriate access control) – with an understanding of the action that will result (based on agreed transaction and reply protocol).

In order for the meta-system to effectively and efficiently communicate critical information reliably between people who may have no prior relationship, irrespective of technology issues, it is likely that formats, standards, security and authentication mechanisms, simple guidelines for service providers, rules for access control, and agreements on transactions and reply protocols will need to be defined.

The challenge for the meta-system is to connect systems and people via systems, and to make explicit a set of definitions and standards. In particular, for systems to be able to communicate, processes for identification and secure authorisation will be needed. These two components will be needed to protect the confidentiality of information where authorisation procedures may be based on explicit agreements or based on a common sectorwide implicit understanding.

To achieve this there is a need to create a networking and data management environment that allows secure, confidential, and fully authorised transactions and queries to be sent between parties, while allowing individual objects to deal with the vast complexity of data types and database structures and applications. Information systems expedite communication. However, the communication still needs to be based on a common understanding (eg, standards and data definitions) as well as agreement about access rights, etc.

Information will be managed by a large number of autonomous systems which interact with each other as necessary to provide a comprehensive range of services to care providers, consumers and support staff. The systems will include those owned and operate by funders, purchasers, providers, consumers and others.

In this way the meta-system will link existing networks, and avoid the need to create central repositories of information attempting to service the needs of the entire sector. That is not to say that centralised systems and repositories may not be required for specific purposes for individual organisations or groups of organisations, but it does imply that these systems will also have specific roles and responsibilities and there should be no attempt to build a system which is all things to all people. All organisations would retain control of their own data and share it on a need to know basis to ensure patient care or where specific agreements apply. The “network of networks” approach and the resulting architecture enables information exchange only when warranted, authorised and agreed to.

Each system will be designed and managed to achieve a particular set of functions. Examples would include:

- consumer health information systems
- practice management systems
- statistical and analytical systems
- common reference systems – eg, indexes
- systems to support specific programmes – immunisation programmes, screening programmes
- business systems – eg, claims processing
- information services and brokers – clinical guidelines and best practice.

Benefit will be gained by ensuring that a wide range of systems can communicate effectively so reducing waste of time and effort, delivering greater integrity and continuity of care to patients, with greater flexibility and convenience.

The systems will, at the discretion of their owners (who will be custodians or owners of the data that resides on the system), be able to communicate with other systems. While the communication between systems will increasing move to be based on electronic messaging, the model obviously incorporates the current non-electronic ways of communicating.

Definitions of data

The key to the success of the system will be a common agreement to a set of standard definitions of data that can be applied irrespective of how the data is stored, accessed or used.

Where will data reside?

Data will be distributed in a range of large and small systems. Data will not be stored in a central repository but are uploaded to systems in facilities by clinicians who receive permission to access patient records.

Data models will be developed which place the consumer at the centre for the information (along with traditional facilities and transaction-based models). These models will be based on an object metaphor which focuses on the information that can be expected to be received from systems about a subject or class of subjects rather than dictate how the data is structured internally to the system (ie, the internal structures will vary to suit the application). This will ensure that systems will be able to continue storing data in the form that best suits them and still participate in the broader community of systems provided that they are able to present information to external world in a common format. External communications will be based on common definitions, classifications and standards.

The models do not prescribe any particular implementation technology.

How will information be accessed?

Information (including patient histories, dictated reports, laboratory data) will need to be accessible on a "clinical need-to-know" basis, by a clinician involved in the treatment of the patient. Ideally, monitoring would mean that if a clinician needs to access the record of a patient electronically without prior agreement, then the fact that the access has been made would be sent to the regular physician, unless the patient has requested otherwise.

How will information be communicated?

Object-oriented software frameworks will enable information systems to seamlessly share information based on the sending and receiving of messages containing properties and authorisation and encryption information. Information will reside on a large number of disparate and dispersed systems which will communicate with standard messages transferred over independent service providers' networks.

