

Review of population health research and health services research in Ireland

VOLUME 1
Executive Summary and Main Report

Health Research Board





Review of population health research and health services research in Ireland

VOLUME 1

EXECUTIVE SUMMARY AND MAIN REPORT

Health Research Board

2011

VOLUME 2 OF THIS REPORT, WHICH CONTAINS THE OUTCOMES OF THE MAPPING STUDIES ON POPULATION HEALTH RESEARCH AND HEALTH SERVICES RESEARCH IN IRELAND, IS AVAILABLE TO DOWNLOAD FROM THE HEALTH RESEARCH BOARD WEB SITE www.hrb.ie

Published by:

Health Research Board 73 Lower Baggot Street Dublin 2 Ireland

T: +353 1 2345 000 F: +353 1 6130337 E: <u>hrb@hrb.ie</u> W: <u>www.hrb.ie</u>

First published 2011 © Health Research Board ISBN: 978-1-903669-16-7

Please cite this publication as:

Hiney, M, Curran, B and Clarke P (2011) *Review of Population Health Research and Health Services Research in Ireland.* Health Research Board, Dublin.

Table of Contents

VOLUME 1 (Executive Summary and Main Report)

	Contents	
	ibles	
	guresedgements	
Forewore		
	e summary	
Intro	oduction	xi
Stra	tegic support, oversight and prioritisation	xii
Out	comes and learning from the mapping study	xiii
Con	clusions	xvii
MAIN RE	PORT	
Chapter		
	Introduction	
	Impetus for a review of Irish PHR and HSR	
1.3	ggg	
	Harnessing PHR and HSR to address health care challenges	
Chapter		
2.1	Introduction	
2.2	Strategic support for PHR and HSR	
2.3		
2.4	Identifying priorities for PHR and HSR in Ireland	
2.5	Shaping the Irish PHR and HSR agenda	
Chapter		28
3.1		
3.2	Building and developing capacity for PHR and HSR	
3.3	Funding of PHR and HSR in Ireland	
3.4	Infrastructure supports for PHR and HSR	
3.5	Outputs from current PHR and HSR	
3.6	Enhancing the use of PHR and HSR evidence	
3.7	Linkage and exchange	
3.8	Conclusions	48
Reference		
Abbrevia	tions and Acronyms	54
	ME 2 (Mapping Study)	
	Contents	
List of Ta		
List of Fi		
Forewore	edgementsd	
Chapter		
-	Introduction	
	Objectives of mapping study	
	Definition of PHR and HSR used for the mapping study	
	Methodological approach	
Chapter	• ,,	

	Introduction	
2.2	Settings for PHR and HSR	9
2.3	Distribution of researcher FTE in the higher education sector	10
	Inventory of relevant academic units in higher education institutions	
	Inventory of non-higher education research centres and organisations	
Chapter		
-	Introduction	
	Skills and competencies of PHR and HSR researchers	
	Role of the HRB in training provision	
	Role of the HSE in training provision	
Chapter		
	Introduction	
	Current research funding landscape	
	Funding support for health-related research	
	Funding support for PHR and HSR	
Chapter	9	
-	Introduction	
	Capital infrastructure for PHR and HSR	
	ICT and health information	
	Support for statistics and experimental design	
	Weaknesses in health information and systems	
	Research ethics committee structure	
Chapter		
-	Introduction	
	Publication output	
	International comparison of research outputs	
	PHR and HSR-relevant grey literature	
Chapter	The state of the s	
-	Introduction	
	Examining the wider impacts of PHR and HSR	
	Follow-up study of selection of respondents	
	Consultation with DoH	
	Overall survey outcomes 8 Mapping of Irish PHR and HSR networks and collaborations	
Chapter	Introduction	
0		
	Existing Irish PHR and HSR-relevant networks, partnerships and collaborations	
	International examples of PHR and HSR networks and collaborations	
Chapter	·	
9.1	Introduction Policy development and approach abroad	
9.2		
9.3	1 7 11	
Annex 1	References	
Annex 2	Abbreviations and Acronyms	
APPEND		
Appendix	· · · · · · · · · · · · · · · · · · ·	
Appendix		
Appendix		
Appendix	·	
	endix 4.1 Survey of health research funding providers	
	endix 4.2 Survey of heads of major PHR and HSR academic units	
App	endix 4.3 Survey of PHR and HSR research performers	155

List of Tables

VOLUME 2 (Mapping Study)

Table 2.4	Summary description of DCU academic units engaged in PHR and HSR	14
Table 2.5	Summary description of NUI Galway academic units engaged in PHR and HSR.	16
Table 2.6	Summary description of NUI Maynooth academic units engaged in PHR and HSF	₹20
Table 2.7	Summary description of QUB academic units engaged in PHR and HSR	21
Table 2.8	Summary description of RCSI academic units engaged in PHR and HSR	24
Table 2.9	Summary description of TCD academic units engaged in PHR and HSR	26
Table 2.10	Summary description of UCC academic units engaged in PHR and HSR	30
Table 2.11	Summary description of UCD academic units engaged in PHR and HSR	34
Table 2.12	Summary description of UL academic units engaged in PHR and HSR	37
Table 2.13	Summary description of UU academic disciplines conducting PHR and HSR	39
Table 2.14	Summary description of PHR and HSR being conducted or commissioned by	
	non-HE organisations	41
Table 4.1a	2008 Expenditure on 'health-related' research by major national agencies	58
Table 4.1b	2009 Expenditure on 'health-related' research by major national agencies	59
Table 6.1	Four categories of research activity included in review	74
Table 6.2	Summary of main bibliometric indicators used in study	
Table 6.3	International comparison of PHR & HSR output and impact	
Table 6.4	Breakdown of publication output into sub-fields	
Table 6.5	Top 10 PHL/ SNOMED level categories	
Table 7.1	Main drivers for research reported by respondents	
Table 7.2	Impacts on health policy reported by survey respondents	
Table 7.3	Impacts on health practice reported by survey respondents	93
Table 7.4	Dissemination strategies used by survey respondents	
Table 7.5	Summary of seven responses in follow-up survey	96
Table A	Profile of major funding agencies contributing to national health research	
	landscape	
Table B	Sample taught courses with specific relevant to PHR and HSR	129
Table C	Organisations in receipt of a survey of potential research funding providers	
	and commissioners	
Table D	Units in the Irish university sector included in the survey	147

List of Figures

VOLUME 1(E	Executive Summary	/ and Main	Report)
------------	-------------------	------------	---------

