

# ***Making Knowledge Work for Health***

**A STRATEGY FOR HEALTH RESEARCH**

**Department of Health and Children**

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## FOREWORD

**Mr Micheál Martin TD,  
Minister for Health and Children**

Those of us with a background in education are well aware that knowledge is a precious commodity. Knowledge-based innovation and new ways of thinking are required for the future development of the health services if continued health and social gain are to be realised.

Our understanding of what makes people healthy on the one hand and, on the other hand, susceptible to disease, has expanded dramatically over recent decades. All the indications are that there are even more significant advances ahead in our understanding of human health and disease. How are we to maximise the Irish contribution to this knowledge revolution? How should we ensure that our health services offer all the benefits of this new knowledge to patients and clients? What role can research play in ensuring that everyone has an equal opportunity for health?

This document, *Making Knowledge Work for Health: A Strategy for Health Research*, addresses these issues. It provides a framework for the development of health research to enhance health and quality of life and help ensure that our research compares favourably with the rest of the world. I believe that an active research community working close to the delivery of health care in clinical settings, laboratories, the community, third-level institutions and the healthcare industry is critical to the improvement of the quality of health services generally. It is vital for professional development and career satisfaction of health service staff. It is also important for the translation of ideas into medical and IT products that can add value to our economy.

The *Strategy for Health Research* emphasises a partnership approach to developing a thriving research culture in the health services, a partnership between health agencies, third level institutions, the research charities and the healthcare industry. The framework proposed in this document is built on the foundation of partnership and provides a structure for much greater co-operation between the interests involved. It also recognises the added value to be gained from co-operation in research for the island of Ireland as a whole.

The core proposals in this document are for a strengthening of support for scientific research for health and the development of an innovative research and development function in the health services. These proposals are complementary and mutually supportive. Funding for both strands of the research strategy will be allocated according to the principle of competitive peer review to ensure quality and value for money.

I believe that the implementation of the *Strategy for Health Research* over the next few years will complement the other initiatives I have taken and intend to take to give Ireland a world-class health service. The framework outlined in this document will foster research, innovation and creativity in a way that will improve the quality of health care and the career satisfaction of staff in the health services and stimulate the development of products that will contribute to the economic well-being and reputation of the nation.

*Micheál Martin*

## EXECUTIVE SUMMARY

1. A strategy for health research is needed because
  - Research is a key factor in promoting health, combating disease, reducing disability and improving quality of care;
  - Research is vital if the health services are to become more efficient and effective;
  - Opportunities for high-quality research are a key factor if we are to persuade Irish health professionals to undertake their postgraduate training and subsequent careers in Ireland;
  - More health research can help achieve other government objectives such as implanting the healthcare industry in Ireland.
2. This document reflects the consultation process and emphasises the importance of a partnership approach to building a research culture for health.
3. There are two complementary but distinct pillars required to support a thriving research culture in the health services:
  - Establishment of a research and development function within the health services;
  - Enhanced support for science for health.
4. Establishment of a research and development function in the health services will involve new structures:
  - Appointment of a Research and Development Officer in the Department of Health and Children;
  - Appointment of Research and Development Officers in health boards and in specialist health agencies;
  - Preparation by health boards and specialist agencies of institutional research strategies that reflect health service priorities;
  - Establishment of a Forum for Health and Social Care Research to advise on agreed research agendas addressing the main objectives of the health services;
  - Submission of proposals for funding of research initiatives consistent with the research strategies;

- Review of proposals managed by the Health Research Board on behalf of the Department of Health and Children, with awards made mainly for five years and paid as part of the annual determination.

5. Enhanced support for science for health will require

- Increased resources through the Health Research Board for research units, programme grants, fellowships and career awards, clinical research centres, equipment, information technology and biological banks.

# 1. The Process so Far

In September 1998, the Secretary General of the Department of Health and Children initiated the process of developing a strategy for health research by inviting the Health Research Board (HRB), as the body with a statutory role in promoting health research, to prepare such a strategy. In January 2000, the HRB published a consultation document entitled ***Making Knowledge Work for Health: Towards a Strategy for Research and Innovation for Health.*** This document was a first attempt to define the role of research for health in Ireland, to identify the challenges in developing research for health and to suggest ways in which research and development could become core activities of the health services. The range of issues reviewed in the document revealed that health research has a wider economic and social significance in preparing for the knowledge-based economy and society. It was written in the context of the Government's increasing recognition of the importance of research to future economic and social development and the contribution that research can make to building peace on the island of Ireland through the implementation of the Belfast Agreement.

The response to the consultation document was positive. Over one hundred organisations and individuals responded with comments and suggestions as to how a strategy for health research should be developed and implemented. There was positive welcome for the document, for the systematic analysis of research for health it produced and the proposals it put forward. The response demonstrated a widespread interest in making knowledge work for health and much support for overcoming the many problems that prevent research contributing effectively to the achievement of health and social gain at the present time. Respondents included health policy makers, health service providers, the health professions, health researchers, those involved in other areas of research policy, voluntary organisations, the Northern Irish research community, the healthcare industry and interested individuals at home and abroad.

On 28 March 2000, the HRB organised a conference in Dublin Castle to which all those who had made submissions were invited, as well as representatives of key organisations with a role in developing a strategy for health research. Over three hundred people attended the conference. In his contribution, the Minister endorsed the need to develop research as a core activity of the health services and expressed his support for a national strategy for that purpose. Spokespersons on behalf of the constituencies involved in research for health presented their response to the consultation document and their vision of a national strategy for research for health.

A summary of the comments received on the consultation document and a transcript of the proceedings of the conference are available on the website of the HRB ([www.hrb.ie](http://www.hrb.ie)). Conference delegates were also presented with the results of a survey commissioned by the HRB and carried out by the CIRCA Group on expenditure on health-related research in 1998. ***Making Knowledge work for Health: A Strategy for Health Research*** reflects the contribution made by those who responded to the invitation to comment or who contributed to the conference, even if it does not include all the detailed proposals made. This strategy

outlines the changes the Minister proposes to make over the next five years to ensure that knowledge works for health and that research contributes to tangible increases in health and social gain for the people of this country.



## **2. Research for Health in a Wider Context**

The formulation of a strategy for research for health is taking place at an exciting time for research generally in Ireland and at a time when new possibilities for peaceful co-operation are opening up on the island as a whole. Investment in research has been identified as critical to the next phase of our economic and social development to enable Ireland to compete effectively in the knowledge based economy.

### **The Technology Foresight Programme**

In the National Development Plan, the Government has committed more than £500 million in the period 2000-2006 under the heading of Technology Foresight for research related to biotechnology and information and communication technologies (ICT). 'Biotechnology' has been defined broadly and research in the basic sciences underlying biotechnology, such as cell and molecular biology, is eligible for funding under the programme. The objectives of this investment are to develop world-class research capability in strategic technologies to underpin the future development and competitiveness of Irish-owned industry, to facilitate R & D by multinational companies in this country, to attract more high-tech companies and to encourage the creation of more Irish-owned high-tech companies. A new organisation, Science Foundation Ireland, has been established, initially as a sub-board of Forfás, to manage this programme. The Foundation issued a first call for proposals at the end of July 2000. The Foundation will fund a small number of outstanding researchers who will lead research teams of 3-12 people located in universities, institutes of technology and research organisations. Awards are being made on the basis of competition and international peer review. Funding of up to £1 million a year is being made available for successful applicants. This is an unprecedented level of funding for the revenue costs of research in Ireland and will have a major impact on the quantity and quality of research that can be carried out in a small number of areas related to biotechnology and ICT. The possibility of establishing stand-alone research institutes to conduct research in areas related to biotechnology and ICT remains an option if they are shown to be necessary to develop world-class capacity in such research.