Standards

Information technology standards tend to evolve very rapidly and are usually determined by product vendors or groups. They are often de facto standards long before they become de jure standards – if they ever make the transition. Many clinical standards and classification systems evolve at a much slower pace and relate more to extension of the common body of knowledge than to revolutionary changes in technology.

The challenge is then to have standards and policies that provide sufficiently explicit business-based definitions and to allow information to be communicated between different systems while ensuring that sufficient flexibility exists to adapt to the changes in the underlying technologies and the associated changes in lower level technology standards.

The goal of the standards will be to provide a common language (independent of medium) which can be used to link information systems of healthcare payers and providers. Doctors, clinics, hospitals, managed care organisations, insurers and other entities can communicate using simple generic information exchange protocols capitalising on the investment made by other sectors in developing robust technical communications protocols, encryption technologies, etc.

While many of the standards are technically actionable now, work is required to ensure that standards can be developed and rolled out in an evolutionary manner and are able to adapt to meet the changing healthcare environment. Having agreed the standards, it will be necessary to promote the adoption of standards, monitor compliance and monitor ongoing developments in the integrated healthcare delivery systems to take advantage of innovations.

Standards can be expected to be technically represented in a message framework comprising a number of layers of standards-based software components, such as enterprise communicators that can be embedded in healthcare applications, to allow seamless interoperability among the applications. Most of the standards will be generic. There will be a wide range of sector specific standards focused on issues that are not addressed in other industries or commerce as a whole and are specific to healthcare – for example, clinical coding of diagnosis, outcome and treatment.

By fully leveraging on current standards and the broad base of skills and services available for implementing these standards, we will be able to substantially reduce the cost and complexity of establishing data interfaces between computer systems, enabling a more seamless flow of information across the sector.

Standards may be technical or simply agreements on approach. The focus of standards development will be on business-based definition of terms, rules, approaches and constraints.

Some of the new standards to be confirmed will:

- allow claims to be raised and reconciled electronically
- allow consumers and clinicians to be uniquely identified and authorised for access
- transfer digital medical imaging data
- transfer generic text
- capture and transmit generic information about a person, such as their name, address, phone number, e-mail user ID, with multimedia support for images, sound clips, etc.

Policies and procedures will be commonly understood for securely transmitting information, and clear guidelines and policies will be available on the practical issues associated with ensuring common concerns about the confidentiality and privacy of information.

Some of the key standards critical to the solution will be:

- identification of products and articles (eg, pharmaceuticals)
- recording of events and outcome (at primary and secondary care level)
- mechanisms for accessing common indexes
- sector specific authentication mechanisms and specific access control approaches and guidelines that are secure and comply with the Privacy Act 1993 and Health Information Privacy Code 1994;
- definition of the information that can be expected from any medical record (electronic or otherwise) – it is reasonable to expect that clinician records will include a common subset of information (complying with a standard) and clinician specific variations (that need not comply with a standard)
- protocols for transmitting diagnostic images
- agreements, such as trusted third party arrangements
- virtual schema for all objects in the meta-system – systems objects with public interfaces for other systems (accessed by messages invoking methods), lists of properties and behaviours (and eventually extended to describe a full range of application specific functionality that can be expected from each object).

In many areas, core technical standards (sometimes several) already exist, and a particular standard may be endorsed.

Likely technology

System standards for communications, transaction management, data elements, coding and syntax, and methods of identification are most likely to be based in future on generic standards such as connectivity using IP over dial-up, ISDN, Frame Relay (and eventually ATM) with protocols such as TCP, sockets, HTTP, FTP, telnet, SMTP and MIME with security based on applications such RSA. Network service providers and commonly available end-user applications will provide interfaces to a wide range of older standards. Standards such as DICOM will be reviewed for medical imaging.