Figure 2.1	Timeline of policy and strategy inputs to health research in Ireland	16
Figure 2.2	National coordinating structures for research and policy	
Figure 3.1	Contribution of major funding agencies to 2008 and 2009 expenditure on	
J	PHR/HSR research (€22.13M and €23.35M respectively)	33
VOLUME	2 (Mapping Study)	
VOLUME	2 (Mapping Study)	
Figure 2.1	Distribution of research full time equivalent (FTEs) across career stages of personnel involved in PHR and HSR in the HE sector	11
Figure 2.2	Cross-tabulation of tenure status against academic discipline of primary degree	12
Figure 2.3	Comparison of number of research active staff (PHS and HSR) currently holding	
	PhD degrees in the Republic of Ireland and Northern Ireland Schools of Nursing a	and
	Midwifery	
Figure 3.1	Gender breakdown by discipline of respondents to skills survey	47
Figure 3.2	Primary affiliation of respondents to skills survey	48
Figure 3.3	Primary degree held by respondents	49
Figure 3.4	Further formal training at masters level	50
Figure 3.5	Topics identified for further formal training at doctoral level	51
Figure 3.6	Research skills acquired though experiential learning	52
Figure 4.1	Relationship between government departments and funders of health research (2009)	57
Figure 4.2	Comparison of overall health related research expenditure relative to expenditure	
	on PHR and HSR by public funding agencies in 2008 and 2009	62
Figure 6.1	Distribution of research activity categories as a percentage of total publications per unit (Category 1-4, 2003-2008)	76
Figure 6.2	Dissemination route used by Irish academic units with core PHR or HSR	
9	activity (Category 1-4, 2003-2008)	77
Figure 6.3	Output of PHR/HSR field as a proportion of total national research output	
Figure 6.4	Total share of highly cited publications in PHR/HSR	
Figure 6.5	Categorisation of Irish public sector grey literature (200-2008) by	
· ·	PHL/ SNOMED TERMS	84
Figure 6.6	Publication format for commissioned publications	
Figure 9.1	Coordinated structure of the National Institute for Health Research UK	
Figure 9.2	UK Research Innovation Pathway	
Figure A	Organisational affiliation of respondents to survey	
Figure B	Career stage of researcher survey respondents	

Acknowledgements

The Health Research Board (HRB) is most grateful to Professor Ian Harvey (Chairperson) and members of the Steering Group for bringing their considerable experience to bear in providing advice and comment on this review. The HRB would like to thank all of those who responded to their requests for information throughout the review.

Members of the Steering Group

Professor of Epidemiology and Public Health, University of East Anglea, UK: Chairperson
Professor of Social Medicine, Karolinska Institute, Stockholm, Sweden
Head of Health Intelligence, Health Services Executive, Directorate of Quality and Clinical Care
Chief Medical Officer, Department of Health and Children, Ireland (replaced by Dr Eibhlín Connolly, Deputy Chief Medical Officer)
Professor, Institute of Applied Health Sciences, University of Aberdeen, Scotland
Professor of Epidemiology and Public Health, Queens University Belfast and Royal Victoria Hospital, Northern Ireland
Professor of Public Health, University College Dublin (representing Faculty of Public Health, Royal College of Physicians in Ireland)
Professor of Health Services Research, Royal College of Surgeons in Ireland
Director of Research Strategy and Funding, Health Research Board
Senior Researcher, Norwegian Knowledge Centre for the Health Services, Oslo, Norway
Professor of Public Health, University College Cork (representing the Irish Forum for Public Health and Epidemiology Departments)
Director of Health Technology Assessment, Health Information and Quality Authority, Dublin (replaced by Dr Patricia Harrington, Acting Director of Health Technology Assessment)
Professor of Epidemiology and Public Health, Institute of Health and Society, University of Newcastle, UK
Health Economist, HSE Finance Directorate
Chief Executive Officer, Institute of Public Health in Ireland

Members of the HRB Research Team

Authors: Dr Maura Hiney, Dr Brendan Curran, Dr Patricia Clarke.

Assistance with data collation: Dr Rachel Barrett, Dr Lone Skobo-Bertelsen and Ms Angelena Rea

The Research Team wish to acknowledge the contributions of Dr Teresa Maguire, Dr. Donna Tedstone-Doherty, Dr Anne Cody, Dr Jean Long and Dr Sarah Craig (HRB), and Prof Frances Ruane and Dr Samantha Smith (ESRI) for their invaluable commentary and input on the final draft of this review. We would also like to thank our international peer reviewers for their very helpful suggestions on strengthening the text of the Main Report.

Foreword

Since late 2009, with the publication of its' *Strategic Business Plan 2010-2014*, the HRB has been on a journey to develop a coherent clinical research system and capacity for population health research (PHR) and health services research (HSR) in Ireland. This review is an important part of that journey. It provides the evidence and analysis that underpins the HRB's plans to strengthen the capacity of the Irish health research system, both university and health sector based, to undertake high quality, relevant PHR and HSR that have a real impact on the health of Irish people and on the way that health care is delivered to them.



Arising from this review, the HRB has developed a plan for its funding activities in support of PHR and HSR in the coming years. Implementation of this plan has been moving at a pace over the last twelve months. Many current schemes have been reoriented to reflect this changed focus and a number of innovative new initiatives in the PHR and HSR sphere will be rolled out in the coming year.

We are doing this because we believe it is important. It can provide the evidence to help Irish policy makers, health services providers and decision-makers, and health care professionals respond successfully to the significant challenges in health that will demand their attention over the coming years. These challenges include changing the way services are delivered, evaluating the health care needs of the population and measuring the relative effectiveness of interventions. They are driven by factors such as Irelands growing and ageing population; peoples changing expectations about their entitlement to services; and the spiralling costs of advances in health care technology.

These challenges are driven by the strategic ambitions of the Department of Health and the Health Services Executive to create a health service that:

- ✓ puts patient safety and quality of service at the heart of its activities
- ✓ prevents and manages chronic diseases in the Irish population
- ✓ promotes and protects the health and wellbeing of children, older people and those with disabilities or mental health problems, all delivered in primary care and community settings
- ✓ explores the linkages between lifestyle, behaviour and health
- examines the impact of complex population health interventions on health and health equity
- √ investigates innovative models of financing of health care

The HSE has also identified the challenge of integrating services across the spectrum from disease prevention through primary and community care to acute hospital care. Addressing these challenges will need a strong evidence base and coherent and integrated strategic planning.

Now, more than ever, we need PHR and HSR evidence to help us address these many challenges. There are strong examples internationally of how PHR and HSR evidence has improved the health of populations and the delivery of their health services. This review examines many of these examples. PHR-driven improvements range from control of infectious diseases resulting from clean water and improved sanitation to recognition of tobacco use as a hazard, from promoting the importance of 'five-a-day' for heart health to community vaccination against annual seasonal influenza. Understanding the effects of these public health initiatives will be increasingly critical as health services are restructured with a focus on cost containment, and as hard decisions are made about where to make investments of public resources.

In the health services, the evidence generated from HSR can help healthcare decision-makers to tackle the challenges they face in a more informed way. Health services researchers conduct studies designed to improve the quality of health care, reduce its cost, evaluate its effectiveness, improve patient safety, decrease medical errors, and broaden access to essential services. Studies range from assessing specific health technologies and approaches to providing care, to evaluating health sector reforms and health care interventions. As health care costs rise and the quest for value for money increases, the role of HSR becomes more and more crucial.

The evidence is clear. Investment in PHR and HSR can deliver real benefits for the well-being of Irish people and the effectiveness, efficiency and equity of the health services on which they depend. The identification of specific strategic goals within the HRB *Strategic Business Plan*, the existence of a working *Action Plan for Health Research*, the on-going reconfiguration of the healthcare and higher education sectors, the government's Innovation Economy strategy, and the planned reform of national scientific research funding, all represent opportunities to raise the profile of PHR and HSR and highlight the critical role that research-informed health policy and practice should play in modern Ireland.