Health policy makers and those responsible for investment in research for economic planning and development share a common interest in the successful implementation of this programme. However, the primary objectives of Science Foundation Ireland and the objectives of funding research for health are different. The logic of the Technology Foresight Programme is economic development, while the purpose of funding research for health is to combat disease, improve health and ensure services of the highest quality. These differing objectives are complementary and both are valid reasons for public investment in research. The Government has recognised the legitimacy of both approaches by making it clear that the funding being made available by Science Foundation Ireland is additional and complementary to any other funding made available for research.

## **Building the research capacity of the third-level sector**

Under the National Development Plan 2000-2006, £550 million is being provided to support research, technological development and innovation in the third-level sector. The aim is to support the development of a world-class research environment in higher education in Ireland by helping to:

- \* improve the research skills and capacity of third-level institutions
- \* raise the quality of teaching and learning activities in the institutions
- \* increase the availability of highly skilled researchers in the labour force
- \* provide greater scope for collaboration between education and other sectors of the economy in respect of research.

This programme, known as the Programme of Research in Third Level Institutions (PRTLTI), is being managed by the Higher Education Authority (HEA) on behalf of the Department of Education and Science. Two rounds of awards have been made under the PRTLTI to date and a third call has been issued. Awards were made following international peer review. Proposals in the biomedical sciences have won a major share of the funding so far awarded. Funding, largely capital, has been made available for the Conway Institute in University College Dublin, an Institute of Molecular Medicine combining the strengths of Trinity College and University College Dublin in the life sciences, a Bio-pharmaceutical Science Network led by the Royal College of Surgeons and a programme of health informatics research led by the Dublin Institute of Technology.

The investment will support a strategic approach by third-level institutions to the long-term development of their research capabilities and will enhance electronic communications in the institutions. It will also support training in R & D skills and the work of the Irish Research Council for the Humanities and Social Sciences and the Irish Research Council for Science, Engineering and Technology.

## **Co-ordination of national research efforts**

The implementation of the Technology Foresight Programme has already provided opportunities to co-ordinate research policy across the key departments responsible and among the key sectors involved in research. The Health Research Board (HRB) was represented on the Implementation Group established by Government to advise it on the detailed implementation of the programme. There will also be a nominee of the HRB/health research community on the Board of Science Foundation Ireland established to manage the programme. A steering group is to be established to assist in co-ordinating the activities of the Foundation with those of other agencies with responsibilities for research and will include a representative of the HRB.

The Irish Council for Science, Technology and Innovation also facilitates co-ordination of research policy. The health research community is not currently represented on the Council. It should be represented, given the contribution of Irish health researchers to the quality of scientific research and technological development in the country. *The Minister will pursue with the Tánaiste and the Minister of State for Science and Technology the appointment of a member of the health research community to the Council, following consultation with the HRB.*

There is also a need to co-ordinate better the range of Government-sponsored supports for funding research. *The Minister proposes that further discussions take place with the relevant Departments to ensure that there is the best possible co-ordination between all State agencies in funding research programmes.*

### **Assessment of adequacy of research equipment and facilities**

The HRB and the Higher Education Authority have commissioned a study to assess the scale of the deficit in equipment and facilities for research in the university sector. The study is being conducted by PREST, a Manchester-based consultancy group specialising in this kind of assessment. Results are expected shortly. It is hoped that the study will provide information for the first time on the adequacy of the facilities and equipment available for research in the university sector. It will provide data on which a programme of investment can be planned and discussed with possible funding providers, among them the Wellcome Trust.

### **Building research capacity on the island as a whole**

The implementation of the Belfast Agreement provides opportunities to build on the successful research initiatives already in place between the research communities on both sides of the border. Close links have developed between the two university sectors and research communities. The research community is by definition international in its outlook: moreover, political borders are increasingly irrelevant to the creation and sharing of knowledge. Closer links have been encouraged in recent years by the North/South Co-operative Research scheme run jointly by the HRB and the Research and Development Office in Belfast, which provides funding for joint research projects related to health, based on competition and peer review.

The co-development of cancer research has been inserted into the Belfast Agreement and there is a political imperative to develop cancer research on the island of Ireland. The Memorandum of Understanding on Cancer Research, signed by the British, Irish and US governments in October 1999, is providing a means to promote an all-island approach to research on cancer. Under its aegis, a joint research programme has been agreed by the National Cancer Registry Board and the Northern Ireland Cancer Registry and will be implemented with funding made available through the consortium established under the Memorandum. Two fellowships in cancer epidemiology are being funded jointly by the HRB

and the Research and Development Office in Belfast, with training facilitated by the National Cancer Institute of the United States. Agreement has also been reached on improving health informatics in clinical services to improve the care of cancer patients. A scholar-exchange programme between Ireland, Northern Ireland and the United States is being established and arrangements are being made to develop an all-island capacity to support participation in clinical trials of cancer treatments sponsored by the National Cancer Institute. *The Minister is committed to maximising the potential of the Memorandum of Understanding to promote research on cancer on an all-island basis and to improve the quality of care of cancer patients. He will support initiatives in other areas of research where an all-island approach would promote closer contact between the two health services and add value to the efforts of researchers to understand disease and improve health and patient care.*

The Technology Foresight Programme provides a particular opportunity to develop the research capacity of the island as a whole and the Minister is pleased that research teams in Northern Ireland will be able to compete for funding. The level of funding to be made available should also facilitate the provision of the kind of research infrastructure necessary to exploit the competitive advantages for research on this island and to ensure that the research community can continue to compete at world-class levels. The competitive advantage lies in the homogenous genetic character of the population of the island of Ireland and the high incidence of genetically influenced diseases. The kind of infrastructure that is required in the future to maximise this advantage includes banks of biological material donated by individuals and families to assist in combating disease and disability, cell lines, colonies of animals with particular characteristics and DNA databases. *The Minister will work closely with the Tánaiste and the Minister for Science and Technology to identify the need for such initiatives and to outline ways in which they could be developed on an all-island basis.*

### **Participation in European Union research initiatives**

A report on expenditure on health research in Ireland in 1998, prepared for the HRB by the CIRCA consultancy group, showed that the EU was the single most important source of funding in that year for health-related research. This is an unusual situation as, in most countries, the main sources of funding for health-related research are the health services or science-funding bodies. EU funding is usually supplementary to funding from national sources. The importance of EU funding for health research in this country in 1998 probably also reflected the particular focus in the Fourth Framework Programme for Research, Technology and Innovation (1995-1999) on explicit support for biomedical research, a focus that has not been repeated in the Fifth Programme. Irish researchers have shown commendable skill in accessing EU funding for research and it is important that they continue to participate in EU-funded research programmes even when the funding available at national level increases significantly. Involvement in EU-funded projects has wider benefits in terms of co-operation with colleagues in other European countries, the development of training opportunities for young researchers and access to research facilities in other member states.

The EU Commissioner for Research, Philippe Busquin, published a discussion paper in 2000 in which he proposed the creation of a single European research area as a means of developing the capacity of the European Union and the member states to compete on the world research stage. Europe is perceived to be losing out to the United States and Japan in terms of investment and support for research and the future economic development of the continent may be affected. *The Minister welcomes the Commissioner's proposals for the development of a common research area in the European Union and for greater co-operation between the research-funding agencies in the member states. The HRB will play an active part in the implementation of these proposals in the field of research for health.*

### 3. Research and Health Policy

Research and the application of new knowledge underpinned the great advances in health and medicine in the nineteenth and twentieth centuries. These advances may be dwarfed by the knowledge that will become available over the next few decades as a consequence of the mapping of the human genome and other discoveries. All the indications are that we are on the eve of one of the most remarkable transformations of understanding of the human body, of health and disease, yet known in human history. This transformation in knowledge will generate much more effective means to protect health and combat disease. The Irish health services must be in the forefront of this transformation and ensure that the benefits of the new knowledge are translated into treatment and care services that are as effective as those available in any health service in the world. The challenge for health policy is how best to engage with the process by which new knowledge is created, communicated and applied, so that

- health can be protected, disease prevented and the effects of disability minimised;
- patients and clients will be guaranteed the most effective diagnosis, treatment and care available;
- the next generation of health professionals will be trained to the highest standards and will maintain their skills over a lifetime;
- the health system achieves its primary objectives of improving the health of the population, responding to people's expectations for better health, and ensuring financial protection against the costs of ill-health (WHO World Health Report 2000);
- The health system contributes to the achievement of wider government goals, such as the building of peace and civil society on the island of Ireland, the reduction of inequality, the protection of the environment, balanced economic growth and development, and plays its part in fulfilling this country's commitments on the international stage.

