Making Knowledge Work For Health - Towards A Strategy For Research and Innovation for Health

Summary of Submissions

March 2000

MAKING KNOWLEDGE WORK FOR HEALTH – TOWARDS A STRATEGY FOR RESEARCH AND INNOVATION FOR HEALTH

SUMMARY OF COMMENTS ON THE CONSULTATION DOCUMENT

The Health Research Board wishes to record its appreciation of the number and quality of the responses to the Consultation Document, particularly given the short period of time in which comments were requested. Over ninety responses were received, from institutions, organisations and individuals. Some commented on particular aspects of the document and others responded to all the questions posed. Overall, there was a positive welcome for the document, for the systematic analysis of research for health it provided and proposals it put forward. The response demonstrates the widespread interest there is in making knowledge work for health and the support for overcoming the problems facing health research at the present time.

This summary of responses has been prepared to inform those attending the conference on the 28th March of the main issues raised during the consultation phase. The summary analyses the responses under the questions posed in the document, as well as mentioning some overall comments. A list of those making submissions is attached as an appendix. The numbers in brackets in the text refer to the submission in which a comment was made. This document and the detailed responses will inform the preparation of the more definitive strategy for health research that will be prepared in the near future.

OVERALL COMMENTS

Many responses endorsed the need for a strategy to guide the development of health research. A number of submissions commented on the audience to which the document is directed and suggested that it should include the broader public sector (2), including local authorities and urban planners. The idea of a health impact assessment for all large developments, on the model of the environmental impact assessments, was proposed. Others stressed the importance of the participation of health consumers and informal carers in developing a research strategy for health. (82,10,43,64) The absence of a reference to research into complementary medicine was raised by one respondent. (43)

One respondent felt that the objective of the document was unclear; it could be viewed as a strategy document, as an account of the HRB contribution to scientific life in Ireland or as a statement why the HRB should be involved in the Technology Foresight initiative. (31) Another considered that the document had failed to appreciate the important role and potential contribution of the voluntary health sector to research for health. (32) One submission pointed to the lack of contribution from basic scientists, physicists, engineers and informatics experts to the document and suggested that this omission be rectified before the strategy is finalised.(49)

One submission considered that there should be more emphasis on the successes of the HRB in funding research in a proper peer-reviewed way that is acceptable to most of the applicants from the research community. (54) Some respondents were unhappy about the use of the research examples included in the text. (26,31,39)

HEALTH AND THE KNOWLEDGE BASED SOCIETY

1.1. Is the contribution of research to greater health and the creation of a knowledge based economy and society adequately described?

Many submissions were satisfied with the description of the contribution of health research, in particular with the emphasis on the importance for health sciences research of the links between scientists and clinicians. (26) A few were unhappy with what they perceived was an overemphasis on the economic benefits of such research. (25) Some felt that there should be greater emphasis on the potential cost savings to the health services of investment in research in rehabilitation therapies, service indicators and quality methodologies. (11,59) Another considered that reference should have been made to the problem of attracting researchers to Ireland due to the current cost of living, particularly the cost of housing. (17)

A number of submissions were unhappy with what they perceived was an overemphasis on the medical and biomedical approach to health and an under-emphasis on the psychosocial and environmental dimensions. (40,42,45,60,74,83) One respondent commented that health should have been defined earlier in the document on the basis of a 'biopsychosocial' model of the factors that affect health. (42) Another submission considered that it would have been helpful if the document had identified clearly our current understanding of the factors influencing health and well-being, including biomedical and genetic factors; wider social, economic and environmental factors as well as those relating to health services and social care. (83) Some respondents pointed out that the document did not recognise the changing nature of disease - from acute to chronic- and did not pay sufficient attention to quality of life and the importance of activity and participation as indicators of health. (74,75) It was suggested by one respondent that reference should have been made to World Bank studies that showed that countries that invested in health (including research) and education reaped the benefits 15-25 years later. (58)

1.2 Is the objective of a strategy to make knowledge work for health appropriate?

There was general agreement with the objective as set out in the document. However, some respondents suggested that the objective as defined was difficult to assess or evaluate. (17,80) One respondent pointed out the development of research and development in the health sector is not necessarily linked to the goal of maximising the potential for commercial deliverables and strengthening the Irish economy. (48) Another considered that the objective should explicitly state the need for a balance between the need to gain new insights and knowledge with the need to improve quality, effectiveness, efficiency and equity of the services for more informed decision-making. (66) Others considered that the objectives did not take sufficient account of the contribution of the behavioural sciences in understanding how a patient's knowledge, understanding and behaviour influence health related behaviours, use of health services and participation in health research. (5,18, 42) One respondent suggested that an objective of any research strategy ought to be the creation of a fertile research environment for Irish researchers that up to now have put their expertise at the disposal of major research centres in the UK and North America. (24) A number of respondents welcomed the inclusion of an all-island dimension in the development of a research strategy for health. (1,15,28,37,70,75,83). The benefits of such co-operation were identified as;

- Identifying and responding to shared health problems
- Genetic epidemiology
- Contrasting models of health service delivery
- Studying the impact of different social and economic changes
- Maximising intellectual and financial resources.(83)

One submission asked that the objective be widened to include the early detection of intellectual disability and the exchange of best practice in relation to intellectual disability on the island as a whole. (47) The importance of promoting public understanding of and involvement in research was stressed by one respondent as an essential objective of a strategy for research for health. (53) Reference should be made in the objective to prevention, by vaccination, as well as treatment of human disease. (54) There should be explicit mention in the objective of the role of research in helping recovery and rehabilitation and a return as soon as possible to economic activity. (4)

2: OVERVIEW OF CURRENT RESEARCH FOR HEALTH

2.1 Does the overview of health research reflect the nature of such research?

This chapter of the document provoked much comment. Many felt that, for different reasons, the description in the chapter lacked balance. One submission proposed that that the document should set out the overall goals of all research in the biosciences – to define the aetiology and pathogenesis of human disease, identify and test new preventative and treatment strategies and evaluate the effectiveness of established therapies and the delivery of care – and that these goals are achieved through different disciplines such as genomics, immunology, epidemiology and health services research. On that basis, the same submission considered that health services research received disproportionate attention in the document. (15)

Other submissions considered that there was an excessive emphasis on genetics. (39,65,88) Gene abnormalities associated with muscular dystrophy, polycystic kidney disease and cystic fibrosis discovered independently of the human genome project and the clinical management of these conditions has not altered as a result. A more important priority is the structural analysis of proteins, which is much more difficult than analysis of genes. Understanding protein structure is the greatest scientific challenge and also the most promising approach to the rational design of drugs. (39) The absence of a specific reference to microbiology in this section of the document was seen as a significant omission. (96)

Some respondents commented on the inadequate reference to the achievement and potential of immunology. Immunology has probably made the greatest impact on the understanding, diagnosis, prevention and treatment not only of infectious diseases but also a range of auto-immune diseases and cancers. Much of the competitive funding awarded in this country by the Wellcome Trust and the HRB reflects the importance of the discipline of immunology. The experience and achievements of Irish scientists in this field puts Ireland on the world map in certain niche areas of immunology.(54,76,89). It is essential that any notional biomedical research programme in Ireland should address the issue of infection and immunity, with specific pathogens in mind. (89)

Given the strength of the Irish pharmaceutical sector, in terms of the concentration of companies with production and processing sites, the design, synthesis and development of new pharmaceutical agents should be included as an area of research to be developed. (46)

One respondent considered that the document did not recognise the potential for high quality research in the clinical laboratory services. (96)

Another submission drew attention to the need to support a variety of research disciplines, depending on the objective to be achieved. The fostering of quality assurance and the formulation of an evidence base in practice are important objectives of research that are inadequately covered in the document. There is a perception that the HRB is orientated towards the support of pure science and has been ill-equipped to adjudicate applications for assistance in health service or practice-based research. There is a danger that if the emphasis is on the contribution of research to economic development that the research and development function of the HRB will continue to be under-resourced. (48)