The review that follows describes clearly the challenges we must address in the coming years, with regard to building a strong, high-quality PHR and HSR system in Ireland. It also highlights the strengths and opportunities of which we should take advantage. The HRB will use this review as a roadmap to advance the implementation of our strategic goals and to monitor our own progress in this area over the course of our strategy. We also hope that the findings in the report can inform and provide focus to the *Action Plan for Health Research*, as the Health Research Group works to implement relevant recommendations in the coming years.

Enda Connolly, Chief Executive

Ender Convolly

Executive summary

Introduction

This review was carried out in the context of the national health strategy, *Quality and fairness: A health system for you* (DoHC, 2001), which aims to 'deliver a healthier population and a world-class health system', and in response to national momentum to make Irish research world class and to use the knowledge generated by that research for economic and social progress. This impetus is articulated clearly in the Government's 2008 strategy for economic recovery and growth *Building Ireland's Smart Economy: a Framework for Sustainable Economic Renewal*, which recognises the crucial importance of health research to Ireland in enhancing health and social wellbeing, developing better quality health services, generating employment opportunities, and establishing Ireland as an international location for innovative health research and commercialisation.

In line with this national momentum, in its *Strategic Business Plan 2010-2014*, the Health Research Board (HRB) has identified health improvement of the whole population, enhanced patient care and improved health service delivery as key drivers of its research investments over the coming years. As the lead agency funding applied health research in Ireland, the HRB has recognised its pivotal role in building and developing capacity within the health research system in areas that can advance these priorities. These include clinical and translational medicine, population health research (PHR) and health services research (HSR.) This review addresses in particular the needs of PHR and HSR.

PHR includes identifying health determinants for individuals and populations, measuring behavioural risk factors, and elucidating ethnic, gender, socioeconomic and cultural differences that affect the health of the population and their current and future demands on health service provision. HSR is a broad range of activities designed to improve the quality of health care provision, reduce its cost, evaluate its effectiveness, improve patient safety, decrease medical errors, and broaden access to essential services. Both PHR and HSR will be increasingly critical as health services are restructured with a focus on quality, safety, efficiency and effectiveness at a time where the public resources available to invest in health services are reducing and very hard resource allocation decisions are required. Having a research-driven health service and a cohort of research-savvy health care professionals within that environment will also be key enablers of the enterprise agenda into the future.

This review of PHR and HSR in Ireland was undertaken with four objectives in mind:

- To establish a baseline description of current research capacity and activity in PHR and HSR in Ireland
- To assess the outputs and impacts of current PHR and HSR in Ireland
- To map the strengths and weaknesses in PHR and HSR in Ireland as it is currently configured and identify deficits that will require attention over the coming years
- To provide underpinning evidence for the development of an action plan for capacity and infrastructure development and for rational research investment in PHR and HSR.

This review of the current PHR and HSR landscape in Ireland is intended to serve as the evidence base for developing much stronger PHR and HSR systems, in terms of their research outputs (peer-reviewed papers and citations), their national impacts (supporting improved policy and practice), their effective organisation (capacity, funding and infrastructure), and the management of their strategic directions (co-ordination and priorities). Through this review key deficits and weaknesses that are

impeding the emergence of an international-quality national system of PHR and HSR have been identified and steps that can be taken to improve the current situation are explored.

Arising from this review, and in line with the objectives stated in its strategy, the HRB will develop an implementation plan in spring 2011 setting out its priorities for funding PHR and HSR from now until 2014 and beyond. But, it is hoped that the evidence provided by this review will also contribute to a wider priority setting exercise for health research in Ireland and will assist other stakeholders who have a vital role to play in developing PHR and HSR (research funding providers, research performers, health care professionals and managers, and policy-makers) in developing specific and collaborative actions to ensure that there is organised and sustained support for PHR and HSR similar to other leaders internationally.

Strategic support, oversight and prioritisation

It is clear from the evidence gathered and the consultations undertaken during this review that there is a lack of explicit support for PHR and HSR within national strategic initiatives that support health research, with the exception of the HRB Strategy which specifically identifies these areas as strategic priorities for investment. While a number of other health stakeholders have identified high-level priorities to drive their own strategies, to date that has been little nationally coordinated priority setting for health research and none in the specific areas of PHR and HSR. This is partly due to the absence of a clear vision and a common set of values underpinning the Irish health research system and to the fragmented nature of the health research system in Ireland.

The establishment of the Health Research Group (HRG) presents an important opportunity for coordination of health research activity and priorities at a national level into the future, and will hopefully address some of the fragmentation currently prevalent in the system. However, the broad agenda of the HRG, articulated in its *Action Plan for Health Research*, makes no reference to coordination or prioritisation of PHR and HSR as key actions, and outlines PHR and HSR-specific actions only in the context of public awareness and knowledge transfer of the outcomes of this research.

Therefore, there is a need for a separate mechanism that brings together relevant stakeholders to develop a specific PHR and HSR agenda. Establishing a PHR and HSR Work Stream under the auspices of the HRG would provide a mechanism for pulling the appropriate stakeholders together while ensuring integration of PHR and HSR priorities within the broader national health research agenda.

Progress in developing a national strategic agenda for PHR and HSR will be enhanced by Department of Health (formerly Department of Health and Children) commitment and engagement at the strategic and policy levels. The focus of Department of Health (DoH) engagement needs to be on; the development of a national framework for research coordination, governance and evaluation within the health service and identification of challenges/issues which can benefit from research and collaboration.

Progress will also be enhanced by HSE commitment and engagement at corporate, clinical and local levels. The focus of HSE engagement needs to be on; the development of people and research skills within the health services such that a culture of R&D emerges; partnering of the health system with others in support of joint research initiatives and investments with the HSE.

Finally, efforts need to be directed at identifying the most appropriate metrics for PHR and HSR, which should be distinct from the metrics for biomedical research. These metrics need to measure progress in terms of achieving a stronger PHR and HSR system and demonstrating how national strategic objectives are being achieved in a transparent and consistent manner.

Outcomes and learning from the mapping study

Internationally, many significant advances in health, health care provision and healthcare systems would not have been possible without PHR and HSR evidence and there are many lessons that Ireland can learn from experience elsewhere. However, Ireland has many unique demographic, geographic, political, financial and behavioural features that demand a home-grown programme of PHR and HSR that is set in an international research context. Developing such a programme will require effort and investment in areas known to lead to world class research in other countries oversight and coordination at a national level, a mechanism for priority setting, investment in training and capacity, development of appropriate funding models, improved infrastructure, a greater emphasis on the linkage between research and outcomes, and a framework for evaluating impact.

This review draws on the learning from the mapping study of current PHR and HSR activity and capacity, and places it in an international context, to identify steps that need to be taken to develop these areas of endeavour.