Such engagement calls for a twin approach to supporting research activities

- support for research in the health, life and social sciences to enable this country to participate in and contribute to the global accumulation of knowledge of health and disease and to the discovery of improved therapies, and
- the development within the health system of a structure to support research and development for the most effective application of knowledge to health problems and to increase the effectiveness of the health system in achieving its primary objectives and wider government goals.

Both approaches are complementary and are essential to the creation of a strong research culture in the health services. They require common measures to support them but, as they are at different stages of development, each approach requires some special measures. This document outlines both the common and the specific measures that will be taken to support the development of a strong research culture. For ease of reference, the first approach is referred to as 'supporting science for health' and the second as 'developing R & D for health'. The differing titles should not be taken to suggest, for example, that research carried out under the heading of R & D is any less rigorous or scientific than that undertaken under the heading of 'science for health'. The distinction does mean, however, that research funded under the heading of 'R & D for health' addresses in a more explicit manner the problems of health and social well-being and service delivery. Research funded under the heading of 'science for health', on the other hand, recognises the need to support innovative ideas that may not have an immediate application but which may contribute to major advances in knowledge and therapy in the longer term.

### **Supporting science for health**

The consultation document (Ch 2) attempted to describe the current understanding of scientific research relevant to health, ranging from the rapidly-evolving field of genomics and proteomics, the related disciplines of cell biology, physiology, pathology and immunology, pharmacology and toxicology, to systems-specific investigations. Bio-engineering and health informatics were mentioned as two areas of research that had significant implications for health. Epidemiology is a discipline primarily concerned with elucidating the causes of disease with a view to prevention. Health services research, health research and practice-based research was identified as contributing mainly, although not exclusively, to understanding the effectiveness of health systems, analysing the extent of inequalities in health and improving professional practice by developing the evidence base for decisions.

The description in the consultation document of the scope of health research provoked much comment during the consultation process from respondents who considered that there was an inappropriate emphasis on certain research disciplines and a corresponding omission of disciplines that have a major contribution to make to understanding health and disease. There was considerable support for a model of scientific research for health based on the disciplines of biology, psychology and sociology, reflecting the complex nature of human health and disease.

The consultation document also outlined the way support for scientific research for health is currently organised and funded. The HRB has traditionally been the main source of funding for individual research proposals, supplemented by funding from Enterprise Ireland and the research charities, with increasing support in recent times from the European Union for proposals involving partners in a number of member states. Funding for such research is made available on the basis of competition and peer review. Because of its complexity and rigour, such research is usually carried out in an academic environment, on the campus of a university or college or in a hospital or other health facility closely associated with a

university or college. One of the strengths of current arrangements is the close relationship that has developed over many generations between the health services and the third-level sector. This relationship has developed mainly to ensure high-quality teaching and training of medical and other health professionals. There was widespread agreement expressed during the consultative process that this relationship should be strengthened to maximise the benefits of science for health. The joint appointment, by the universities/colleges and the health services, of staff with a primary commitment to research is an example of the measures that are required to strengthen this relationship. Not only are such appointments critical to developing the capacity for scientific research for health in this country, they are also important to ensure that young health professionals can train in a high-quality research environment. An active research environment is one of the best ways of guaranteeing high-quality patient and client care and of enhancing the professional satisfaction of health staff. *The Minister acknowledges the critical link between research and the quality of health care. He fully endorses the need for closer relationships between the third-level sector and health providers to strengthen the capacity to conduct high-quality scientific research for health. He will encourage formal agreements between the universities and their associated teaching hospitals to underpin the partnership for research.* Proposals to address the issues of careers in research are made in section 5 of this document.

The relatively low level of funding available for scientific research has been a major handicap in maximising this country's contribution at world level to the creation of knowledge in the health and life sciences and to developing a vigorous psycho-social dimension to research for health. While the funding made available by the Higher Education Authority under the PRTL, together with that committed by Science Foundation Ireland, demonstrate the Government's recognition of the importance of research to future economic and social development, additional funding is also needed to support scientific research for health, with objectives more specifically linked to protecting health, preventing disease and enhancing patient care and professional satisfaction. *The Minister acknowledges the need to enhance the resources available to support science for health and that the objectives of such funding, while complementary to the objectives of the HEA and Science Foundation Ireland, are distinct and require dedicated support.*

From the responses to the consultation document, there would appear to be considerable satisfaction with the manner in which current funding is distributed to support science for health – awarded by the HRB on the basis of competitive peer review. The main problems identified in the consultation process were the relatively low level of funding available for such research – about £6 million a year at the time – and a concern that the HRB did not provide sufficient support for health research in social science disciplines, primary care, health technology or on issues related to professional practice. Some of the criticisms of the research funded by the Board arise from the fact that at present it is the only source of funding for research activities in the health services. With the development of a research and development function, other sources of support will become available for research activities more closely linked to the objectives of the health services that would be more appropriately funded at regional or local level.



## Supporting research and development for health

Advancing research and development (R & D) for health presents a different challenge to that of supporting science for health. Support for science for health, although limited, is long established and procedures well developed. There has not, however, been an organised approach to developing research and development as a means to assist health providers in achieving their primary objectives of improving health, meeting people's expectations and ensuring financial protection against the risks of ill-health. The health services have not yet developed the equivalent of the institutional research strategies that have been fostered in the universities to support the teaching activities of staff and to position academic staff to apply for other types of external research support. Nor has research and development been used sufficiently to enable the health services make an effective contribution to achieving wider government objectives, such as combating inequality. Such research is essential if health policies and interventions are to be of the highest quality, effective and efficient or, in the modern idiom, to be evidence based. Within the health services, there is great potential for strong institutional research strategies building on patient and client involvement, the skills of the large number of professional staff employed, well-developed infrastructure such as the clinical laboratories, the demographic and financial data that are routinely collected and an overall concern among staff with delivering high-quality and effective services. As outlined in the consultation document and confirmed in the consultation process, research in areas of immediate concern to the health services – public health research, health services research, practice-based research and research related to personal social services are underdeveloped, despite individual examples of high-quality work. *The Minister proposes to address this issue by formally establishing an R & D function for the health services at national and regional level with the primary objective of improving the evidence base for health policies and interventions.*

There are a number of initiatives underway in the Department of Health and Children that are relevant to developing R & D for health. A new health strategy document is in preparation that will update *Shaping a Healthier Future* (1994), and provide guidance for the development of the health services over the next 8 years. The new health strategy will provide a framework in which R & D will play an important role in supporting decision making for health. The policy statements and the structures established to reduce mortality from cancer and cardiovascular disease, those dealing with health promotion, environmental health, women's health, the national children's strategy and others in preparation, provide immediate guidance on the objectives that an R & D policy should be supporting. The development of a public health information system that will provide the information on which to conduct research and inform decision making is at an advanced stage. The Report of the Chief Medical Officer for 1999 identified health inequalities as a major challenge for health policy and the health services. The Nursing Policy Division of the Department is consulting widely on a nursing and midwifery research policy that will complement the development of the profession and provide the evidence to support decision making in nursing and midwifery. These developments will complement and guide the establishment of a national R & D policy for health.

The establishment of an R & D policy that is multi-disciplinary and built on partnership with those organisations that have an interest in research requires leadership at national and health

board level. It requires a structure in which consensus can be achieved on the priorities for R & D at national and regional level. It requires investment in developing research skills, in facilities for research and in new communication technologies. It should be funded in a way that will ensure that R & D is embedded in the health services, that the research and development activities are of the highest quality and that there is transparency and accountability in the allocation of funding. The Minister outlines his proposals for the establishment of an R & D function in the health services in the following sections.