A number of submissions commented that the understanding of epidemiology as portrayed in the document was inadequate (17,68,87). The following definition was suggested '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 (68) It was emphasised that epidemiology as a scientific discipline is primarily concerned with elucidating the causes of disease, with a view to prevention, while laboratory science focuses primarily on the mechanisms of disease with a view to treatment. Epidemiology also addresses the diagnosis of disease (the definition of abnormality) and prognosis. For these reasons, epidemiology is a basic science in both clinical medicine and public health. Epidemiology is not an 'applied discipline' as indicated in the HEA's call for proposals in 1999 under the research investment programme. (68) There is a great deficiency in epidemiological research in relation to disease in this country (58). Ireland has certain opportunities for competing internationally in genetic epidemiology – the nature of the population, its accessibility and the ready availability of health outcome data – which mean that this country could make an important contribution across a range of diseases. (87)

There was a view that nursing and midwifery research received inadequate attention (51,70,78,83,96) Nursing research was described in one submission as focusing on 'understanding human needs and the use of nursing interventions to promote health, prevent illness and effectively treat illness'. (78) Research in nursing and midwifery is required to provide the evidence to inform practice. Given the proportion of health care work that is performed by nurses, and assuming that it should be research-based, it is of considerable importance that nursing research has a chance to flourish. It will find it very difficult to do so if it is forced to compete for funding with disciplines that have a long history and a deep culture of research. There is a need to develop schemes whereby, at least in the short to medium term, funds are ring-fenced for the use of nursing researchers. What is required is a carefully formulated strategy in relation to the position of nursing in health and health care research, possibly developed on an all-island basis. (70)

The chapter was criticised for its inadequate understanding of the contribution of sociology and psychology to research for health. (40,43,53,74,75,92) A priority ought to be the

exploration of social and theoretical issues relating to health. Current sociological concerns include not only the impact on health of external factors such as economic setting but of cultural issues such as how people come to adopt health-related attitudes and methodological issues about how these should be studied. Attitudes and behaviour supportive of, or detrimental to, health are often deeply embedded in culture and assessing them requires subtlety and usually a mullet-methodological approach. The HRB could play an important role in helping to build an interpretive, qualitative research knowledge base in Ireland and encouraging the use of various research approaches in line with national health needs and research priorities (43,74,75)

Some respondents commented on the inadequate discussion of the potential of information technology and health informatics to research for health. (42,49,96) No distinction is made between health informatics and bio-informatics - the latter is non-existent in Ireland, while that of health informatics is well established. (17) Others noted the absence of a mention of the contribution of biochemistry or medicinal chemistry to biomedical research. (27,55,88) Reference should be made to research in palliative care. (18)

There was a welcome for the emphasis on practice-based research (33). However, it was pointed out that the research undertaken by physiotherapists, language therapists and occupational therapists is not limited to practice-based research and that they are involved in a much wider field of research for health. (75) There was concern about absence of reference to veterinary research. (57) The overview of health services research makes no reference to the contribution of sociology. The lack of detail in this section contrast with the detail given under the biomedicine. (60)

One respondent suggested that the term 'health research' be replaced by 'public health research which is defined internationally as research addressing the determinants of health in the population. Public health research is a broad, multi-disciplinary field that is increasingly influenced by the work of researchers with a background in sociology, applied psychology, anthropology, economics, organisational theory, in addition to the more traditional public health disciplines of epidemiology and biostatistics. This change in terminology would help integrate research in this field nationally and internationally. (68)

Reference was made in one submission to the number of important databases that are not currently being fully exploited –the HIPE Information system, GMS prescribing data and VHI data. (20)

Within health services research, greater attention should be paid to assessing inequalities in access and service provision between public and private patients to developing initiatives to reduce these inequalities. (42,43,74)

The absence of involvement of the research charities/voluntary health sector in HRB was identified as a shortcoming of the organisation. (32)

2.2 Is the definition of research appropriate?

Many submissions commented that the definition of research proposed was over-simplified and not comprehensive enough to encompass qualitative as well as quantitative perspectives. (42,51,56,63,67,75,80) Research that tests existing knowledge and produces new knowledge that may not be generalisable should also be recognised as research. (33) The definition should be broad enough to include the assessment of the needs of health professionals who will undergo education and training, the work required to produce clinical audit and pilot programmes. (18) Surveys, routine data collection, the planning and monitoring of research and some software development should not be excluded from a working definition of research. (17,91) The word 'generalisable' should be replaced with the word 'reproducible'. (17) Putting research findings in the public domain is desirable but it is not part of a definition of research. (17,15,31) Some submissions favoured a more general statement, such as 'research is conducted through a process of systematic enquiry by scientific principle. (33,94)

3. SUPPORTING RESEARCH - A SHARED RESPONSIBILITY

3.1 Are the responsibilities of those organisations whose work affects health research directly or indirectly accurately described?

The shared nature of the responsibility was endorsed by many respondents. There is a growing imperative to develop strategic alliances amongst all those engaged in the research enterprise – between the purchasers and providers of research, between public sector bodies and increasingly between public and private sector organisations. These alliances are necessary

- to foster training and career development in research
- to establish major shared facilities such as tissue banks, cell lines, colonies of animals with particular characteristics, DNA databases and patient cohorts
- to develop major areas of science such as genome mapping, brain mapping and clinical research
- to organise and manage large scale, multi-focal trials
- to agree issues of general policy, such as the ethics of research and the use of animals. (63)

A number of submissions clarified or expanded on the contribution made by different organisations to research for health, including the Higher Education Authority (62), the Technology Foresight initiative (35), an Bord Altranais (33,64,94), the Irish Cancer Society (18), the Department of Public Health Medicine, UCD (17), the Institute of Public Administration (67), the European Molecular Biology Organisation (31), the European Union (69), the Irish Sudden Infant Death Association (50), and the Irish Pharmaceutical Healthcare Association (56). The Department of Health and Children is currently preparing a research strategy for nursing and midwifery. (64)

A number of submissions commented on the exclusion of some health research from the terms of the HEA research investment programme. (8,68,95). Laboratory work with a bio-medical application is eligible but not population or individual based research, including

epidemiology, clinical research and the health related social sciences. At present, no agency appears to have responsibility for the capital funding required for such research. (95)

A funding structure for research based on four pillars was put forward in one submission. These structures would involve:

- The unified teaching and research budget to the universities as a block grant. The institution is free to decide on disbursement between teaching and research,
- The funding of individual research proposals/projects following competitive application and peer review, on the model of the funding provided by the HRB and Enterprise Ireland,
- The funding of institutional research strategies following competitive application and peer review, on the model of the HEA programme for research in third level institutions,
- Mission oriented research where institutions respond to invitations for research proposals in priority areas identified by government, such as proposed under the Technology Foresight initiative.(62)

3.2 Are the conclusions appropriate?

There was very strong agreement that research should be a core activity of the health services (17,33,49,51,68,83) A government commitment to rank biomedical and health sciences research among the nation's most critical priorities and key public investments should be sought. (63)

A number of submissions considered that a considerable responsibility exists on the health service to undertake and fund research, particularly where service directed problems are clearly identified. It does not make sense to commit large resources to service units without giving them the resources to identify and solve the key knowledge deficits that must be overcome if they are to complete their mission. (49)

The absence of a reference to the involvement of voluntary organisations in the development of research for health in the conclusions was regretted. (18)

4. PRIORITIES FOR HEALTH RESEARCH

4.1 *Are the priorities identified for each area of health research the right ones?*

There was general agreement with the priorities, with some reservations. One submission considered that there should have been an attempt to prioritise research and suggested a focus on disease states or health issues that are particularly prevalent in the Irish population. (92) A mechanism for defining priorities for research should be established, on the model of Denmark, Sweden and New Zealand. This has had the effect of galvanising public opinion in those countries. (39) Another respondent suggested that there should be some discussion of the ethical principles involved in prioritising research. (64)