Building and developing research capacity

Relative to other disciplines, expertise and research skills for PHR and HSR in both the academic community and among health care professionals are underdeveloped. This review identified a number of areas in which progress needs to be made in order to build and develop capacity in PHR and HSR:

- Most PHR and HSR in Ireland is conducted in higher education institutions, teaching
 hospitals and research centres affiliated with them, although a number of independent
 research organisations, in particular the Institute of Public Health in Ireland and the
 Economic and Social Sciences Research Institute are important contributors of PHR and
 HSR evidence.
- Although a wide range of academic units undertake some PHR and HSR, there is a strong interdisciplinary² focus in academic units whose primary focus is PHR and/or HSR. A significant difficulty identified by the mapping study is a lack of experienced academic staff to supervise post-graduates, provide the taught elements of graduate programmes in PHR and HSR and to mentor future generations of PHR and HSR researchers.
- There are limited opportunities for early stage training in PHR and HSR at present, with the HRB being the primary funder of capacity building initiatives in these areas, and targeted training at both post-graduate and professional level may need to be increased.
- The majority of respondents who subsequently developed research careers in PHR or HSR indicated that they obtained their primary degrees in one of six subjects, namely medicine, psychology, nursing, social sciences, biological or biomedical sciences or health sciences.

¹ In this review **healthcare** refers to the system, while **health care** refers to actions by people who work in the system and by patients, that result in the delivery or consumption of services, respectively.

 $^{^{2}}$ The term '**interdisciplinary**' is used to refer to all three categories of multi-, inter and trans-disciplinary research

- Areas in which skills deficits were identified include health economics, biostatistics, epidemiology, qualitative skills, randomised control trials and intervention research³, and health technology assessment. Encouraging the formation of multi-skilled teams will be vital to address this deficit, supported by the hiring or training a small number of multi-skilled individuals.
- Even where health care professionals would like to develop a research career, there is no
 clear career structure and strategy for staff development in either the higher education sector
 or the healthcare sector, which is being worsened by the current capping of staff recruitment
 and promotion. Very few health care professionals have dedicated time set aside for
 research.

Research funding support for PHR and HSR

The importance of PHR and HSR research as a driver for quality, efficacy and efficiency in health care delivery and improvement of the health of the population is not always understood at governmental level or by the public. As a result this review found that, despite concerted government efforts over the past decade to develop overall research capacity in Ireland, there is still significant underinvestment in PHR and HSR.

- To date, the bulk of Irish health research expenditure has been in the areas of basic and applied biomedicine with investment in PHR and HSR remaining low. The HRB and DoH are the primary funders of PHR and HSR. Where funding is provided by other agencies, its scope is limited by the remit of that agency. Ireland now needs to move from current underinvestment in the areas of PHR and HSR to a high-quality, resourced and integrated health research system that can deliver the necessary evidence to inform health policy and practice in a form amenable to action
- The funding models used by many Irish funding agencies for health relies heavily on models developed for laboratory- and specialism-based biomedical and clinical research. These are not appropriate for much of PHR and HSR, since they do not facilitate a flexible interdisciplinary approach or encourage non-traditional outputs that will have policy and practice relevance. Other countries have developed innovative funding models specific to PHR and HSR which can provide a framework for development of appropriate funding support for the Irish PHR and HSR community.
- The scope and breadth of current health research funding needs to incentivise applicants to include more interdisciplinary research in PHR and HSR within their programmes. Areas identified by this review for increased support include funding of cohort studies, longitudinal studies, intervention research, practice-based research, support of translation of results into policy and practice, and randomised control trials.
- Partnership funding with relevant agencies and organisations will allow the HRB to leverage support for its PHR and HSR agenda and achieve maximum impact from its investment.
- In the context of what happens in other countries, the HSE's current commitment of resources to research and development (R&D) is very modest. In developing R&D within the health services into the future it will be crucial that dedicated research funding is ring-fenced in the health services budget, that the respective roles of the HRB, the HSE and the DoH in

Intervention research is an emerging field of research in the social sciences that integrates approaches to research which seek to yield results that can be put to practical use by practitioners, administrators and policy makers (see Rothman J and Thomas EJ (1994)). It focuses on the development of knowledge about interventions, the design and adaption of new and existing interventions and packaging and disseminating knowledge about innovative interventions.

relation to research are clearly defined, and that there is appropriate coordination across these agencies.

Infrastructure supports for PHR and HSR

The environment in which PHR and HSR research takes place and the infrastructural supports available to researchers will have a significant influence on what research can be carried out, and the quality of that research. This review identified some significant infrastructure deficits in the Irish system. The practices of PHR and HSR involve collecting, analysing, collating and sharing data. Therefore, robust datasets are a vital tool with which PHR and HSR practitioners can address research questions. This review identified a number of areas in which progress needs to be made in order to provide adequate and integrated data for PHR and HSR.

- Despite the large investments that have been made nationally in buildings and facilities with a health focus, little infrastructure investment has been targeted towards the specific needs of PHR and HSR. The HRB is currently the primary funder in this space, although investments made by other agencies may ultimately benefit PHR and HSR.
- There is no integrated Ethics Committee structure in Ireland. The fragmented nature of RECs creates significant problems for researchers in terms of time delays in gaining ethical approval, which is particularly burdensome in the case of multi-centre studies. A leaner REC structure would result in more consistent quality of opinion and there are a number of developments underway to address this issue. Most notably specific provision is being made in the upcoming Health Information Bill, due for publication in 2011, for the allocation of responsibility to HIQA for national coordination of Research Ethics Committees.
- There are no unique personal identifiers (UPI) across the Irish healthcare system. This hampers linkage of health data, which would facilitate both PHR and HSR and create the possibility of tracking resource utilisation and health outcomes across the healthcare system. It is intended that the forthcoming Health Information Bill will provide a clearer legal basis for the deployment of UPIs in Ireland.
- Even if UPIs were available now, this would not resolve core weaknesses in national health information systems including limited or no Irish research data in many areas (e.g. the primary, continuing and community care sectors), lack of comparability of available datasets which prevents their linkage, lack of harmonized standards across datasets, lack of access to information on private health care and difficulties in accessing existing data sets in the public system.
- There is a need for clarity regarding the secondary use of patient data in health research in Ireland and the provisions of the Data Protection Acts 1998 and 2003 in this regard. The need for a legislative framework to enable health information to be used in medical and social care research will be addressed in the forthcoming Health Information Bill.
- Where the secondary use of anonymised data is permissible there is limited capacity at present for quantitative and qualitative analysis among the health research community.
- Development of data repositories where researchers can both lodge and access datasets generated through many local, regional and national surveys has been slow. ISSDA provides a repository for social sciences and social care data and the Institute of Public Health (IPH) Population Health Observatory includes a collection of health-related datasets, but for much health-related data, the options are very limited.

- There is also little support available for maintenance of established cohorts, for which biodata, bio-specimens and medical history have been collected, and which represent a valuable national asset.
- Outside of the higher education sector, access to published literature can be difficult. There
 are a number of initiatives underway that attempt to address this issue. Open Access
 initiatives driven by Irish funding agencies, including the HRB, focus on peer-reviewed
 research articles and their pre-prints. The HSE has developed its own on-line publication
 archive (LENUS), to put both its peer-reviewed and grey literature publications into the public
 domain, while the Institute of Public Health (IPH) Population Health Observatory includes a
 collection of databases containing reports and grey literature,

Knowledge production and use

Current PHR and HSR evidence is under-utilised in policy development. This knowledge arises from 'traditional' scholarly and scientific research activity and through the commissioning activities of Government departments, statutory agencies, and NGOs. This review identifies some of the factors that have given rise to this situation and highlights areas where changes need to be made.