## 4. Building a Culture that Fosters Health Research

Supporting science for health and R & D for health are core activities of the health services because they have a critical role to play in achieving greater health and social gain. The **Partnership for Prosperity and Fairness** recognises for the first time the link between investment in research and improvements in health service planning and delivery. This section outlines the steps that will be taken to support both aspects of research for health so that they can contribute to making Ireland a healthier place in which to live and to the achievement of related government objectives. The measures outlined will, over time, develop a culture that fosters research, that respects the pursuit of new knowledge, that addresses the major health problems of the population and in which practice is changed by the evidence of research and its application.

### Promoting research for health through partnership

There was strong support expressed during the consultation process for a partnership approach to supporting research for health. Such an approach is the norm in countries with strong health research sectors. A partnership is required between the health services and the universities, institutes and colleges, the voluntary service providers, the research charities and the healthcare industry. Close links with third-level institutions are necessary to ensure that the research capacity of the academic sector is harnessed to the objectives of research for health – both of science for health and of the R & D function of the health services. The voluntary sector is a major provider of hospital and care services and has an important contribution to make to a thriving research culture. The research charities, such as the Irish Heart Foundation, the Irish Cancer Society, Fighting Blindness, have been raising money for research for many years on behalf of their respective client groups and have a critical role to play in maintaining the interest and support of the public for research. Links with the healthcare industry – the pharmaceutical and medical devices industries in particular – are needed to facilitate the testing of products developed in the laboratory and to facilitate the growth of a strong industry-based research function in this country. *The Minister endorses a partnership approach to building a research culture. The measures he proposes to take to strengthen the partnership approach to research for health are discussed in this and subsequent sections.*

### Support for science for health

The support required to strengthen the contribution of science for health requires increased investment in strategic priorities, rather than organisational or structural changes. Current support for science for health is provided mainly by the Health Research Board which funds on the basis of competitive call and peer review. The HRB funds proposals from individual or small groups of researchers, with the support of their institutions, in a broad range of disciplines related to human health and disease. It funds fellowship programmes to attract

postgraduate students of high quality to research careers in a health-related discipline. The fellowship programme is also designed to build a critical mass of research skills in health-related disciplines, such as epidemiology, health services research and nursing/midwifery research, that are underdeveloped in this country.

Based on responses to the consultation document, there appears to be considerable satisfaction with the manner in which funding is currently distributed to support science for health through the HRB. The HRB provides the structure through which support can be enhanced at national level for science for health. The role of the HRB in supporting science for health is to fund research proposals of national or international significance in scientific disciplines related to health and human disease and, through its fellowship programme, to attract high-quality graduates to a career in research and to build research capacity.

The priority for the future is to build a critical mass of high-quality research in the health-related sciences that reflects the potential of Irish researchers to promote health and combat disease, makes a major contribution to the quality of patient and client care and creates a stimulating training environment for health professionals. A small number of critical steps is required if this goal is to be achieved. The establishment of a sufficient number of well-funded programmes of research that link scientific advances in the laboratory with research investigations in the clinical setting is vital to achieving this goal. Funding for a research programme would only be awarded following competitive call and international peer review. These programmes of research, which are likely to be carried out in teaching/research hospitals and closely linked with their associated universities, would provide a major source of training opportunities for health professionals at postgraduate level. There is considerable scope in developing programmes of research for co-operative arrangements between researchers in both parts of the island.

Research activity on this scale needs infrastructural support in the major teaching hospitals. Clinical research centres (CRC) have proved remarkably successful in the United States and Great Britain in advancing knowledge of illness and improving the care of patients. There was general agreement expressed during the consultation process that one of the best ways of developing the infrastructure for research in the teaching/research hospitals was by the provision of clinical research centres. A CRC provides the physical space and facilities in major teaching/research hospitals to support and develop the research activities of clinical and academic staff. The research carried out in such a centre is patient focused and is aimed at both developing a better understanding of disease mechanisms and evaluating novel therapies. The clinical facilities normally include a small number of overnight beds, a day ward and outpatient areas. Dedicated laboratory facilities may also be provided. The CRC provides a resource for research teams in the hospital and associated university who have won funding for their investigations from public organisations such as the HRB, research charities and the healthcare industry. By fostering a culture of research in the hospital, a CRC makes a major contribution to the postgraduate training of doctors and other health professionals and to continuing professional education. Such centres provide a means by which clinicians and the healthcare industry can test innovative products and the benefits of new therapies are translated quickly and effectively into improved patient care. They also provide a means by which scientists and health professionals who wish to make a career in

research can be employed and work in an interdisciplinary environment. Through common protocols and agreed ethical guidelines, a CRC also helps to ensure the highest standards of research throughout the hospital. As with other funding for research, proposals to develop CRCs in the major teaching/research hospitals should be funded on the basis of competitive call and international peer review.

Another priority is to attract the best graduates into a career in health science and to ensure that there is a career path that is sufficiently attractive to retain them in the field. The absence of such a structure is seriously impeding the development of research at present. This issue is one that needs to be addressed by complementary initiatives under science for health and as part of the R & D function in the health services. Under science for health, the main emphasis will continue to be on fellowships to support health professionals and scientists in developing their skills in health research. In addition there is a need to introduce means of support for more senior personnel – competitive senior research fellowships that would be tenable for five-year periods. The creation of permanent research posts, including posts of physician scientists, and of protected time for research for health professionals in permanent posts, both of which are critical to a thriving research culture, are considered in more detail in section 5 of this document.

The research project grant scheme is the main source of support for health research offered by the HRB at present. The Board has recently reviewed the scope and organisation of the scheme to reflect better the science underlying research for health and to encourage proposals in some areas that have not traditionally been covered by the Board. Project grant funding will continue to be a major part of the support offered by the Board as it is an important way of developing new ideas and training research personnel. Such support will complement funding for research programmes in which the proposed research is more complex, requires a longer time span to develop and involves a wider range of disciplines.

The HRB also proposes to carry out an independent evaluation of the impact of its research funding activities to assess the extent to which they are contributing to knowledge of health, disease and disability, to high-quality treatment and care of patients and clients, to training young health professionals to the highest standards, to making health research careers attractive and to addressing research skill shortages.

In future, the HRB's support for research will be more explicit in its focus. The Board will support proposals of an innovative nature in the health and life sciences and proposals involving the transfer and applicability of knowledge from the health and life sciences to the clinical area.

*The Minister considers that the HRB should continue to be the lead organisation in supporting science for health. He agrees that the strategic priorities for supporting science for health are investment in programmes of research, clinical research centres and greater career support for researchers. He considers that funding for this investment should be channelled through the HRB. He also supports the proposed refocusing of the Board's activities in relation to science for health.*

## Support for research and development for health

The putting in place of an R & D function in the health services requires organisational and structural changes, as well as significant investment. The challenge is to develop a research culture in the key health agencies at national and regional level. The nature of the task suggests that the development of this culture should be the responsibility of a small team of people, headed by a senior person with a national profile in health research and a good understanding of the health services, working within the policy-making structure of the health services, the Department of Health and Children. *For these reasons, the Minister proposes to appoint a person with a strong track record in research and an understanding of the health services to the Department of Health and Children at a senior level to assist him and the Department to develop an R & D function in the health services. In carrying out this role, the R & D Officer will be asked to ensure co-ordination with measures to support science for health. The person will be head of a small Health R & D Office. He or she will be responsible for*