Research Centres

There was general agreement with the need for research centres or research institutes based in teaching hospitals. There should be a policy of establishing larger research institutes based on the combined strengths of the teaching hospitals and universities. (49) A major role of such

institutes should be generating and maintaining biobanks of material donated by patients for research purposes. (41) A number of submissions said that such centres/institutes were also needed to develop research in hospitals which were not traditionally seen as teaching hospitals and for research on health taking place outside the hospital. (83) It was suggested in one submission that 'institute' was a better name than clinical research centre as it would avoid the connotation of continuous clinical trials.(41) The research programme of each institute should be reviewed every 10 years for productivity by a panel including international experts. A poor review would involve withdrawal of support. A policy is needed to ensure that intellectual property generated in such research institutes is protected and exploited to the benefit of patients and researchers. The point was made that full-time scientific and medical researchers must be supported by technicians and administrative staff so that they can compete successfully for grants to support their research teams. (41)

Research Units

There was support for funding a large number of research units, on the model of those funded under the successful HRB scheme. Such units are essential to create the necessary critical mass to address relevant research topics and they also bridge the gap between basic science and clinical practice (63) It was suggested that these units should be oriented towards commercial partnership and clinical application from the outset. (32) Another submission emphasised the need for specialised units with a mixture of service support and research functions, on the model of the Pharmaco-economics unit at St James's Hospital. (49) A number of submissions suggested that community settings were also appropriate for research units in epidemiological and health services research. (17,59,66) Consideration should be given to the concept of regional research groups that are bringing together a range of disciplines and organisations in Northern Ireland to research a common theme. (83)

However, expanded funding for research units should not be at the expense of ongoing funding for research projects. (71) There is also a need to protect funding for high quality, fundamental research (31). It is such research that frequently gives rise to the most effective improvements in biomedicine. There is also a need to foster 'blue skies' research, on the model of the Wellcome Trust scheme. (8,76,80,96) One respondent suggested that the HRB should make a strong case for introducing major project and programme grants along the lines of those of the Wellcome Trust. (54)

Career Structures

Overwhelming agreement that the absence of good career structures and protected time for research are a major handicap to the development of research and that action is urgently required involving all agencies with responsibility for employment in the health services. (6,8,17,21,39,44,49,53,62,63,69,92, 27,76,80,86,89,95,96) One submission drew attention to the critical role played by Comhairle na nOspideal in regulating senior medical and biochemistry posts in the health services and the role it could play in implementing a national research strategy for health. (81) Another suggested that the growth of private insurance in this country made it very difficult to attract young physicians into areas where a large amount of their time will be spent conducting research. (86)

One respondent expressed caution about following the US research career model in medical research, where reverence for basic research and relative disdain for clinical research in recent years has been one of the factors leading to a crisis in academic medical centres. A better

model may be the liver unit at the Barcelona Hospital clinic directed by Juan Rodes, founded in 1968 and now regarded as the foremost clinically based centre of hepatology in the world. The unit integrates clinical and basic researchers. (39)

The absence of a career structure and poor salaries are a major handicap in attracting high calibre scientists to work in health related research. As employment opportunities increase in other better paid fields, this problem will get worse if something is not done. (76,89) An equivalent career post to that of the consultant clinical scientist in the NHS should be considered in Ireland. (89) There is also a need to recognise the potential of laboratory staff to contribute to clinical research and the need for fellowships, career structures and protected time to do so effectively. (8,96) Appropriate financial support for post-graduate research, supportive mechanisms to develop research as a career and the preparedness of third level institutions to cope with the anticipated increase in research activity are recognised as issues that require resolution. (62) One submission proposed more structured support for PhD students, on the model of the UK 5 year demonstratorship-type positions. (53) At present, there is no career position in a community speciality that has dedicated time for research, a situation that clearly needs to be changed. (8)

One submission drew attention to fact that the full time nature of the GMS contract does not facilitate participation in research by participating doctors and proposed joint appointments between health boards and universities in general practice, on the model of other clinical disciplines. (95)

The importance of research to continuing education of health care providers was stressed in submissions (33,41) The need for more research training opportunities was mentioned by a number of respondents. (68,95) Great emphasis should be placed on graduates receiving formal training in clinical research. (39) Training in epidemiology and biostatistics are of particular relevance to ensuring high quality clinical, epidemiological, public health and health services research. Consideration should be given by the HRB to offering a fellowship programme that would include a one-year, full-time master's programme in epidemiology and biostatistics. The Wellcome Trust Training Fellowships in clinical epidemiology provide a model that might be followed. (68) Interested clinicians should be given the opportunity to pursue a Ph.D. programme. (89)

Epidemiology

The section on epidemiology does not mention primary care or mental illness, although both are neglected areas. (3,63) There is a need for dedicated training in epidemiology if its contribution to research for health is to be realised. (59,63) Information systems for the health sector is an area of research that needs to be developed. (63)

Health Service Reseach

One submission considered that the balance between different aspects of health research needed to be tilted further towards behavioural science type health research, health services research and practice-based research, particularly because this kind of research addresses the local and national needs of the health and social services. It will not be carried out elsewhere and is unlikely to be funded internationally. (3) One respondent argued that a compelling case can be made for a health services/policy research unit, independent of the existing medical schools and the Department of Health and Children, can be made. The RAND Institute in

Santa Monica, California is a relevant model. A unit could become the definitive provider of data and analysis for decision making purposes, analysis of regional and socio-economic disparities in access to care and the use of therapies of proven efficacy for serious and common ailments such as myocardial infarction. (39)

One submission addressed the difficulties faced by those involved in health services research (HSR) in publishing in international, peer-reviewed journals as by definition, the context of their work is of national or local interest. HSR researchers could be encouraged to publish in their parent disciplines and the HRB could develop a publication series that would make available major Irish health services research. (53) Another proposed that each health board should develop a formal strategy in relation to research that would involve ring fenced funding based on strategic priorities at a regional and national level. (95)

Practice-Based Research

If practice-based research is to be valued and developed, it requires the same explicit and comprehensive recommendations as made for health services research. (95,83)

4.2 Are there other improvements that could be made in any area of health research?

Primary Care Research

Some submissions considered that specific emphasis should be placed on the need for primary care research and that 'pump-priming' on the model of Scandinavia, Holland and the UK is required. (8,95) A special effort is needed to develop the skills of primary care practitioners to enable them to make an important and unique contribution to the overall health research agenda. This will require infrastructure support – premises, personnel and IT- and research training. The model that has been used to support health services research is suggested. The HRB should consider introducing Primary Care Research Fellowships for clinicians in primary care to enhance research capacity and that ideally could be held on a part-time basis. (95)

Other Issues

Improvements could be made in raising awareness of the contribution of research to clinical practice, education and management, and health boards could play a major role to this effect. Health boards might organise annual research conferences focusing on health, illness and disability and promote partnership with the university sector. (51) Insufficient attention is paid in the document to the need to involve industry in bringing potential therapies through to the market place for patients. (32) Some pilot schemes to promote greater links between research institutions and the pharmaceutical and medical devices industries were proposed. (63)

There should also be reference to the need for research in this country on women's health, the long-term protective benefits of breast feeding against disease and the increasing importance of complementary and holistic medicine. (30,43,60) Prescribed drug usage was also suggested as a fruitful field for research. (45) Environmental impact issues are having an increasing impact on health service activity. There is little evidence available on which to make decisions and they should be the subject of research. (72) There should have been greater attention paid in this chapter to research into learning disabilities, mental illness, and premature deaths attributable to suicide (6,34,58,60)

Exempting research equipment and consumables from VAT should be considered (15)

The CIRCA study on research expenditure should be repeated on a 5 yearly basis. (59,66)

4.3 How should research in personal social services be addressed?

There is support for extending the remit of the HRB to include research relevant to personal social services, rather than establish a separate body as in the UK. Respondents proposed that the HRB could establish a research committee to evaluate research proposals in this field. (53,63,95) Consideration should be given to establishing a research unit in health and social care. (92) One submission envisaged a role for health boards in encouraging and funding this kind of research. (18) Some submissions proposed that research for personal social services should be included under the heading of health services research (17,74), while another considered that it had a different focus to health services/health research and that the agenda needed to be set outside the health research agenda. (91) One respondent suggested that the proposed Health Research Forum should be called the Health and Personal Social Services Research Forum (37). The definitive strategy for research for health should be called a strategy for research for health and personal social services (10). The need for a multi-disciplinary approach to personal social service research was stressed by one respondent. (42)

4.4 Should there be agreed research agendas for priority objectives of the health services?

There is general agreement with the proposal for research agendas. The potential benefits of the agreed research agendas would be to facilitate concerted action, highlight gaps that should be addressed and minimise duplication and overlap of effort. (63,77) The research agenda should not be too narrowly defined (32) There is a need to agree a research agenda in the core areas of cardiovascular research, mortality reduction, cancer, mental illness and health equity. (37,63) However, some respondents felt that it was important to retain flexibility to meet local and national needs. (17,51) Others considered that support for future research should be based on health need and greatest gain on a population basis. (59) Another argued that rare disease should not be ignored. (32) Paediatric research should be a defined element of any national strategy for health research (21).