- In general the quality of the peer-reviewed output of PHR and HSR by Republic of Ireland researchers is high. This review found that while Ireland produced a relatively small peerreviewed publication output compared to countries of a broadly similar national population, this output had the third highest impact among the selected countries and the visibility of Irish publications among the most highly-cited publications internationally was relatively strong.
- Irish PHR and HSR researchers rate themselves as being quite active in engaging end-users of research and influencing national health policy, clinical practice or health service provision and report consistent efforts to engage key stakeholders and end-users of research throughout the research process. The dissemination strategies employed by researchers varied from the traditional academic outputs of peer-reviewed publications and scientific presentations, to informal and formal linkages with stakeholders in the health policy and service provision sectors. Academic units in which reports and other publications (letters, editorials, commentary, factsheets, rapid response articles, journal abstracts, fact sheets and guidelines) accounted for a significant proportion of overall publication output also described themselves as having a policy-focused ethos and were more likely to undertake policy-oriented commissioned studies.
- In contract to the last finding, the demand for research evidence remains weak among policy makers and health managers. However, it is acknowledged that from a political perspective, research evidence is only one factor that shapes decisions. Government agendas are also shaped by political commitments, party platforms, and the views of key political leaders. These pressures can lead to the selective use of research evidence rather than the systematic use of research evidence. It is critical that the distinction between these approaches is clear, such that Ireland does not move from a little-evidence basis for policy to a selective evidence basis for policy.
- The observed disconnect between the demand for and supply of research evidence to inform policy may be due in part to the observation that there are fundamental differences between the research and policy communities including different timeframes, vocabularies and priorities, as well as a lack of understanding about the realities of each other's work environment. This report found that even within the health policy community, commissioning practice did not show a close connection between the policy and operational aspects of health.

- Factors that researchers considered important enablers of policy impact included effective timing of research, its contextual relevance in addressing a key knowledge gap for policymakers and service providers, the development of on-going relationships with stakeholders, the commitment of time and resources to dissemination processes and structures, and responsiveness of stakeholders to the research evidence.
- Factors that researchers identified as barriers to effective knowledge transfer included a lack
 of organisational support for dissemination activities, lack of funding and incentives for such
 activity, unwillingness or inability by researchers to invest time in wider dissemination activities
 and to present research in an appropriate format for decision-makers, and a lack of leadership,
 time and resources in the health policy and service sectors to engage research providers.

Networks, collaborations and linkages

International experience assessed during this review identified the critical importance of creating networks, collaborations and linkages as key to building strong PHR and HSR. The lack of effective connection between the generation of high-quality research evidence and policy formation and between policy formulation and its' implementation in the Irish healthcare system became clear during the review.

- There are only a small number of formal networks and consortia in existence in Ireland that link practitioners and interested stakeholder groups to a common purpose.
- Where linkages exist, they are primarily informal, which of itself can be a very positive mechanism for interaction but should not be the only one. Targeted investment in the creation of formal linkages between policy makers and the research community should help to bridge this 'knowledge gap'.
- Resources invested in the development of multidisciplinary networks of practitioners and
 researchers and in the development of communities of practice would stimulate innovative
 thinking and practice, and service to increase overall capacity to tackle complex health
 questions. There are many models internationally on which these networks could be based.
- Implementation of the HRG Action Plan for Health Research over the next three years should help to improve high-level links between the research funding providers and policy organisations. However, linkages relevant to PHR and HSR between these stakeholders may need to be developed through different routes.
- Whenever possible, Ireland should utilise its closeness to the UK by developing networks on an all-island basis which would seek to transfer learning and best practice and jointly leverage the sharing of research capacity, infrastructure and funding from the wider UK systems. This approach could help to address the small scale of activity in Ireland and provide a comparative system against which to benchmark our progress.
- Joint metrics covering both policy-makers and researchers would underline the interconnectedness of efforts, although such metrics would need to be very carefully constructed to avoid distortions in the evaluation of outcomes.

Conclusions

The weaknesses, gaps and key areas for focus outlined in this review need to be recognised and addressed in a collaborative, innovative and flexible manner by all stakeholders in the health research system. The past decade has seen very significant increases in public expenditure on health but with very little research and evidence - particularly on effectiveness and evaluations of interventions both at

a population level and in clinical settings. There is now consensus over the role of PHR and HSR in improving the health of the Irish population and the manner in which the Irish healthcare system functions. This comes at a crucial time for Ireland as it faces into its worst economic crisis since the foundation of the state. However, this presents the health services and the broader health research system with the challenge of looking creatively and innovatively at how services and health care can be better delivered in an era of reduced funding.

Possible mechanisms to affect change are many. The existence of a working *Action Plan for Health Research*, the on-going reconfiguration of the healthcare and higher education sectors, the government's 'Smart Economy' strategy, and the planned reform of national scientific research funding, all represent opportunities to raise the profile of PHR and HSR by highlighting the critical role that research-informed health policy and practice can play in modern Ireland. Progression in PHR and HSR will depend on a strong ethos of partnership involving many services, disciplines, organisations and individuals. Networks and collaboration should cover the distance between the designers of policy and those tasked with delivering it on the ground, and filter across boundaries within and between government departments. Linkages and collaboration should also be nurtured across jurisdictional borders since there is much that Ireland can learn from the experience of other countries that have successfully developed robust PHR and HSR systems.

MAIN REPORT

Chapter 1 Need for a review of PHR and HSR in Ireland

1.1 Introduction

This review was carried out in the context of the national health strategy, *Quality and fairness: A health system for you* (DoHC, 2001)⁴ which aims to 'deliver a healthier population and a world-class health system', and in response to national momentum to make Irish research world class and to use the knowledge generated by that research for economic and social progress. This impetus is articulated clearly in the Government's 2008 strategy for economic recovery and growth *Building Ireland's Smart Economy: a Framework for Sustainable Economic Renewal*⁵, which recognises the crucial importance of health research to Ireland, in enhancing health and social wellbeing, developing better quality health care services, generating high-tech employment opportunities, and establishing Ireland as an international location for innovative health research and commercialisation.

In line with this national momentum, in its *Strategic Business Plan 2010-2014*⁶, the Health Research Board (HRB) has identified health improvement of the whole population, enhanced patient care and improved health service delivery as key drivers of its research investments over the coming years. As the lead agency funding applied health research in Ireland, the HRB has recognised its pivotal role in building and developing capacity within the health research system in areas that can advance these priorities. These include clinical and translational research, population health research (PHR) and health services research (HSR.) This review addresses in particular the needs of PHR and HSR. The HRB is also committed to ensuring that the knowledge generated by the research that it funds can be transferred into the policy and practice realms through comprehensive knowledge transfer and exchange initiatives.