- *The development of an R & D function for the health services;*
- *Supporting health boards/ERHA and national, specialist health agencies funded by the Department in the preparation of institutional research strategies;*
- *Formulation of agreed research agendas to assist in the development of institutional R & D strategies and to guide the commissioning of research, assisted by a Forum for Health and Social Care Research, which he or she will chair;*
- *Liaison with the HRB in relation to supporting science for health;*
- *Adoption within the health services, following consultation with the HRB, of agreed procedures for the commissioning and funding of research;*
- *Co-ordination of the research-related activities of the Department of Health and Children;*
- *Promoting partnership between the health services, the third-level sector, the research charities and the healthcare industry;*
- *Co-ordination of R & D activities with those funded by other Government departments;*
- *Encouraging dissemination of research funded under R & D initiatives;*
- *Promotion of the importance of research and development within the health services and to the general public.*

*The R & D Officer will be provided with the administrative support necessary to carry out the responsibilities attached to the post. He or she will be appointed a member of the Health Research Board.*

## Forum for health and social care research

Important policy documents have issued from the Department of Health and Children in recent years that have set objectives and targets for the health services, for example those dealing with preventable morbidity and mortality from cancer and cardiovascular disease, improving women's health, oral health, and alcohol and health. However, with few exceptions, these documents have not considered what research is needed to understand the reasons why certain health problems are so prominent in his country, to identify the most effective interventions and to evaluate the effectiveness of policies and services designed to combat those problems. If the R & D policies of health agencies are to address health issues in the most effective way, guidance is needed on how research can best contribute to improving health and making services more effective. *The Minister proposes to establish a Forum for Health and Social Care Research to achieve a consensus on agreed research agendas for the major objectives and targets of the health and personal social services. These research agendas would be available to guide decisions in relation to priorities for investment in research and to identify the organisations that are in the best position to conduct or commission the research. The membership of the Forum would include representatives of service providers, relevant professional bodies, the research community, the voluntary sector, the research charities, the third-level sector, experts from Northern Ireland and the healthcare industry. Members may change depending on the topic of the research agenda. In the case of combating cancer and promoting cardiovascular health, the R & D Officer might ask the Cancer Forum and the Cardiovascular Strategy Group to prepare agreed research agendas for their areas. In both cases, additional people may have to be involved to provide the range of expertise that is needed.*

## R & D Officers and research strategies

The health boards and the ERHA are legally responsible for the funding and administration of health services. Health agencies such as the Food Safety Authority, the Irish Medicines Board and the National Cancer Registry Board have been delegated executive functions that are more effectively carried out by a specialist organisation. There is a need to establish a strong R & D function at health board/ERHA level and in specialist agencies to support the achievement of health objectives and to support their planning and service responsibilities. The assignment of responsibility within the health board/ERHA/specialist agency and the preparation of an institutional R & D strategy for health are critical to the establishment of a strong research culture. *The Minister proposes that each health board/authority appoint an R & D officer at a senior level within the organisation. Responsibilities of the the R & D officer would include*

- *formulating and implementing a R & D strategy for the organisation and the agencies it funds that reflects national and regional priorities for the health services;*
- *ensuring appropriate consultation with the third-level sector, the voluntary sector, the research charities and the healthcare industry in the region in the preparation of the strategy;*

- *preparing proposals for funding to implement the regional strategy;*
- *promoting research skills and opportunities within the region/organisation;*
- *liaison with other health boards/authority and national health agencies in the formulation of a research strategy and research proposals;*
- *implementing agreed research proposals;*
- *ensuring good research practice in the commissioning and conduct of research funded by the board/authority;*
- *ensuring that all research funded by the board/authority involving humans or animals is approved by an appropriate research ethics committee;*
- *encouraging the dissemination of research findings;*
- *ensuring that there are systems in place to manage and monitor research activities.*

In preparing the R & D strategies and the proposals for funding, each health board/authority will be guided by the objectives of the health services as set out in the new health strategy and relevant policy documents and the recommendations of the Forum for Health and Social Care Research for agreed research agendas in key areas. Each R & D strategy will also have to address the issues of career support and access to information technology and the provision of infrastructural support such as a health research centre for research activities in the health services. In addition, each health board/authority will have to specify how they intend to develop links with the third-level sector, the voluntary sector and the health research charities and the healthcare industry as part of their R & D strategies. The institutional R & D strategies will provide the foundation on which agencies will be invited to submit proposals for funding for implementation. The process proposed is described in detail in section 10.

### **HRB support for R & D**

The HRB will also have a role in supporting the development of an R & D function in the health services. As outlined in section 10 of this document, it will be involved in evaluating and advising on research proposals based on the institutional R & D strategies of the health boards and specialist agencies. It will continue to commission research on behalf of the Department, linked to objectives and targets of health policy. Its intra-mural research programme, much of which is related to priorities in the health services, will continue to provide the information and analysis that are essential to building a strong R & D function. Through its Fellowship Programme it will be building research skills and capacity that will benefit R & D for health, as well as science for health. The consultation document also proposed that the HRB would develop an advisory role on procedures for commissioning and funding research throughout the health services and a national role in relation to ethical



standards in the conduct of research involving humans and animals. These proposals received widespread support during the consultative process. *The Minister supports these proposals.*

The membership of the Board of the HRB should, as far as possible, reflect the partnership approach to health research described above. *The Minister proposes to broaden the membership of the Board to include representatives of health service providers, the research charities and the healthcare industry. As proposed in the consultation document, he considers that the nominees of the third-level sector and the academic community should include all the universities on the island of Ireland. To encourage co-ordination of research activities, both within the health sector and between health research and the research to be funded by Science Foundation Ireland, he proposes to include a nominee of the Tánaiste and Minister for Enterprise, Trade and Employment. The Minister will also ensure that there is balanced representation of research disciplines on the Board.*

### **The research charities – supporting research for health**

The Irish Research Charities Association, representing a number of voluntary organisations such as the Irish Heart Foundation, the Irish Cancer Society, the Children’s Research Centre, that raise and allocate funding for research, has proposed that science and research should be a beneficiary category of the National Lottery and that funding for health research be made available from this source to charities on a matching-funds basis, to be awarded by competitive peer review. The allocation of funding from the National Lottery to voluntary organisations to fund research appears to be perfectly compatible with the purposes of the Lottery. *The Minister supports this proposal in principle and would support the allocation of funding from the National Lottery to charities that fund research according to agreed procedures for funding research. The research funded should reflect the research agendas agreed by the Forum for Health and Social Care Research on which the research charities will be represented.*

## 5. Supporting People in Research

One of the most effective ways of promoting good research is to invest in high-quality people. This issue is common to supporting science for health and to the establishment of a strong R & D function in the health services. Supporting people of high quality to engage in research emerged from the consultative process as the single most important step that is needed if research is to achieve its potential in this country. Few opportunities exist at present for health professionals to make a career in research or to pursue their interest in research as part of their contractual obligations. Those who wish to do so often make their careers abroad. The number of people engaged on a full-time or near full-time basis in research will always be a small minority of those employed in the health services. However, their influence on the quality of care and on the training environment of health professionals is out of all proportion to their numbers. A greater, but still relatively small, number of health professionals would like to have protected time to develop research interests in addition to their service commitments. They could make a major contribution to developing a research culture in the health services and developing a more attractive training environment. A third group of professionals who are well disposed to research are those who have had some training in a research discipline and who are in a position to interpret new knowledge and apply it to improve the quality of patient care and the effectiveness of service delivery. They require access through information technology to up-to-date research findings and encouragement to keep abreast of current research findings. An increase in the time and opportunity for research in the health services by high-quality professionals will increase understanding of health and disease and will contribute to improved patient care, to more effective health services and to a more attractive working and training environment for staff.