4.5 If there should be such research agendas, how should they be agreed and financed?

The research agenda should flow from the national health strategy, and the key sub-strategies that are developed, such as combating cardio-vascular disease. (91) In agreeing and financing the research agendas, there should be a broad representation of professional groups, voluntary organisations and client groups and a balance between quantitative and qualitative methods. (75)

5. PROMOTING HIGH QUALITY RESEARCH

5.1 Are the proposed guidelines for commissioning research acceptable?

There is general agreement that guidelines are required for commissioning research and with the guidelines proposed in the document. There is concern about the extent to which public

funding for health research is currently allocated without peer review or equality of opportunity in application for funds. There should be national advertising and peer review where more than £20,000 of public funding is involved. (53) The need for each health agency to have its own commissioning procedures was raised in one submission and it was suggested that the HRB could carry out this role. (69) There should be agreement on the ownership of data, on the nature of the report and the data to be returned to the organisation commissioning the research. (42)

5.2 Are the proposed guidelines for competitively funded research acceptable?

There is support for the proposed approach to competitive funding. (48,51) Some submissions expressed dissatisfaction with methods in which some funding for research was disbursed, by comparison with those used by the HRB. (48) It was suggested that the same peer review of external projects should apply to intra-mural projects in the HRB. (53) The issue of data ownership in competively funded research needs to be addressed. (17) The importance of referring to the provision of feedback to applicants in any guidelines was stressed. (63,95).

5.3 Should the HRB have a role in assuring quality in commissioning and competitive funding of research in the health services and in good research management?

There is agreement with this proposal among those who addressed this question. (1,6,51,63,91,66,95) One submission emphasised the need for all those involved in assessing research proposals to be themselves actively involved in research. (51) Another respondent suggested that quality assurance might come from a number of sources - the Health Research Forum, centrally in the health board and through links with other research institutions. (20)

One respondent proposed that one way of highlighting good quality research for health would be to have a national competition each year that would help put such research 'on the map'. There could, for example, be a health research medal awarded for the work of professorial departments, senior researchers, student researchers and the best science book of the year. (23)

5.4 Are the safeguards for human subjects of research and for animals used in research adequate, and if not, what more is required?

There is agreement about the importance of the ethical dimension among those submissions that responded to this question, although some respondents felt that the issues should have received more detailed attention. (24,34,37,53,74,85) Issues that need to be explored include the concept of harm, the appropriateness of interventions as well as new issues thrown up by advances in medicine, bioethics and the health sciences. It is crucial to perform up-to-date philosophical analysis of these developments (74,85) No systematic documentation or research has as yet been compiled or undertaken for issues connected with Irish cases. Such research is necessary to support the formulation of national guidelines on public policy on health issues. (85)

One submission considered that the safeguards for human subjects of research currently in place are comprehensive. Additional safeguards would not necessarily result in better

research or patient care but could be prove a disincentive to the conduct of clinical research in this country. (56) There should be consumer representation on ethics committees and institutional review boards. (82) The Government should ratify the forthcoming Council of Europe protocol on medical research and the Council of Europe Convention on the protection of animals used for experimental and other scientific purposes. (63) The importance of training of research students in the ethics of research was stressed. (34) Two submissions commented on the inadequate provision for ethical assessment of research in the community. There is an urgent need to provide a framework for the ethical consideration of community based research or university based research that is primarily community-based. (8,17,95) One submission commented on the difficulty in ensuring that hospital ethics committees had available to them all the expertise they needed to assess research proposals and suggested that a national research ethics committee be considered. (24)

Some submissions proposed that the HRB may have a valuable role to play in assisting all those involved in research for health to achieve a national set of common principles of good practice that would save staff time spent developing these guidelines in individual institutions. (53,37) The HRB could also be more proactive in promoting good research practice in the management of research staff, particularly students. (53) The HRB should produce a policy document on the issue of 'ownership' of DNA and body tissue for the research community. (58)

One submission regretted that the document had not addressed the problem of indemnity necessary for pharmaceutical clinical trials in humans. It suggested that there was urgent need for an indemnity agreement that could be used by all institutions once a clinical trial had been passed by the relevant ethical committee(s). (8) One submission referred to the ethical problems in conducting clinical trials for new drugs for childhood problems, even when the evidence suggested that the new drug had less serious side effects than the conventional treatment and the need to find a way around this problem (9) The importance of the evaluation of new therapies was stressed and their potential for economic and health gain for our society. (48)

Ethics committees should be independent of the firm/organisation sponsoring the trial or the research. (58)

5.5 How can the dissemination of the results of health research be improved?

One submission stressed that responsibility for the dissemination of research findings and their implications is shared by all professional groups and their organisations. (1) Practical suggestions as to how dissemination could be improved included a proposal that all research projects should have an in-built dissemination, implementation and audit plan and that disclosure of research results should be a condition of the grant funding. (59,17,18) The HRB should support current national journals, especially those recognised by Indexus Medicus and make seed funding available to develop peer-review journals in various disciplines. (51,95) The development of new all-Ireland journals should be considered. (95) There is a need for a dedicated journal for health services research. (79) The HRB could publish position papers on research issues of public concern. (63)

The HRB should encourage dissemination of research that it funds by making available on its website reports on finalised or ongoing research. One submission suggested that the website could be expanded with a new or branched site for the general public and that the Board could also publish a 'Journal of the HRB'. (58) A data archive of all on-going and completed research in health is required. (17, 67,94) The HRB might develop such a database on its website. (67) Another submission suggested that the HRB could be a 'one-stop-shop' to find out what is going on in health research in Ireland. The website could become a virtual campus with copies of papers available in PDF format. (79)

The document confuses 'dissemination' with 'exploitation' of research results. A number of universities are actively involved with industry in the exploitation of research findings and a number of other useful models exist. (15)

The issue of dissemination should be addressed as part of the research agenda in a given 2-3 year period. (91)

Some submissions emphasised the importance of creating popular awareness of the excitement of the work being carried out by Irish scientists to ensure that there will be growing and ongoing public support for this essential national enterprise. (32,63)

6. STRUCTURES TO SUPPORT RESEARCH FOR HEALTH

6.1 Are the proposed structures adequate to ensure that knowledge works for health?

Co-ordination of National Research Effort

The need for greater co-ordination of research effort at national level was commented on by many submissions. It was suggested in one submission, however, that because research is a much broader activity than covered by science and technology, that the remit of the existing co-ordinating group that is jointly chaired by the Office of Science and Technology and the Department of Education and Science, should be expanded to cover all research funding. Such a group could have a key role in ensuring that there is full co-operation between all state agencies involved in funding research programmes. (62)

A number of submissions considered that the HRB should have a role in the implementation of the Technology Foresight initiative (21).