1.1.1 Objectives

PHR and HSR are not new areas of research endeavour for Ireland. The HRB has invested in excellent people and projects over a number of years, which has gone some way to raising the profile and importance of these areas. However, the HRB, through its current strategy, wishes to drive a stepchange in the quality, quantity and translation of Irish PHR and HSR into policy, practice and economic advancement. Therefore, the overall aim of this review was to support the strategic objectives of the HRB to continue to develop a high quality PHR and HSR system in Ireland by:

- Establishing a baseline description of research capacity and activity in PHR and HSR in Ireland
- Mapping the strengths and weaknesses in PHR and HSR in Ireland as it is currently configured and identify deficits that will require attention over the coming years
- Assessing the outputs and impacts of current PHR and HSR in Ireland

Department of Health and Children (2001b) Quality and fairness: A health system for you. Dublin, Stationary Office. http://www.dohc.ie/publications/quality_and_fairness.html [Accessed 19/05/2011]

Department of the Taoiseach (2008) Building Irelands Smart Economy: a Framework for Sustainable Economic Renewal. http://www.taoiseach.gov.ie/eng/Building Ireland's Smart Economy/Building Ireland's Smart Economy .pdf [Accessed19/05/2011]

⁶ Health Research Board (2009) Strategic Business Plan 2010-2014; the future of Irish health research. Health Research Board, Dublin. http://www.hrb.ie/publications/hrb-publication/publications//490/ [Accessed19/05/2011]

 Providing underpinning evidence for the development of an action plan for capacity and infrastructure development and for rational research investment in PHR and HSR

This review is presented in two volumes. Volume 1 takes a broad look at the factors that influence the level and quality of PHR and HSR in Ireland, in terms of the management of its strategic direction (oversight, co-ordination and priorities), analyses the learning from the mapping studies and considers the steps which will be needed to address the many challenges that face us and how those challenges, and the research questions to which they give rise, can be framed in the context of the Irish population and the Irish health services.

The analysis in this review is informed by the data presented in Volume 2 which is intended to serve as the evidence base for developing a much stronger PHR and HSR system, in terms of its effective organisation (capacity, funding and infrastructure), research outputs (peer-reviewed papers and citations, grey literature), and its national impacts (knowledge production, policy and practice impact). It also looks at what we can learn from international models of PHR and HSR.

1.1.2 What is meant by PHR and HSR?

PHR is a relatively new term that is considered to include, but be distinct from, traditional definitions of public health, health promotion and social epidemiology. In general, it can be viewed as a field that analyses health outcomes, patterns of health determinants and policy interventions that link the two. The populations involved are often communities or geographic regions but they can also be other groups such as employees, ethnic groups, prisoners or disabled persons. The 'determinants' include medical care, public health interventions, aspects of social environment (income, education, employment, social support, culture) and of physical environment (urban design, clean air and water), genetics and individual behaviour. As these rarely operate independently, PHR is concerned with interactions and patterns.

HSR examines how people get access to health care, how much that care costs and what happens as a result of that care. Its primary goals are to identify the most effective ways to organise, manage, finance and deliver high quality care; reduce medical errors and improve patient safety. The roots of HSR lie deeply in the world of applied science somewhere at the intersection of public health, public and healthcare administration, policy analysis, community health, and traditional academic disciplines like economics, sociology and political science. While grounded in theory, HSR must be research that can be applied by health care professionals, health managers and all others who make decisions or deliver care. HSR requires many disciplines to deal with pragmatic issues of quality, access, cost, efficacy and efficiency. The research domains for HSR are individuals, families, organisations, institutions, communities and populations. If a researcher is studying something that effects health care or is affected by healthcare⁷, then that researcher is doing HSR. This broad definition implies that HSR can be done by those who don't normally consider themselves health services researchers.

There is much debate in the literature about precise definitions of PHR and HSR, about whether they are fields of research or concepts of health, about whether they should be considered as separate, over-lapping entities or subsets of each other. This review considers both within the one report. A number of factors were considered in doing this:

⁷ In this review **healthcare** refers to the system, while **health care** refers to actions by people who work in the system and by patients, which result in the delivery or consumption of services, respectively.

- they are both grounded in strong methodologies, some of which overlap
- they require interdisciplinary⁸ approaches; improvements in PHR and HSR require the attention and actions of multiple actors (legislators, policy makers, managers, providers, clinicians, individuals, researchers)
- they need to be linked to policy, practice and decision making and as such both need to pay
 particular attention to the knowledge transfer and partnerships that exist between all actors in
 order for positive change to occur
- they both have a need for dynamic adaptation to new problems being placed on their agendas
- those involved in PHR are among the many actors engaging in HSR. This 'blurring' or overlap
 is particularly evident in a relatively small PHR and HSR research community in Ireland

It is, however, acknowledged that the needs of, and issues tackled by, researchers in PHR and HSR can be different and where appropriate these are considered separately.

1.2 Impetus for a review of Irish PHR and HSR

Now, more than ever PHR and HSR are central to effecting change in health policy, healthcare system organisational efficiency and effectiveness, as well as cost effective interventions at the patient level. Research is vital in providing the new knowledge needed to improve health outcomes and reduce inequalities. Research is even more important when resources are under pressure - it identifies new or more effective ways of promoting healthy behaviours, preventing, diagnosing and treating disease, and of developing and refining services and systems that underpin these activities. Research is essential if we are to increase the quality and productivity of the Irish health system and to support growth in the economy.

From an enterprise perspective, PHR and HSR can inform the wider innovation value chain in the healthcare system and in health R&D in general, and can act as the bridge between needs and priorities and the product/service design process. Many evidence-based products and services designed to meet health care needs have less impact than anticipated due to issues such as relevance, usability, accessibility, feasibility, timeliness, quality, behaviours and mind sets, compliance, skill-mix and cost and financing. HSR ensures that public and private investment in new products, services and technologies gets adopted and implemented in a manner capable of creating public value as well as private gain. PHR and HSR represent opportunities for delivering significant social and economic benefits to the exchequer through direct and indirect savings and reallocation of resources. But they also provide opportunities for engagement with private enterprises in areas such as services science, e-health and assisted living technologies.

The research landscape in which PHR and HSR is taking place in Ireland is rapidly changing. When the work for this review was initiated in early 2008 there was little explicit support for PHR and HSR either at national strategic level, or within the health services. Much has changed in the intervening three years:

 The HRB has made a strategic shift towards providing greater support for PHR and HSR and will be introducing a suite of new funding schemes in the coming years to underpin this change in emphasis.

⁸ The term '**interdisciplinary**' is used to refer to all three categories of multi-, inter- and trans-disciplinary research

- The Health Information and Quality Authority (HIQA) has begun to catalogue and develop standards for the myriad of health information systems in Ireland, and has been tasked with developing an integrated Research Ethics Committee Structure for Ireland.
- The Health Information Bill, due for publication in 2011, will provide a legislative framework for addressing a number of important infrastructural deficits in the Irish health research system, including coordination of Research Ethics Committees, provision for the development of a UPI and provision of clarity around the secondary use of patient data in health research.
- The Department of (DoH), which established a dedicated Research Unit in 2008, is driving significant strategic research-relevant initiatives such as the development of a Health Information Bill that will facilitate a national ethics committee structure, the development of a Unique Personal Identifier and electronic health records, and the legislative basis for linkage of existing health information data.
- A national Task Force on Prioritisation of Research has commenced its deliberations, assisted by Forfás, which will have a significant impact on where research expenditure is directed in Ireland over the coming years. There are opportunities within the Health, Wellbeing and Ageing Strand of this exercise to ensure that the contributions of PHR and HSR to health and social care provision and as key enablers of the enterprise agenda are recognized.
- The Health Service Executive (HSE) is shifting its service delivery focus to a population health approach⁹ and is striving to link chronic disease management and the development of care pathways to the identification of evidence gaps and research priorities. This will create an increased demand for high quality, health-services relevant PHR and HSR to support this transformation agenda.