### Medical research consultants

There is no formal recognition in the health services of posts of medical research consultants or physician scientists as they are called in the United States. The HRB has already proposed changes in the academic consultant contract that would facilitate the joint appointment by university/RCSI and health boards/hospitals of consultants with a major commitment to research and a minor service commitment. These appointments are critical to developing clinically-oriented research to achieve the potential that exists in the universities and health services for such research. They are common in systems with a world profile in biomedical research. *The Minister agrees that there is a need to create academic consultant posts with a major commitment to research and will support changes in the consultant contract to this end.*

### Research scientists

Another problem highlighted in the consultative process was the lack of opportunities in the health services for a range of scientists to pursue a career in research or a career in which research and service commitments are combined. Most scientists in health research are

employed on short-term contracts linked to funding for particular research projects. A small number of scientists are employed in permanent posts in services in which the research and service dimensions cannot be separated if the highest quality treatment, care and prevention is to be provided, as in clinical genetics and in bone marrow transplantation and in public health departments of some health boards. Because there are so few permanent posts in the health services, most health research scientists pursue careers abroad, or as university lecturers, or in private industry and their skills are no longer available to the health services. An increase in the number of posts for scientists in the health services is required to support the development of science for health and of an R & D function. The existing posts provide a model on which a more structured approach could develop. Another model that could be pursued is that of joint appointments by the universities/RCSI and the health services of scientists with a major commitment to research and a minor service load, on the model of the academic medical consultant posts discussed above. *The Minister agrees with the need to provide a career structure for research scientists in the health services, with either a full-time commitment or as a joint appointment with an academic institution.*

### **Protected time for research**

A small but significant number of staff in the health services have the interest and capacity to engage in research of a high quality. Their difficulty is that most have no protected time for research. Research activities must be pursued in their own time and sometimes at their own expense and often on top of heavy service commitments. The development of a strong R & D function in the health services would allow clinical staff and managers the opportunity of protected time for research either for a defined period or on an on-going basis. *The Minister agrees with the need for protected time for research and proposes that this issue be addressed by health boards/ERHA and specialist agencies in developing their R & D strategies.*

### **Supporting professional interest in research**

The interest of many professional staff in research and its relevance to their practice could be encouraged with a relatively small amount of support. A basic requirement in the modern age is that all staff in the health services have easy access to the Internet and to databases such as the Cochrane Collaboration, the Web of Science and Index Medicus and that they are trained in how to make best use of the information available. Library and information services are vital to providing this support. The potential of library and information services to support the emergence of a research culture in the health services is dealt with in section 6. These services are also necessary to support professional training and the continuing education that is an increasingly important part of professional life.

### **Attracting graduates to health research**

The strength of the economy is making it increasingly difficult to attract graduates to a career in research. Young people with good degrees have so many choices that they must be

persuaded that a career in health research will be at least as rewarding and satisfying as one offered by any other sector. Health professionals should be encouraged to develop research skills during their career, without damaging their career prospects or putting themselves and their families under undue strain. An increase in the stipend paid to research students on HRB grants, opportunities to undertake a Ph.D. on a part-time basis and more structured supervision by academic departments would assist in making research training more attractive. *The Minister considers that these issues should be addressed by the HRB in developing its schemes for career support.*

### **Building research capacity in specific disciplines**

The consultative process highlighted certain deficits in research capacity that need to be addressed, both to support science for health and the R & D function in the health services. Foremost among these deficits is the lack of research training opportunities in epidemiology. Epidemiology has been defined as the study of the distribution and determinants of disease, other health-related states, or events in specified populations and the application of this study to the control of health problems. It is concerned with understanding the causes, diagnosis and prognosis of disease. Epidemiology is a basic science in both clinical medicine and public health. However, there are few opportunities to train in epidemiology at an advanced level in this country. The Fellowships in Cancer Epidemiology, jointly offered by the HRB and the R & D Office in Belfast under the Memorandum of Understanding on Cancer Research, provide the first opportunity for advanced training in the discipline in this part of the island. There are no postgraduate training programmes in epidemiology, although a programme has been proposed by one university. *The Minister recognises the importance of addressing the deficit in research capacity arising from the absence of postgraduate training opportunities in epidemiology. He will consider ways of supporting such training, in consultation with the HRB.*

## 6. Developing the Infrastructure for Research for Health

Although people are the primary target of investment in developing a research culture in the health services, researchers needed space, reliable equipment, consumables, and access to information technology, to libraries and to sophisticated databases and biological banks if they are to function effectively.

### Clinical research centres

The Minister accepts that the best way of providing the necessary infrastructural support for research activities in the teaching/research hospitals is to fund clinical research centres. Such centres provide a focus on the hospital campus for high-quality research activities, with close links to the associated university or college and involving research charities and the health care industry in their activities. They provide the physical space for research activities and essential research equipment, access to high quality information systems and a structure in which people with valuable research skills can be employed.

*The Minister is pleased that funding has been committed under the National Development Plan to begin the process of developing clinical research centres on the campuses of teaching/research hospitals. The Minister proposes to invite the HRB to award this and any further funding for such centres on the basis of competitive, international peer review. The competition would be open to teaching/research hospitals and their associated universities/colleges. Proposals must be supported by institutional research strategies agreed between the hospital and the associated university.*

The case for research centres focusing on research other than that carried on in university-linked teaching/research hospitals was well made during the consultation process on the Discussion Document. The need for dedicated space to support research into primary care or childcare was persuasively made by a number of key interests. *The Minister proposes to meet this need by asking health boards in preparing their research strategies to identify the capital requirements for space, equipment and information technology required to support their priority proposals. Health boards, in preparing proposals for funding to implement these strategies, may include the cost of providing such centres.*

### Equipment for Research

The Minister signalled his appreciation of the deficit in the infrastructure for research for health when he made £2.7 million available to the HRB for competitive funding for research equipment in 2000. This funding was matched with a further Stg£460,000 made available in a joint call by the Wellcome Trust. This investment, combined with smaller amounts in recent

years, has helped to address some of the deficits in health research equipment in the universities and teaching/research hospitals. The PREST survey referred to above will assess the adequacy of equipment and facilities for research in the university sector and benchmark it against best practice. It is likely that some deficits identified in the university sector will be remedied by a combination of investment by the Higher Education Authority and by the impact of funding from Science Foundation Ireland . *The Minister will continue to provide funding for equipment for health research via the HRB, based on competitive call and peer review.*

### **Libraries and information services**

Libraries provide a key support service in the knowledge economy, especially in areas of research and education. Health libraries occupy a central role both in providing those engaged in research with a means of accessing in an organised way relevant and up-to-date literature and in disseminating the results of research to support the delivery of high-quality, evidence-based treatment and care. The specialist health libraries and the geographically dispersed health board libraries provide an invaluable resource for staff engaging in research and seeking research results. Health library and information services are operating in a rapidly changing environment where technology is providing the potential for universal access to information. If adequately provided with new information technology, researchers throughout the country can be given access to the best databases in the world.

The Library Council, in a 1999 publication, singles out health libraries as having a particularly important role to play in the development of the information society and in supporting research. The National electronic Library for Health (NeLH), established recently in the United Kingdom, makes extensive use of the library and information resources and expertise of the NHS to promote more effective use of research findings. There is a need in this country for a national health information service that would be in the form of a ‘virtual library’ relying on electronic links between existing health libraries. The existing collaboration between health libraries in relation to access to research collections provides a model for further development of this concept. *The Minister supports such an initiative and will ask the person to be appointed as R & D Officer to the Department to plan the establishment of such a service with the relevant interests.*

Funding has also been provided in the National Development Plan to improve information technology in the health services. This funding, by improving access to information technology for health staff, will assist in supporting a research culture.