Coordination of Health Research at National Level

There is general support for the structures proposed, particularly for a Health Research Forum and for representation of the health research community on the Irish Council for Science and Technology. The Forum would encourage convergence between the need for health research as perceived by policy and decision makers on the one hand and the research priorities set by the research community on the other and the document should emphasise this role in greater detail. (69) It could have an all-Ireland perspective. (1) Some considered that the Health Research Forum should be attached to the HRB, to ensure independence and a 'bottom-up' approach. (15,91) Others thought it should be attached to the Department of Health and Children. (63). Another agreed that a co-ordinating body/forum is required but considered that it should be independent of the Department of Health and Children. (17) There should be

consumer representation on the Forum. (82) The professional nursing organisations should be included in the national co-ordinating arrangements for research. (33)

Promoting Research at Regional Level

There is widespread support for the regionalistion of research endeavours and the development of a partnership between health boards and third level institutions. (20,37,38,51,52,63,66,67,68,80,88,95) The co-operation of the health boards is seen as critical to the success of epidemiological, health service research, health research and practice-based research and requires the formal involvement and funding of boards. It is also seen as important for the development of clinical trials. The Public Health Departments could lead this function of research co-ordination at a local and regional level, although health boards need to ensure that all disciplines are supported to conduct their own research. (20,37,66) One submission identified the following as necessary if health boards were to meet this challenge;

- A culture that fosters research
- A structure within which trained researchers work
- A structure and a process that enables as many people as possible to have basic training in research methods
- Improvement to information systems
- Better access to information systems
- Information and communications technology and presenting proposals (20)

The geographically dispersed health board libraries provide an invaluable resource for staff involved in research. If adequately provided with new information technology, researchers can be given access to the best databases in the world. (61)

A number of submissions emphasised the importance of links with third level institutions, for example, to help bridge the training gap in health boards (20,66,95) A difficulty identified in one submission was that many of the academic institutions are not oriented towards health services research and are not familiar with framing research questions relevant to health services. (20) One suggestion to get around this problem was the appointment of a University linked epidemiologist or research co-ordinator to the region. (66) The person appointed to co-ordinate research at health board level should have the necessary academic and research qualifications to take on the job. (51) The role of this person should be to facilitate research and eliminate unnecessary bureaucracy, rather than adding to it. This person should be able to offer a 'one-stop' service for pharmaceutical companies that wish to carry out clinical trials in health board hospitals. (56) Another submission suggested that it might be better to co-ordinate through a committee composed of members representing a variety of disciplines. A specially designated post could carry the responsibility for overseeing the implementation of the programme agreed by the committee. (43) A small number of joint appointments and studentships have been created between the health board departments of public health and the third level institutions that could be further developed, particularly to support health services research. (2,14) Joint ventures involving the HRB and the health boards might be usefully explored. (63)

One respondent proposed that the health boards should as a group establish a research and development unit that would commission research addressing specific, agreed priorities, using the expertise of the HRB in research management and peer review. (68) The importance of a health board budget line for research was stressed. (36)

6.2 If not, what other structural changes are required?
One submission proposed that research co-ordinators are also needed in the larger hospitals to ensure a co-ordinated approach to research with the third level sector. (16) Health boards, in funding the hospitals, should provide funding for research as part of the normal budgetary process. If this funding were made available, health boards and hospitals could agree their research programme through the annual service plans. (16)

One submission suggested that there is arguably a case for a National Health Statistics Institute, on the model of the French CREDES, to co-ordinate and publish national health statistics. (67)

One of the major deficiencies in research in this country is in the area of technology assessment. There is a need to establish a permanent structure to conduct this function, to develop guidelines and protocols. Consideration should be given to contracting expertise from abroad to start this process. (20,88)

One submission suggested that the universities/colleges might develop a research support and strategic research advice service for health boards, on the model of the Welsh University-based research support units funded by the Welsh health department (83)

Consumers should take an active part in working with industry and scientists to design clinical trials. (82) A Platform incorporating all relevant parties, similar to the European Platform for Patient Organisations, Science and Industry should be established to promote medical scientific research with a view to expediting the development of navel therapies, treatments and diagnostics. (32)

7. MAKING KNOWLEDGE WORK FOR HEALTH

7.1 Are the steps outlined above to enhance health research the right ones?
Commitment of the Minister and Department
There is general agreement with the steps proposed under this heading. The key to initiating a successful strategy will be obtaining the commitment of the Minister and the Department of Health and Children. (63) There is widespread concern about the inadequacy of funding for research and support for the proposal that a proportion of the non-capital health budget be allocated for research. Funding for research should be at the same level as that of comparable OECD countries. (63) The research agenda should be an integrated part of the national health strategy. (91) The research charities/voluntary health sector should be involved in developing a national research strategy for health. (32) The Department of Health and Children should ensure that there are no unnecessary administrative delays or impediments in the research process. (56)

7.2 Are other steps required? 7.3 If so, what are they?

Increasing the links between the HRB and the pharmaceutical sector could offer great potential for developing research in Ireland and providing employment for science graduates and postgraduates. (71,76) Consideration should be given to agreeing a common approach throughout the health services on issues such as indemnity for clinical trials. (56)

While the document deals with the need for links with the pharmaceutical industry and associated laboratory research, the need for parallel developments with the medical devices and medical equipment industry are inadequate. Ways in which the health service could become a catalyst to increase the commitment of the medical equipment industry to conducting research within the country are not highlighted. Identification of strategically important directions requires consultation with medical physicists and bio-engineers in the hospital service and the universities, as well as in the industry. (49) The Government should consider some form of private-public partnership to ensure that more biotechnological and pharmaceutical research takes place in this country and the HRB could play a pro-active role in such an initiative. (54)

One submission drew attention to what it described as the 'missing chapter' in the document. While the document acknowledges the role that research can play in economic development, it fails to describe it adequately. There is a need for the HRB and Enterprise Ireland to work closely to devise ways in which the two organisations could bring their particular expertise together to the benefit of the economy (29)

There should be a partnership between statutory and voluntary organisations in the development of a strategy for health research. (18) The Department of Health and Children should support the research charities' request that medical research be included as one of the areas to be funded by the National Lottery. (18)

An overall co-ordination body for research should be appointed. (17) Consideration of efficient use of resources indicates that a cross-border body on health research should be instituted as part of the process of building cross-border implementation bodies. (70) It was suggested that it may be premature for the HRB to offer research grants on an all-island basis and that co-funding arrangements may be more suitable at present. (63)

Given the importance of networking to competitive advantage in commercial and academic enterprise and the propensity of Irish medical and science graduates to emigrate, the HRB should sponsor development of a single database of Irish medical and scientific graduates, available on the web, which is kept up-to-date to foster effective networking. The HRB should sponsor conferences which could be held at strategic locations at regular intervals to catalyse networking of Irish graduates. (39) There is a need to foster research societies for scientists in Ireland. (76)

The HRB might consider seconding staff from the university or health service to assist it develop a strategic approach to research for health. (53)

The HRB could play a valuable role in developing the unique patient identifier that is so vital to the establishment of patient databases. (53,83)

The HRB should have a role in working with the health boards and the Health Board Executive Agency in regard to a research agenda at health board level. (91) The need for closer links between the health boards and academic research units should be given more attention. Health boards are the first to identify the issues and research questions to be addressed; the research community should be charged with providing the answers. (69) There should be representation of nursing and midwifery on the Board of the HRB and and the HRB should have a nursing/midwifery research advisory division. (33,64,94)

The HRB might consider establishing a centre or unit for interdisciplinary health research (74)

One submission suggested that there may be a conflict of interest for the HRB to be a main channel of public funding for research at national level and, to be at the same time a growing research body (37). Another expressed support for the role of the HRB in co-ordinating research on the mental health services. (38) Membership of the Board of the HRB should include more than one nominee of the health boards (37). It should also include a representative of the research charities/voluntary health sector. (32) It should include one or two members with no vested interest, other than that of creating a health population. (45)

The following were proposed as the main functions of the HRB vis-á-vis the health services;:

- To encourage and stimulate research from a broad base of disciplines and between disciplines
- To work towards ensuring equity in terms of involving people, groups and centres in the different regions
- To circulate information on a sufficiently regular and effective basis in relation to key areas of health and social services research
- To disseminate research findings
- To monitor and work towards ensuring the quality of health and personal social services research
- To continue to enhance cross border co-operation in relevant areas of research (37).