While all of these initiatives are very welcome, they underline the fragmented nature of support for PHR and HSR within the Irish health research system at present, with several organisations developing initiatives that are frequently not integrated with the activities of others in this realm. This situation has not been helped by a lack of strategic support for, and understanding of, the role of PHR and HSR in providing evidence to support the development of a more equitable health system for the Irish population, and its potential in developing efficiencies and reducing costs in the health services on which they depend.

1.2.1 The case for Irish PHR and HSR

Internationally, many significant advances in health and health care provision would not have been possible without PHR and HSR evidence and there are many lessons that Ireland can learn from experience elsewhere. However, there are strong reasons why a home-grown programmes of research needs to be developed. Ireland has a unique demographic in Europe, with a population that is growing ¹⁰, diversifying and ageing ¹¹, all of which have major implications for the use of our health system.

⁹ Health Services Executive (2006) *Transformation Programme 2007-2010.*

http://www.hse.ie/eng/services/Publications/corporate/transformation.pdf [Accessed19/05/2011]

¹⁰ CSO (2006) Principal Demographic Results. http://www.cso.ie/census/documents/Amended%20Final%20Principal%20Demographic%20Results%202006.pdf [Accessed19/05/2011]

¹¹ CSO (2008) Population and labour force projections, 2011- 2041. http://www.cso.ie/releasespublications/po_lab_project.htm
[Accessed19/05/2011]

The Irish lifestyle, as captured in the SLÁN (Survey of Lifestyle, Attitudes and Nutrition in Ireland) 2007 survey 2 poses many health risks for the nation. Such risks include uncontrolled elevated blood pressure and cholesterol levels, obesity, alcohol consumption and smoking. Despite the rise in prosperity in Ireland, and overall improvements in the health of the Irish population, rates of mortality and morbidity are consistently higher for lower socio-economic groups.

The structure of the Irish healthcare system, as laid down in legislative and policy documents, is uniquely complicated when compared with other countries¹³. Using the 'health basket' framework to compare healthcare systems in Ireland, UK, Canada, Australia, Sweden and France, this uniqueness was attributed to the combination of user fees, which are higher than in other countries, particularly in primary care; the complex structure of entitlement restrictions; and the wide and varied nature of the cost sharing basis that is applied to the majority of services, most of which factors have not been researched in any way.

The focus of the healthcare system is shifting from treating terminal diseases to managing the growing incidence and prevalence of chronic diseases, (diabetes and its complications, hypertension and coronary heart disease, stroke, parkinsonism, dementia, (treated) cancers and so on). However, there is a lack of epidemiological data on these conditions, and few information sources exist at community or general practice levels in Ireland, making evaluative and effectiveness research difficult to perform. Therefore, a comprehensive evidence-based approach that is appropriate to Ireland's needs, priorities and resources should be developed which reflects our unique demographic and epidemiological status; our processes of social and economic change; our politics and ideology, and our public policymaking processes.

Challenges facing the Irish healthcare system 1.3

The DoH and the HSE, in their respective strategies, have identified a number of key challenges for Irish health and the healthcare system. Principal among these are:

- ensuring patient safety and quality of service
- prevention and management of chronic diseases in the Irish population
- promoting and protecting the health and wellbeing of children and families
- provision of support and interventions for mental health in primary care and community settings
- supporting people with disabilities to live independent lives
- enhancing the quality of life of older persons and supporting them in their homes and communities rather than in institutions
- examining the impact of complex population health interventions on health and health equity
- exploring the linkages between lifestyle and behaviour choices and health
- investigating innovative models of financing of health care

In addition, the HSE has identified the challenge of integrating services across the spectrum from disease prevention through primary and community care to acute hospital care, to allow the patient to be managed at the most appropriate level for their care needs and to provide integrated care and transitions across 'boundaries' of care.

¹² Morgan K et al. (2008) SLÁN 2007: Survey of Lifestyle, Attitudes and Nutrition in Ireland. Main report. Dublin: Department of

Health & Children. http://www.dohc.ie/publications/slan07_report.html [Accessed19/05/2011]

13 Smith S (2009) The Irish 'health basket': a basket case? Eur J Health Econ. DOI 10.1007/s10198-009-0171-4

The main drivers of these challenges of provision, utilisation and need in the Irish healthcare system have been identified by the Expert Group on *Resource Allocation and Financing in the Health Sector* (2010)¹⁴ as 1) demographic changes as they relate to a growing and ageing population; 2) changing expectations among health care consumers about their entitlement to services; and 3) the cost implications of advances in health care technology. Addressing these challenges and drivers in a climate of limited resources will require a change in the way services are currently being delivered. These issues are considered in more detail here.

1.3.1 Demographic changes in the Irish population

On the basis of population projections by the Central Statistics Offices, Layte *et al.* (2009)¹⁵, in looked at the impact of demographic change in Ireland on health care utilisation and health care need, and suggested that an overall increase of approximately 11 per cent in the Irish population up to 2021 is likely. The demographic structure of this larger population is projected to have fewer younger people and a greater number older people, especially of 65 years or over. This changing demographic structure will increase health care requirements in all services, since older people are more intensive users of health care services, especially at the end of life. The authors projected that unless there were major changes in practices in the Irish hospital sector, there would be a need for a 54 per cent increase in inpatient beds and a 64 per cent increase in day beds over the next 10 years. They suggested that there will also be increased demand for primary care services of between 32-48 per cent, especially in the older age groups; an overall increase of 24.5 per cent in outpatient consultations which would be increased still further by worsening epidemiological trends; and an increase in demand for residential long-term care for people aged 65 years and over of up to 59 per cent.

The increasing burden of chronic institutional care for the elderly is strongly associated with increased lifespan without commensurate reductions in disability. It is also influenced by changing attitudes of family members about taking elderly relatives into their homes in order to provide care, and increased geographical dispersion of extended families leaving 'no one nearby' to care for older disabled relatives in their own homes. As the Expert Group $(2010)^{12}$ point out, the issues around ageing and health care utilisation are complex and make it difficult to predict precisely what the impacts will be, other than that there will be increased demand for health services.

1.3.2 Changing expectations

There is evidence emerging in the literature that changing expectations about health service provision and access is an important driver of increased health care spending, and may even exceed the influence of an ageing population on growth in spending (Layte *et al.*, 2009). Access to, provision of, and ultimately spending on, health care in a resource limited environment can be controlled by rationing, either explicit or implicit. Explicit rationing includes limiting access to certain facilities or elective surgeries, for example, through waiting lists. Implicitly, access to specialist services may be somewhat dependent on the ability of users to negotiate this access, which Layte *et al.* (2009) observed is correlated with social class and education.

The Expert Group on Resource Allocation and Financing in the Health Sector (2010) noted in their report that societal attitudes towards explicit and implicit rationing of health care services have

. .