### **National patient/client identifier and data protection**

A number of factors have been identified as hindering research in the health services. One of these is the absence of a national patient/client identifier that would allow much better assessment of health outcomes and the quality of care patients and clients receive in the health services. This issue is being addressed in the context of the proposal of the Minister

for Social, Community and Family Affairs that every citizen is assigned an RSI number from birth. *The Minister proposes that the same system be used in relation to the health services, with due regard to the need to protect the confidentiality of the professional/client relationship.*

Problems have also arisen in relation to the development and maintenance of databases and registries designed to promote the health and well-being of the population or sectors of the population and their compliance with data protection legislation. These databases and registries, which must be managed on computer, need to achieve maximum coverage of the relevant population if they are to meet their objectives. In addition, with many of these databases and registries, it is essential to record personal information, including name and address, to enable the individuals to be followed up on a regular basis. Under the existing data protection legislation, an individual can refuse to allow personal information to be recorded on computer. Under the proposed amendments to the existing data protection legislation, this right to refuse consent is protected. *The Minister proposes that, where a database or registry is being developed or maintained for the benefit of the health or well-being of the population or a sector of the population, he may exempt that database by order from the consent requirements of the data protection legislation. All other rights of the individual to be informed about the existence of the database and obtain, update or correct the personal information held will be preserved.*

### **Shared high-cost facilities**

There is an increasing need to develop and maintain high-cost facilities, such as banks of biological material, cell lines, colonies of animals with particular genetic traits and highly specialised items of equipment, to enable researchers to conduct research of the highest quality and on equal terms with researchers in other countries. The possibility of providing such facilities on an all-island basis has been referred to earlier, in the context of the opportunities provided by the Higher Education Authority and Science Foundation Ireland to fund infrastructure on this scale. *The Minister will work closely with the Tánaiste and the Minister for Science and Technology to support such initiatives and to identify ways in which they could be developed on an all-island basis.*



## 7. Promoting High-Quality Research for Health

### Commissioning and competitive funding of research

The consultation process indicated widespread support for proposals in the consultation document to establish agreed procedures for the commissioning and competitive funding of research by all the agencies involved, with the HRB acting in an advisory role in this capacity. *The Minister proposes that the R & D Officer, in consultation the HRB, should issue recommended procedures for the commissioning and funding of research, to be adopted by all health agencies involved in supporting research with public funds. It would be a condition of any funding allocated for research by the Department of Health and Children that such procedures are followed in funding or commissioning research.*

### Research ethics

During the consultation process, a number of issues in relation to research ethics were raised. There was widespread acceptance that all research involving human subjects should be reviewed by an objective process to ensure that the research proposed will be conducted to the highest standards of research ethics. The absence of an objective review of all such research at present was identified as a deficit that needed to be addressed. *The Minister proposes to address this problem by asking health boards, in preparing their R & D strategies, to ensure that there is a reasonably accessible means to review the research ethics of all studies involving human subjects and to ensure that no funding is made available from public funds for such studies without an objective, ethical review.*

Another problem identified was the absence of standard guidance on best practice in relation to research ethics, other than clinical trials of therapeutic substances. There was agreement with the proposal in the consultation document that the HRB might develop a role in preparing such guidance. *The Minister proposes to ask the HRB to take on the role of developing guidance on research ethics and good research practice to assist the research community and those funding and reviewing research proposals.* Little information exists on research ethics committees, other than those involved in statutory reviews of clinical trials under the Control of Clinical Trials Act. *The Minister proposes that the HRB collect and make available on its website information on research ethics committees, their membership and procedures in relation to research, other than clinical trials.*

### International conventions

The Council of Europe Convention on Ethics and Biomedicine was adopted in 1996 and opened for signature in April 1997. The Convention, and its accompanying protocols, is one of the most important statements of ethical research practice agreed at international level. Of the EU member states, it is understood that only Finland has been in a position to sign the



Convention and that some of the other member states have difficulties in becoming signatories. In the case of this country, consultation will be necessary before signature is possible. *The Minister proposes that his Department commence examination of and consultation on the Convention and take whatever action may be appropriate with a view to signing the Convention.*

### **The use of animals in research**

Under the European Directive of 1986 that governs the use of animals in research, it is not permitted to use animals for research purposes if another means is available of achieving the same purpose. While there is a long tradition of licensing the use of animals in research in this country, it has not been the practice to ask researchers to justify the scientific validity of use of animals in the proposed study. The HRB now requires the approval of an ethics committee of the scientific validity of the use of animals in research projects before funding is approved. The HRB also proposes to offer funding for research projects that examine the possibility of replacing the use of animals in research, as required under the European Directive. *The Minister supports these initiatives in the interest of ensuring best research practice in the use of animals in research. He proposes that a similar approach should be taken by every health agency involved in funding or conducting research that involves the use of animals.*

## **8. Maximising the Economic Potential of Research for Health**

The health services and the healthcare industry share a common objective in combating disease and promoting health. Both depend on research for advances in knowledge that generate the novel diagnostics and improved therapies on which high-quality patient care depends. The health services are a major customer of the healthcare industry because of the quantity of pharmaceuticals and medical devices they purchase. Less obviously, the healthcare industry is an important customer of the health services because it requires access to patients to test novel therapies and devices. No new pharmaceutical product or medical device can be sold on the market unless it has been tested rigorously and the final stage of testing can only be done with the co-operation of staff and patients in the health services.

Despite some examples of joint research activities of high quality, the extent of co-operation between the health services and the healthcare industry at present does not reflect the extent of their shared interests in developing more effective diagnostics or therapies. Nor does it reflect the fact that 18 of the 20 top pharmaceutical companies in the world and 75 medical device and diagnostic companies manufacture in Ireland. There is considerable potential to improve the level of co-operation between the health services and the industry. Such co-operation will benefit patients as those enrolled on clinical trials tend to receive better treatment and new therapies sooner than they would otherwise. It would enhance the research culture in the health services by increasing the opportunities and funding for research. It would offer opportunities for qualified researchers in this country that currently are only available abroad. It would also contribute to the wider government objective of encouraging the healthcare industry to undertake more of its research activities in this country, as such companies tend to remain in countries where they have strong research interests.

### **R & D strategies and the healthcare industry**

A number of difficulties need to be overcome if the potential for co-operation between the health services and the healthcare industry in research is to become a reality. There has been a certain reluctance to encourage clinical trials in the health services because of difficulties that arose in the past. The Irish legislative framework for the conduct of such trials is now one of the most rigorous in the world. The legislation guarantees that the interest of those who participate in clinical trials is paramount.

A second difficulty has been agreement with hospital management on the level of indemnity to be given by the healthcare industry to cover patients participating in clinical trials.

The preparation of institutional R & D strategies by health agencies provides an opportunity to address these difficulties and to define the relationship of the health services and the healthcare industry. The resolution of difficulties and increased co-operation will be

facilitated by the appointment of an R & D Officer to the Department of Health and Children and of regional officers to each of the health boards/ERHA. The R & D officers will have an explicit remit to facilitate co-operation with the healthcare industry. The provision of clinical research centres in major teaching hospitals and health research centres in the community will provide vital infrastructure to support a much-enhanced level of clinical trials. The further implementation of the Memorandum of Understanding on Cancer Research on the island of Ireland will provide opportunities for participation in high-quality trials supervised by the US National Cancer Institute (NCI). The model of clinical trials supported by the NCI, in which the clinical trials are conducted by independent research associations funded by the Institute rather than by the healthcare industry, provides a model that could be usefully developed in this country. *The Minister favours much closer co-operation between the health services and the healthcare industry in research in the interests of improved patient care and of enhancing the attractiveness of this country as a long-term location for the industry. He considers that the arrangements outlined in this strategy document will facilitate a much better working relationship.*

### **Healthcare Industry-Patients' Organisations Platform**

The research charities are in discussion with the healthcare industry about the establishment of a Healthcare Industry-Patients' Organisations Platform on the model of the European Platform for Patients' Organisations, Science and Industry operating successfully on a non-profit basis at EU level. The aim of the Platform is to improve communication between the healthcare industry and the organisations representing patient groups and to foster co-operation in developing new therapies to combat disease. *The Minister would welcome the establishment of a Platform to facilitate dialogue and linkages between the healthcare industry and the research charities. He looks forward to discussing in due course how the health services can support this important initiative.*

### **Information technology and health services**

The health services provide a unique laboratory in which the advances in information technology can be applied to develop novel solutions to problems of a clinical and management nature. Strong links have already been forged between some of those involved in health informatics research and the health services but there is scope to develop more and wider linkages. The establishment of a health informatics research programme in Trinity College and the Dublin Institute of Technology, with capital funding provided by the Higher Education Authority, is a most welcome development. It will provide new opportunities for co-operative research between the academic institutions and health agencies. The HRB is proposing to give greater encouragement in future to research proposals in health informatics. *The Minister welcomes these developments. He considers that the proposed R & D strategies to be prepared by health agencies will also strengthen relationships between the health services and the third-level sector and lead to more research in health informatics with therapeutic, managerial and commercial applications.*

## Health research and intellectual property

The rigorous protection of intellectual property rights is essential if the commercial potential of research in the health and life sciences is to be maximised. The ‘product’ of research is the intellectual property or new knowledge generated by the research, which is increasingly becoming a commodity. It is knowledge, produced by research, that increasingly determines the economic viability or otherwise of companies. Since research in the health and life sciences is at the forefront of the production of valuable knowledge, the protection and exploitation of the intellectual property produced by research must be given a high priority.