APPENDIX LIST OF SUBMISSIONS RECEIVED

1. Prof. Ingrid Allen	Research & Development Office, Belfast
2. Dr. Joseph Barry	Department of Public Health Medicine, EHB
3. Prof. Colin Bradley	Dept. of General Practice, UCC
4. Mr. Tony Briscoe	Irish Business and Employers Confederation
5. Nessa Burke & Miriam Lynch	Health Research Board, Dublin
6. Mr. Jerry Buttimer	COPE Foundation, Cork
7. Dr. G Johnston Calvert	The Royal College of Psychiatrists
8. Dr. P A Carney	Clinical Science Institute, NUI Galway
9. Dr. Anthony Carroll	University College Hospital, Galway
10. Mr. Bob Carroll	National Council on Ageing and Old People
11. Brian Caulfield	UCD School of Physiotherapy
12. Judith Chevasse	Health Research Board, Dublin
13. David Coleman	School of Dental Science & Dental Hospital
14. Dr. Rosaleen Corcoran	Public Health & Planning, North Eastern Health Board
15. Dr. Art Cosgrove	President, UCD
16. Mr. Martin Cowley	Mater Hospital, Dublin
17. Prof. Leslie Daly et al	Dept. of Public Health Medicine & Epidemiology, UCD
18. Mr. Barry Dempsey	Irish Cancer Society
19. Prof Michael Dexter	The Wellcome Trust
20. Dr. Patrick Doorley	Midland Health Board
21. Mr. David E. Doran	Children's Research Centre, Our Lady's Hospital for Sick Children
22 Mr. Liam Doran	Irish Nurses Organisation
23. Dr. David J Dowsett	Medical Physics Consultants
24. Dr. Declan Lyons	Regional Hospital, Limerick
25. Dr. Louise Drudy	Dept. of Obstetrics & Gynaecology, Rotunda Hospital
26. Prof. B. Drumm	Children's Research Centre, Our Lady's Hospital for Sick Children
27. Dr. David Evans	Dept. of Public Health, Western Health Board
28. Mr. Clive Gowdy	Dept. of Health, Social Services and Public Safety, Belfast
29. Mr. Dan Flinter	Enterprise Ireland
30. Ms. Forestier-Donnelly	La Leche League of Ireland
31. Prof Frank Gannon	European Molecular Biology Organization, Heidelberg, Germany
32. Mr. Michael Griffin	Fighting Blindness
33. The Irish Nursing Research Interest Group	
34. Ms. Mary M.Keane	Hospitaller Order of St John of God
35. Dr. Killian Halpin	Forfas
36. Dr. Karena Hanley	The Irish College of General Practitioners
37. Mr. Pat Harvey	North Western Health Board
38. Mr. Brian Howard	The Mental Association of Ireland
39. Dr. Kevin Horgan	Merck Research Laboratories, USA
40. Prof. Jack E. James	National University of Ireland, Galway
41. Mr. Nicholas Jermyn	St. Vincent's University Hospital, Dublin
42. Orla Keegan	Bereavement Service, Research and Education
43. Patricia Kennedy	Department of Social Policy and Social Work, UCD
44. Dr Dermot Kenny	Clinical Research Centre, Royal College of Surgeons in Ireland.
45. Ms. Alice Leahy	Trust, Dublin

46. Dr. Anita Maguire	Department of Chemistry, UCC
47. Ms. Gina Magliocco	National Federation of Voluntary Bodies, Galway
48. Dr. Niall Maguire	Irish College of General Practitioners, Navan
49. Prof. J. F. Malone	Faculty of Health Sciences, Trinity College, Dublin
50. Prof. T. Matthews	Irish Sudden Infant Death Association, Dublin
51. Prof G McCarthy	Department of Nursing Studies, UCC
52. Dr. McCulloch	School of Public Policy, Economics and Law, University of Ulster
53. Prof. Hannah MacGee	Health Services Research Centre, Royal College of Surgeons in Ireland.
54. Prof. Kingston Mills	Department of Biology, NUI, Maynooth
55. Dr. Paul Murphy	Department of Chemistry, UCD
56. Ms. Anne Nolan	Irish Pharmaceutical Healthcare Association
57. Dr. Diarmuid O' Callaghan et al	Faculty of Veterinary Medicine, UCD
58. Dr. Eadbhard O' Callaghan et al	St. John of God Hospital, Dublin.
59. Dr. Anne O' Connor	Faculty of Public Health Medicine, Royal College of Physicians Ireland
60. Prof. Pat O' Connor	University of Limerick
61. Mr. Frank O' Deorain	North Western Health Board
62. Mr. Sean O Foghlu	Policy and Planning Department, HEA
63. Dr. Vivian O' Gorman	Royal College of Surgeons in Ireland
64. Ms. Siobhan O' Halloran	Department of Health and Children
65. Prof. Denis O' Mullane	Oral Health Services Research Centre, Cork
66. Dr. Orlaith O' Reilly	South Eastern Health Board
67. Mr. Tim O' Sullivan	
68. Prof. Ivan J Perry	Department of Epidemiology & Public Health, UCC.
69. Prof. Ivan J.Perry et al.	Health Services Research Group, UCC
70. Prof. Sam Porter	School of Nursing and Midwifery, The Queen's University of Belfast
71. Dr. Michael Rowan	Department of Pharmacology and Therapeutics, TCD
72. Dr. R.J. Russell	TCD
73. Mr. Peter Smith	UCD
74. The Sociological Association of Ireland/ Sociology of Health and Illness group	
75. Physiotherapy, Occupational Therapy and Clinical Speech & Language Therapy, Trinity College, Dublin	
76. Dr. Derek Sullivan	School of Dental Science, TCD
77. Mr. John Thompson	Department of Finance
78. Prof Pearl Tracey	School of Nursing and Midwifery, UCD
79. Ms. Elaine Walsh	Postgraduate Research Student
80. Ms. Maggie Walsh	The Academy of Medical Laboratory Science
81. Prof. Michael Walsh	St. James's Hospital, Dublin
82. Ms. Brenda Wheeler	The Irish Patients Association
83. Dr. Jane Wilde	The Institute of Public Health, Dublin
84. Dr. John Williams	Research and Education Foundation, Sligo
85. Prof. Markus Worner	Department of Philosophy, NUI, Galway
86. Prof. Shaun R. McCann	Department of Haematology and Oncology, TCD
87. Prof. Terry Dwyer	University of Tasmania, Australia
88. Dr. Sheelah Ryan	Merlin Park Regional Hospital, Galway
89. Cliona O' Farrelly	Education and Research Centre, St. Vincent's Hospital.
90. Ms Yvonne Smalley	Irish Anti-vivisection Association
91. Ms Maureen Lynnot	BUPA, Ireland
92. Prof. Roy McCelland	Department of Mental Health, Queen's University, Belfast
93. Ms Mary Colgan	Dublin City University

94. Mr Eugene Donoghue	An Bord Altranais
95. Prof. Andrew Murphy	Association of University Departments of General Practice in Ireland
96. Prof Martin Cormican	Bacteriology Department, NUI Galway

DR. Ard Cosgrove

NB shift in the ideology regarding the funding of Health research from a constant drain or expenditure to an investment

(NB) of knowledge based society

Relevance of education + Research to economic development

private/public partnership in funding of research

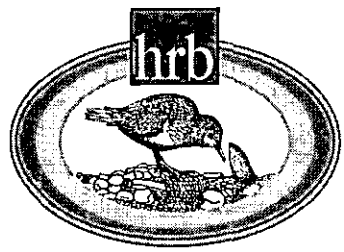
National Development Plan committed €3 million? (research) has been allocated

- communication of the key role of research
- social gain
  health gain
  economic gain (socio-economic contribution of health research)
- Medical / Health research contributes % of total research output
  Physic 10% each
  Chem 10%
- trans-disciplinary??

foster collaboration between clinicians + researchers (3rd level institutions) & between other institutions

The researcher is the cornerstone on which research policy/programme is built

need for a career path — Addressed in the strategy document



Health Related Research In Ireland 1998

Summary Of A Survey Commissioned By The Health Research Board

Circa Group

March 2000

HEALTH RELATED RESEARCH IN IRELAND 1998
SUMMARY FINDINGS OF A SURVEY COMMISSIONED BY THE HEALTH RESEARCH BOARD

Scope of the Survey

The health research sector was defined as research and related activity in all pure and applied sciences including economics and social sciences and investigations, tests, clinical trials, experiments, analyses and other studies in the sphere of medical, health and health-related research. It excluded undergraduate education and training, information services, routine data collection, routine software development and routine planning and monitoring services.