Network service providers

Network Service providers will be supplying generic services to a wide range of sectors based on reliable and available, open, secure, networks which provide adequate volume and bandwidth and will:

- support automated exchange of healthcare-related clinical, financial, and administrative data
- facilitate automated messaging and transaction management
- provide gateways to external knowledge sets, ie, public and private knowledge bases of clinical research, medical practice guidelines, educational resources, and decision support tools
- support remote communications utilising personal computers and other personal communications devices from remote sites
- carry out management functions such as network management, backbone network management, protocol conversion, remote facility fault detection and isolation, network and resource capacity planning tools, and ensure reliability and availability
- provide a level of security based on IDs and passwords, firewalls, encryption technologies and certification procedures
- provide a translation service
- provide store and forward mail capabilities as well as mail boxes
- develop information resources and services attractive to their specific target group of customers, provide ways of organising the data available over the Internet in a way that meets their clients needs
- market the systems and services to their clients.

Some key systems

Within the meta-system there are some key distributed systems where each organisation will retain responsibility and control over its own internal data systems and databases. Examples of the types of systems are outlined below.

Systems which support common indexes

Unique identifiers are an essential element of any structured system and will need to identify systems, users, consumers, etc, for a range of processes, such as authentication or common reference.

It will probably be important that these systems are operated to serve the sector as a whole by trusted non-profit organisations as there may also be a role to play in the future in holding keys and other information necessary for authorisation and token generation.

Indexing and possible authorisation systems which will provide common entity indexing and authorisation information using a simple common network communications protocol example may include:

- index of consumers – based on the National Health Index (NHI) which would be a key to ensuring that consumers are dealt with consistently and can inquire of their status on any system
- index of clinicians – a voluntary index which would provide information on qualifications, accreditations, fee structures, work locations/contacts, QA/performance, core competencies, contact details, and possibly associated practices
- index of providers – practices
- index of purchasers
- index of facilities – diagnostic laboratories, etc.

Specialised care-oriented systems

Examples of specialised care-oriented systems are:

- clinical, lab, radiology
- patient management systems – providers (practice management, patient management
- business and facilities management systems.

Programme-based systems

Programme-specific systems which will aggregate databases to support end-user transaction processing requirements (eg, clinical and organisational bench-marking processes and clinical and operational decision support applications), and will include data focused on specific diseases, treatment patterns, clinical outcomes, patient satisfaction and functionality measures, and treatment costs. Used to support analysis and policy development. Examples may include:

- screening systems
- specialised databases assembled from the results of automated queries on systems or regular feeds of information.

Glossary

ACC	abbreviation for the Accident Rehabilitation and Compensation Insurance Corporation
ATM	Asynchronous Transfer Mode, ie, a variable-bandwidth transmission
Audit	multi-disciplinary assessment of clinical practice, procedures and processes usually focused on the outcome of the service
Authentication	verification of user identity
Bandwidth	a measure of a communication technology's carrying capacity
Benchmarks	the goal set to be attained in the process of comparing the quality, prices or scope of services against similar one or common standards
Broker	an agent who negotiates contracts of purchase
Casemix	distribution of a group of patients into categories reflecting differences in patients' diagnoses or conditions
CAT/CT	Computerised Tomography – scanner
CHE	Crown Health Enterprise – the largest publicly owned providers which are based around one or more public hospitals
Clinical practice guidelines	systematically developed statements to assist providers' and consumers' decisions about healthcare to be provided for specific circumstances
Confidentiality	prevention of unauthorised disclosure of information
Consumer	a person receiving or entitled to receive healthcare services
Cost/benefit	assessment which takes into account costs and benefits of a process, as well as the revenue it generates