The expense and delay of filing patents to protect intellectual property in member states of the European Union has deterred many researchers from protecting the intellectual property of their research or has encouraged them to file for patents in the USA, with potential loss of income to the Irish economy. *The Minister welcomes the decision of the European Council in Lisbon in March 2000 to ensure that a Community patent is available by the end of 2001 so that patent protection in the European Union is as simple and inexpensive to obtain and as comprehensive in its scope as that obtained in the United States.*

*The Minister welcomes the recent publication by the Irish Council for Science, Technology and Innovation of **Commercialisation of Publicly Funded Research (2001)**. While the report acknowledges that the primary outputs of research are knowledge and education, it emphasises the increasing opportunities to derive economic benefit from the enhanced commercialisation of research. The Council recommends that research funding agencies such as the HRB should encourage commercialisation of the results of the research they sponsor by allocating funding for the initial stages of commercialisation and by auditing research projects already supported to review the possibilities for commercialisation. The Minister welcomes these recommendations and notes that the HRB, in a major call for proposals for research programme grants earlier this year, indicated that it would support for the first time the initial costs of protecting any intellectual property arising from the research funded. The Minister will encourage the HRB to increase support for researchers to commercialise the results of their research in implementing this strategy.*

## 9. Maintaining a Dialogue on Research for Health

A number of those who responded to the consultation document commented on the continuing need to keep the public informed of advances in scientific research relevant to human health. The pace of change is so fast and the advances are so complex that there is a danger that an unbridgeable gap will open between the research community and the general public. The challenge of explaining how advances in understanding of health and disease can benefit individual patients and clients and of how research is vital to high-quality care is an on-going one. So also is the need to convince the public to support and participate in high-quality research activities. The trust and confidence of the public in research can too easily be undermined by poor communication or by bad experiences.

The academic community is increasingly aware of the need to explain scientific advances and to maintain public confidence in science. Several universities have taken the initiative in organising ways in which interested lay people can find out more about scientific advances. The media are also devoting more attention to science. In the annual Graves lecture, the HRB and the Royal Academy of Medicine provide an opportunity for a leading health researcher to explain his or her work to a wider audience. National Science and Technology Week, organised each year by the Office of Science and Technology as part of an EU-wide initiative, provides an important platform for encouraging interest in science-related matters. The HRB will shortly be appointing a communications officer to encourage a better understanding of the research funded and carried out by the HRB. However, more could be done to build a greater understanding and support for research for health among the general public. This is a task that needs to be shared by those with an interest in promoting research for better patient and client care. The research charities – the Irish Heart Foundation, the Irish Cancer Society, Fighting Blindness, the Children’s Research Centre and many others – have a critical role to play in explaining the advantages of research and its importance to improving quality of care. The bodies representing the health professions have an important influence on public opinion and are a significant source of support for health research. Health agencies are in a position to inform public debate on issues for which they are responsible by making relevant research findings easily available to the public. *Given the importance of maintaining public confidence in and support for research, the Minister proposes to develop, in consultation with the key interests, a national and regional approach to the dialogue on research for health.*

## 10. Funding Research for Health

The health services, with a turnover of just over £4 billion a year and employing almost 80,000 people, is the biggest enterprise in the country. It is not, however, supported by research activities appropriate to the importance of its objectives, its size or complexity. The consultation document estimated that expenditure on research funded from non-capital public expenditure on health amounted to £8.5 million in 1998, or 0.26% of total public expenditure on health. The CIRCA Group, in its analysis of expenditure on health research in 1998 prepared for the HRB, estimated that spending from all sources by health boards, hospitals and health agencies amounted to £12 million. By contrast, expenditure on R & D in the National Health Service in England and Wales in 2000 was Stg£500 million, in addition to Stg£350 million expenditure by the Medical Research Council. Expenditure on R & D alone amounted to 1.6% of NHS spending in 2000 in England and Wales.

### Funding science for health

Additional funding is required to put in place the measures outlined in previous sections to achieve the potential benefits from science for health – an outstanding contribution to understanding health and disease, the highest quality treatment and care of patients and clients and a first-class training environment for health professionals. In addition, capital funding over a five-year period is required to provide the infrastructure of clinical research centres, career support, equipment and information technology required to support excellence in science for health. This funding will be channelled through the HRB and awarded according to its high standards of competitive call and peer review. A high priority will be attached to supporting research activities that strengthen the opportunities for research training for medical and other health professionals. The HRB will also focus its funding more on innovative research for health and on research that translates advances in the basic sciences into improvements in patient care. *The Minister proposes that the budget of the HRB should be gradually increased to support high-quality science for health as proposed in this document.*

### Funding R & D for health

There is no existing budget line for R & D for health. The development of an R & D research function that will underpin the achievement of the primary objectives of the health services and contribute to the achievement of other government policies will require current and capital funding. The Department of Health and Children will take the lead role in allocating this funding. This funding will be made available for research activities on the basis of competitive, peer-reviewed proposals from health agencies that are consistent with the agency's research strategy. This is the model that was followed successfully by the Higher Education Authority in implementing the Programme for Research in Third Level Institutions.

*The Minister proposes that the Department will make funding available to the health boards/ERHA and specialist agencies in the first year to enable them to appoint R & D Officers and to prepare institutional R & D strategies. A regional R & D strategy should assess existing research strengths and weaknesses in the area, select issues for research from targets established for the health services at national and regional level or from the agreed research agendas prepared by the Forum for Health and Social Care Research, clarify the relationship with the voluntary health sector and the teaching/research hospitals that it funds, specify the linkages that will be developed with third-level institutions and the healthcare industry and outline how research funding will be managed and monitored and activities reported. It is envisaged that the R & D Officer in the Department will work closely with the regional R & D officers to ensure co-ordination of effort in the preparation of the regional strategies.*

*In the second year, the Minister proposes to make current and capital funding available for research proposals that are consistent with the research strategies prepared by the boards/ERHA and the specialist agencies. He will ask the HRB to manage the call for proposals and to recommend which proposals should be funded based on international peer review. The proposals for funding should be consistent with the regional strategy and with health service objectives and targets at national level. Other conditions that must be met by those participating will include:*

- Proposals should address how careers in research and protected time for research will be supported;*
- Proposals should address how the necessary infrastructure for research will be provided;*
- Proposals should involve a broad cross-section of disciplines represented in the health services;*
- Proposals should involve at least one university/third-level institute, including Northern Ireland institutions;*
- Proposals should demonstrate involvement of voluntary service providers, research charities and independent hospitals, where applicable;*
- Proposals should describe how the research findings will be disseminated and translated into practice;*
- Where feasible, proposals should have an all-island dimension.*

*Further funding will be made available on the same basis in subsequent years. Awards, other than for career support, will be made for five years. Funding for career support will be ongoing. Funding will be made available to health agencies as part of the annual determination by the Department of Health and Children. In the third year, there will be a review of the effectiveness of the research programme funded, carried out by external assessors. At the end*

*of five years, the health boards/ERHA and the specialist agencies will be required to compete again for continuation of revenue funding for research, other than that awarded for career support. Information on the research being funded under the programme should be included in the annual report of the health board/ERHA/specialist agency.*