Data collection

Mailing lists and databases of active health researchers were compiled with the assistance of HRB, Forfas, Wellcome, and others. Questionnaires were sent directly to all active health researchers in the HE sector, to companies considered to be active in health research and to relevant government agencies, hospitals, health boards and voluntary bodies. A comprehensive target group was identified covering both research performers and, as a control on data derived from the performers, funding Agencies and Departments. Questionnaires were specifically developed for each of the principal sectors, namely Government Departments, Agencies, Higher Education, Hospitals, Voluntary Organisations, Health Boards and Business.

A total of 559 questionnaires were issued and were followed up by personal contacts and/or phone calls.

Response to the Survey

Table 1. Survey Target and Response Rate

Sector	Mailing Target No.	Overall Responses	Reporting Exp.
Higher Education	221	119	95
Hospitals	46	18	17
Business	179	62	11
Vol. Orgs	86	50	16
Health Boards	9	5	5
Gov. Depts.	11	9	5
Agencies	7	7	4
Totals	559	270	153

Summary Findings

Table 2. Summary of Overall Expenditure – Research Performers

SECTOR	No	CAPITAL IR£	No	CURRENT IR£	No	TOTAL IR£
Higher Education	59	2,213,398.50	87	9,703,625.55	**95**	**11,917,024.05**
Hospitals	11	352,000.00	17	1,991,603.00	**17**	**2,343,603.00**
Vol. Orgs	2	4,611.00	8	283,668.00	**8**	**288,279.00**
Health Boards	1	4,000.00	5	658,000.00	**5**	**662,000.00**
Gov. Depts.	0	0	1	91,174.00	**1**	**91,174.00**
Agencies	1	78,000.00	4	2,261,350.00	**4**	**2,339,350.00**
TOTALS	**74**	**2,652,009.5**	**122**	**14,989,420.55**	**130**	**17,641,430.05**

Table 3. Health Research Expenditure – Business Sector

SECTOR	No	CAPITAL IR£	No	CURRENT IR£	No	TOTAL IR£
Business	7	1,730,000.00	10	10,051,231.00	**10**	**11,781,231.00**

Table 4. **Research Perspective 1 – Current Expenditure**
Higher Education, Hospitals, Health Boards, Agencies.

Value of Research Addressing:	Value IR£
Biomedical *(health-related biological sciences) – excluding clinical trials*	9,625,371.68
Other	1,887,135.20
Epidemiology and public health	1,465,615.11
Health services research	1,143,452.46
Clinical trials	493,004.10
Total	**14,614,578.55**

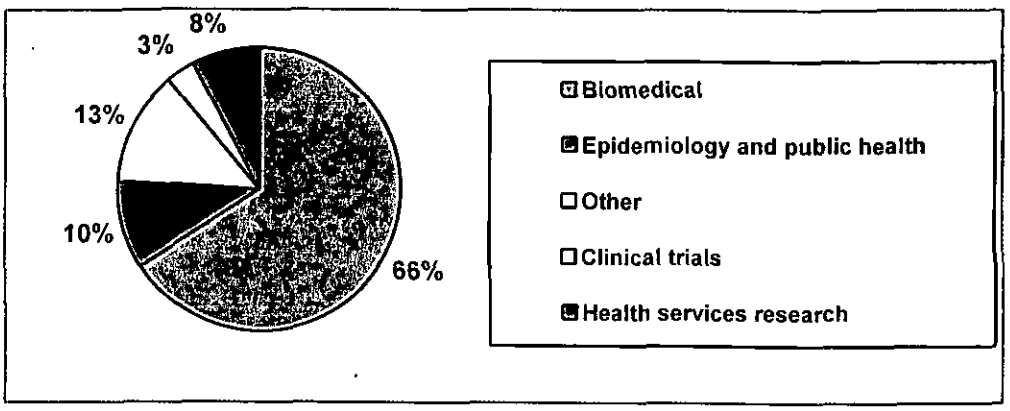


Table 5. **Research Perspective 2 – Current Expenditure**
Higher Education, Hospitals, Health Boards, Agencies.

Value of Research Addressing:	Value IR£
Understanding, diagnosis and treatment of disease	8,033,974.17
Health promotion and disease prevention	3,407,374.55
Other	1,771,567.60
Improving effectiveness of health and personal social services	947,183.15
Continuing care of dependent, disabled and vulnerable patients	454,479.01
Total	**14,614,578.48**

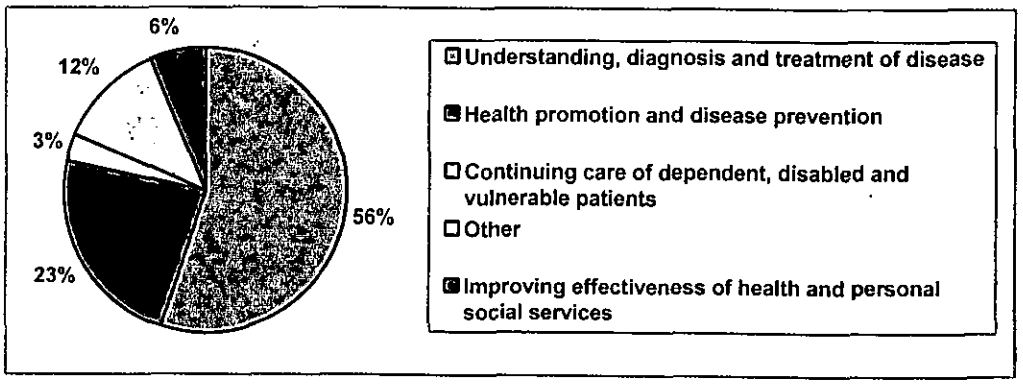


Table 6. **Research Perspective 3 – Current Expenditure**
Higher Education, Hospitals, Health Boards, Agencies.

Value of Research Addressing:	Value IR£
Cellular /molecular/genetic studies	5,994,214.68
Nutrition, food hygiene and food safety	2,071,908.20
Clinical medicine and surgery, including paediatrics and obstetrics	1,408,082.30
Studies of whole organisms/isolated tissues	1,208,992.05
Neuro sciences including psychiatry	1,198,114.38
Other	920,578.66
Biomedical engineering	715,080.40
Primary care – clinical and public health research conducted in primary care setting	417,398.16
Substance abuse and addiction	364,348.76
Other health related safety research *(radiological, environmental etc.)*	315,860.56
Total	**14,614,578.15**