Cost-effectiveness	desired impact or effect produced per unit of cost
Disability	physical, psychiatric, intellectual, or sensory limitation of independent function to the extent that ongoing support is needed
E-mail	electronic mail – a system whereby a computer user can exchange messages with other computer users via a communication net
ECG/EKG	the abbreviation for the electrocardiogram
EDI	Electronic Data Interchange, eg, batch data transfer of medical event information
Electronic health record	the collection of health-related information regarding one person and his/her lifetime's healthcare and wellness documentation
Electronic medical record	a collection of patient information consisting of scanned images and text linked by a person identifier (synonym to the computerised medical record)
Entity	the things with separate and real existence that we need to know or hold data about (eg, people, objects, events, etc)
Evidence-based	based on valid empirical information
FTP	File Transfer Protocol – an Internet protocol for sending and retrieving files from file servers which also includes the ability to navigate directory trees
Funder	the Government's agent responsible for funding health and disability support services
Healthcare	all services provided directly to consumers or directly affecting their health; also includes health promotion, prevention, cure, rehabilitation, and services to ensure environmental health
Health status	the state of health of an individual, group or population measured against accepted standards
HTML	Hypertext Markup Language – a language for preparing compound hypertext pages for the World-Wide Web

HTTP	Hypertext Transfer Protocol – a protocol for moving hypertext pages across the network and to manage communication between World-Wide Web clients (browsers) and servers
Hypertext	a data storage and search mode that facilitates the location of related information stored in different files, locations, and sequences, where each reference may open additional sources
Imaging	medical procedures such as X-ray, CAT scan, echocardiography, angiography, etc.
Indicator	a quantitative measure for monitoring clinical care
Information system	a system of functions concerning the acquisition and transfer of information to a user or a group of users
Information technology	technology dealing with information processing, storage, and transmission
Integration	the interconnection of different subsystems or systems into a broader system providing complex functions which require close interactions between its components
Interface	the connection of two independent systems which communicate with each other
Internet	an international communication system and the largest collection of networks that enables computers around the world to communicate with each other
IP	Internet Protocol – an unchecked broadcast packet-switched protocol, one of the two fundamental protocols of the network (see TCP)
IPA	Independent Practitioner Association – group of practitioners (mostly general practitioners) which is formed to provide its members with common services
ISDN	Integrated Services Digital Network – a digital technology for telecommunications with higher bandwidth and better signal quality

Managed care	the system of purchasing services where providers are given responsibility for ensuring that a defined population receives a defined set of services in a co-ordinated way (synonym to the integrated healthcare)
Meta-system	the set of all systems, organisations and people linked together for handling health information
MIME	Multipurpose Internet Mail Extensions – a protocol for exchanging multipart multiformat messages by electronic mail
MRI	Magnetic Resonance Imaging – a clinical imaging method similar to X-rays and CAT scans
Multimedia	a method of combining text, sound, graphics, and full-motion or animated video within a single compound computer document
Network	a system of interconnected components or circuits
Outcome	final consequence or result; a recorded change in the wellbeing of a consumer which is presumed to be or to have been caused by a healthcare event
Peer review	the review conducted by a similarly qualified clinician in the same field
PIN	Personal Identification Number
Prevention	the total of all medical and social measures aiming at promoting health, preventing diseases and disabilities, and preventing or slowing down the spread of diseases
Protocols	rules agreed in advance that are to be followed in decision making unless an exception is sought
Provider	the health service facility or health service worker, eg, a hospital, a general practice clinic, an individual doctor, a nurse
Purchaser	the organisation, which decides at a detailed level and in consultation with its clients, what services should be provided, what mix of services would best meet clients' needs and how those services should be provided (see RHA)

Repository	a place where information is deposited or stored
RHA	Regional Health Authority; there are four RHAs which are funded by the Government on a population-based formula with the role of purchasing total healthcare on behalf of their population
Security	security against threats resulting from the technical features or individual persons involved in an information system
SMTP	Simple Mail Transfer Protocol – an underlying protocol and service for Internet-based electronic mail
Sockets	interface between Unix standard I/O and network communication facilities
Standard	an accepted or approved proposition of a norm or general pattern to be followed and against which others are judged or measured
TCP	Transmission Control Protocol – a connection-oriented error-detecting and correcting-protocol that runs on top of IP and one of the two fundamental protocols of the Internet (see IP)
Telemedicine	the use of telecommunications in the course of providing healthcare services
Telnet	client and server programs for establishing a terminal-oriented connection across the network
World-Wide Web	a collection of cross-referencing hypertext page servers connected by the Internet

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