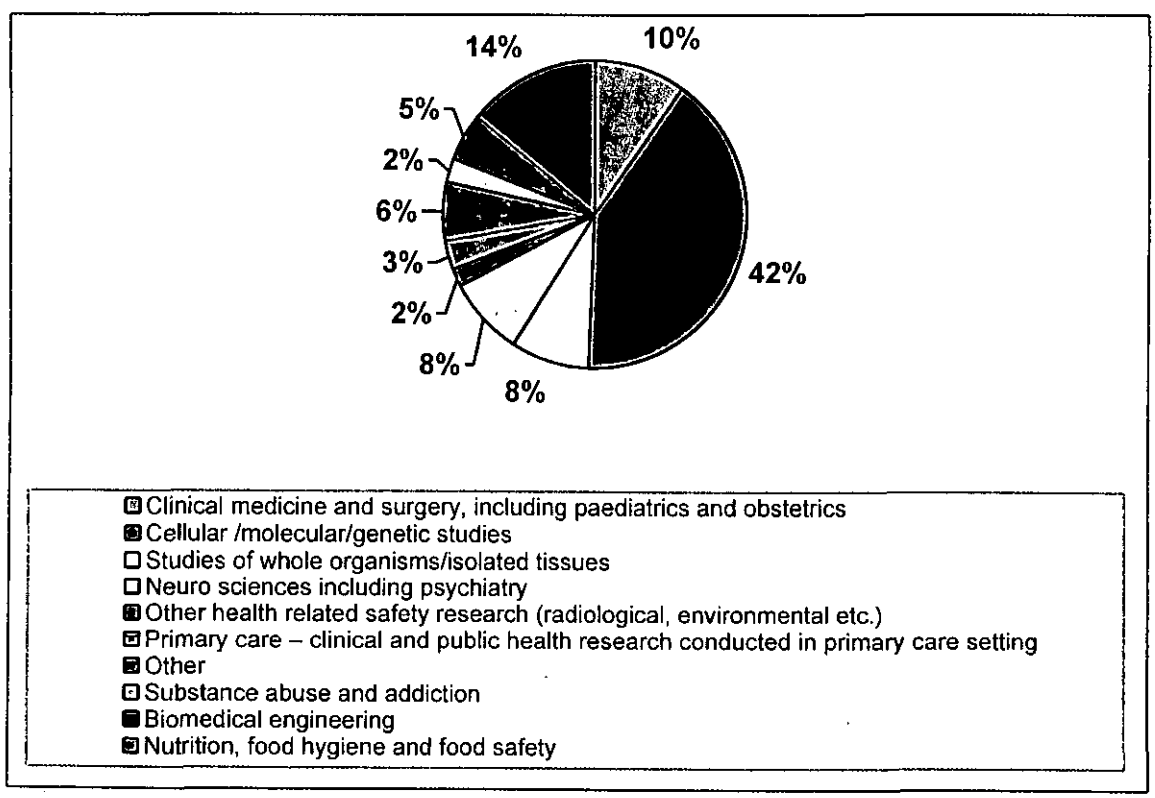


Table 7. **Source of funding for research in Hospitals and Higher Education Sectors - Capital**

Funder	Value IR£
Health Research Board	458,031.99
EU	401,891.97
Enterprise Ireland	293,187.40
Other Govt.	390,291.25
College	339,099.11
Wellcome	177,260.55
Vol. Orgs	171,791.88
Industry	166,258.65
Other	138,085.71
Dept. of Health	29,500.00
	2,565,398.51

Table 8. **Source of funding for research in Hospitals and Higher Education Sectors - Current**

Funder	Value IR£
EU	2,448,568.82
Industry	1,495,681.56
Health Research Board	1,549,985.88
Enterprise Ireland	1,017,909.89
Other Govt.	1,476,633.90
College	1,060,835.30
Wellcome	749,809.12
Other	931,046.29
Vol. Orgs	519,972.47
Dept. of Health	43,8100.56
Total	**11,688,543.79**

Table 9. Summary of Manpower Employed in Health Research

Sector	FTE
Higher Education	614.25
Hospitals	59.73
Business	115.10
Vol. Orgs	7.7
Health Boards	21.62
Gov. Depts.	7
Agencies	48.15
Totals	**873.55**

Commentary

The quality of the data derived from the survey varies considerably from sector to sector. Keys observations in respect to the principal research performing sectors are as follows:

The Higher Education Sector.

The situation in respect to availability of data on research activities in the Universities is improving considerably and the Research Offices of the different campuses are increasingly capable of providing reliable information on research contracts involving personnel in their College. There are difficulties, however, in supplying **expenditure** data on an annual basis and the Colleges, including the researchers themselves, would find it easier to provide information on **income**. It is also the case that a comprehensive sectoral survey, such as this one, makes demands on the College's central research information systems, which they still have difficulty in meeting. Nonetheless, it was possible to use data provided centrally in a few cases to check the quality of data provided on questionnaires by individual researchers. Even so, the primary means of data collection for this survey was from the active researchers.

In the light of the information received from the Research Offices and the control data acquired from the funding Agencies and Departments the consultants believe that the survey data represents no more than 80% of the total spend on health-related research in the Higher Education sector. The totals provided for the HE sector are therefore conservative.

Business

The consultants experienced great difficulty in obtaining information from firms in the Business sector. Despite an intensive process of direct follow-up calls to the

companies that were identified as constituting the Health sector, the response rate was just 30%. There are several factors which explain this low rate. Firstly the reticence of firms to reveal confidential data on R&D performance to third parties, a widely recognised 'questionnaire fatigue' which exists in industry and the innovative nature of the information being sought, particularly in respect to the analysis of research expenditure.

The closest it is possible to get to the health sector from existing data sources is a two sector proxy based on the pharmaceuticals and instruments (incl. medical instruments) sectors. The total R&D expenditure of these two in Ireland, according to Forfas sources, is in the order of £110m. Our survey managed to account for some £12m.

Health Boards

It is apparent that there is no system for recording or monitoring research activity or expenditure in the Health Boards. With considerable difficulty, 5 of the Boards have been able to make data returns. On their own admission this data is of questionable quality. It is apparent, however, that the Boards account for a significant level of expenditure and it is clearly desirable that they be assisted to put in place systems for recording and monitoring the research activity for which they are responsible.

MAKING KNOWLEDGE WORK FOR HEALTH – TOWARDS A STRATEGY FOR RESEARCH AND INNOVATION FOR HEALTH

Dublin Castle Tuesday 28th March 2000

PROGRAMME

08.30 Registration
Tea/Coffee

09.00 Welcome
Professor Michael Murphy, Chair, Health Research Board

09.15 Research for Health and the Third Level Sector

Dr Don Thornhill, Chair, Higher Education Authority
Dr Art Cosgrove, Conference of Heads of Irish Universities
Discussion
Chair: **Dick Ahlstrom**, Science Editor, Irish Times

10.00 The Research Community and Research for Health

Professor Dermot Kelleher, Department of Clinical Medicine, St James' Hospital/ Trinity College
Bridgeen McCloskey, Chair, Irish Research Scientists Association
Professor Hannah McGee, Department of Health Services Research, RCSI
Dr Evelyn Mahon, Department of Sociology, Trinity College
Discussion
Chair: **Professor Ingrid Allen**, Director, R & D Office, Belfast

11.00 Tea/Coffee

11.30 The Challenge of Making Knowledge Work in the Health Services

Dr Kevin Kelleher, Director of Public Health, Mid-Western Health Board
Mr John O'Brien, Chief Executive, St James's Hospital
Discussion
Chair : **Dr Edward Walsh, Chairman,** Irish Council for Science, Technology and Innovation

12.30 Lunch

13.45 The Voluntary sector and Making Knowledge Work for Health

Mr John McCormack, Irish Research Charities Group
Dr Dennis Boyle, President, Irish Heart Foundation
Discussion
Chair: **Professor Geraldine McCarthy,** Department of Nursing, NUI - Cork

14.30 **Mr Micheal Martin, T.D.** Minister for Health and Children
'Towards a Strategy for Making Knowledge Work for Health'

14.45 Making Knowledge work for Health and the Healthcare Industry

Ms Anne Nolan, Chief Executive, Irish Pharmaceutical Healthcare Association
Sharon Higgins, Chief Executive, Irish Medical Devices Association
Mr Martin Lyes, Divisional Manager – Science and Innovation, Entreprise Ireland
Discussion
Chair: **Mr Michael Kelly**, Secretary General, Department of Health and Children

15.45 **Shaping the Strategy for Making Knowledge Work for Health**
OPEN FORUM

Chair: **Professor Michael Murphy**, Chair, Health Research Board

16.30 Close of conference and thanks
Dr Ruth Barrington, Chief Executive, Health Research Board