¹⁴ Report of the Expert Group on Resource Allocation and Financing in the Health Sector (2010). Chaired by Prof Frances Ruane and published by Department of Health and Children, Dublin.

http://www.dohc.ie/publications/resource_allocation_financing_health_sector.html [Accessed19/05/2011]

15 Layte R et al. (2009) *Projecting the impact of demographic change on the demand for and delivery of health care in Ireland*. ESRI. http://www.esri.ie/UserFiles/publications/20091023164031/RS013.pdf [Accessed19/05/2011]

hardened in recent years. For example there is increased resistance to rationing based on comorbidity or overall frailty, which disadvantages vulnerable groups such as the elderly and those with chronic disability, even where the benefit of some treatments may be negligible or only marginal in these groups. Some weak policy decisions and out-dated approaches to service delivery have also influenced attitudes about entitlement and access to services, particularly where entitlement is seen as arbitrary and unfair and not based on evidence-informed policy. The Expert Group suggests that managing expectations about fair access to health care will require more transparency in terms of the priorities for health nationally, and evaluation of the effectiveness and cost-effectiveness of different services.

1.3.3 Technology and increased efficacy of interventions

The increased demand for health care that will stem from demographic change in the Irish population, and changing expectations about access to care are certainly significant, but a third key driver of increased health care costs is the slow shift of medical practice towards more expensive diagnostic procedures and treatments, whether or not they are properly evaluated first for their cost-effectiveness. Brick et al. (2010)16 noted that new health care interventions such as stents and drugs for heart disease, drugs for cancer, rheumatoid arthritis and metabolic disease, diagnostic imaging technologies such as PET/CT scanning and other interventions can contribute very significantly to patient wellbeing and quality of life. However, they can also add greatly to the cost of health care provision 1/. Competitive procurement and evaluation of the relative effectiveness and safety per unit cost of those interventions will be essential to enhancing their value for money. Health Technology Assessment (HTA), driven by HIQA and the HSE, will play an essential role in evaluating what diagnostics, interventions and pharmaceutical treatments should form part of the Irish health service package. Good HTA at national level is directly linked to good quality national PHR and HSR, providing a strong argument for increasing capacity in these fields.

1.3.4 Changing the way services are delivered

An ageing population, increased expectations of access to services, and spiralling costs of health technology, combined with the financial crisis faced by Ireland, makes the current way in which care is delivered unsustainable. This situation demands improving and/or changing the way services are delivered through a reconfiguration and intensification in the use of healthcare resources and levels of efficiency. Achieving greater accountability to the public on healthcare expenditure is a further challenge, that will require increased monitoring, reporting and dissemination of information about cost, utilisation and quality so that the allocation of resources can be seen to be equitable, timely and appropriate, and based on a strong evidence-driven foundation. This ambition will require significant development in health system structures in the coming years.

In June 2009 the HSE published the Health Status of the Population of Ireland 2008 report 18, which proposed that the needs of an ageing Irish population are best addressed by placing emphasis on primary and community care, on acute care delivered by interdisciplinary teams and on stronger linkages between primary and acute care service delivery. A 2009 international review of current policies to prevent the onset of old-age disability, or the promotion of so-called 'healthy ageing

¹⁶ Brick A et al. (2010) Resource Allocation, Financing and Sustainability in Health: Evidence for the Expert Group on Resource Allocation and Financing in the Health Sector. Economic and Social Research Institute 596p. http://www.dohc.ie/publications/resource_allocation_financing_health_sector.html [Accessed19/05/2011]

Unpublished data reported in Health Service Executive National Service Plan 2007, published 11 January 2007.

¹⁸ HSE (2009) Health Status of the Population of Ireland 2008 http://www.lenus.ie/hse/bitstream/10147/69698/1/Health%20Status%20Web%20PDF.pdf [Accessed19/05/2011]

policies', highlights opportunities to ensure that the current middle-aged population will be healthier and more independent when they reach old age 19. In addition, changes in society such as smaller family sizes, increase in commuting to work and increased marital breakdown, all affect people's sense of well-being and put pressures on the delivery of health services.

The HSE has prioritised action on reducing the seven major risk factors posed by unhealthy lifestyles, identified in the WHO strategy Gaining Health20, that are known to contribute to the major causes of death and chronic illness/disability (elevated blood pressure, tobacco use, alcohol use, high cholesterol, obesity, low fruit and vegetable intake and lack of physical inactivity.) This list is, of course, 'social determinant free', and the social/cultural environment will act as a driver for these risk factors resulting in differential impacts on various socioeconomic groups across the population, in particular lower socioeconomic groups (see for example Farrell et al. 2008)²¹. To address these priorities, the HSE is now moving to follow best international practice by introducing structured protocols to identify service delivery issues that must be addressed in each clinical programme and the potential solutions that can be considered²².

Brick et al. (2010), in preparing evidence for the Expert Group on Resource Allocation and Financing in the Health Sector, noted that Ireland is not alone in seeking to address issues around sustainability and resource allocation in health sector financing. Healthcare expenditure, as a proportion of gross national income (GNI)²³ is rising in many countries across the EU and OECD, leading to international concerns that health care costs will soon be unaffordable.²⁴ The major spending increases in health since the late 1990s have merely seen Ireland 'catch up' to typical OECD spending levels.²⁵ The proportion of Ireland's GNI spent on health increased from 7.3 per cent in 2000 to 9 per cent in 2007, although this was still lower than the EU15 average (9.6 per cent). However, 2009 total health expenditure data for Ireland would suggest that this proportion had risen sharply in the last three years to 15.2 per cent of GNI, although the impact of a real decrease in average income per capita over the past three years may have had an influence on this apparent jump in health spending as a proportion of income.

In a situation of limited resources for unlimited needs Brick et al. (2010) recommended, among other things, moving toward a resource allocation model based on population health and evaluation of the health care needs of that population. Within the healthcare setting, development of robust clinical evaluation will become increasingly important in assessing and improving the quality of care, the development and implementation of clinical practice guidelines, addressing the stock versus flow problem for medicines, and in effecting improvements in patient safety. Collaborations of economists, clinicians, managers and policy makers will be needed to design integrated health systems that examine the trade-offs between the cost and quality, and economically produce the health outcomes desired by patients and their families.

¹⁹ Oxley, H (2009) *Policies for healthy ageing: an overview*, OECD Health Working Papers No. 42. http://econpapers.repec.org/paper/oecelsaad/42-en.htm [Accessed19/05/2011]

World Health Organization (2006) Gaining Health - The European Strategy for the Prevention and Control of Noncommunicable Diseases. Geneva, World Health Organization, www.euro.who.int [Accessed19/05/2011]

²¹ Farrell C et al. (2008) *Tackling health inequalities. An All-Ireland approach to social determinants*. Institute of Public Health in Ireland.

http://www.iph.ie/publications/tacklinghealthinequalitiesanallirelandapproachtosocialdeterminants [Accessed19/05/2011]
This initiative is being driven by the Clinical Leads within the Directorate of Quality and Clinical Care.

Unlike most other countries in Europe, a significant proportion of Ireland's GDP refers to profit exports - for this reason, GNI is a more meaningful measure.

²⁴ OECD Health Spending and the Economic Crisis. See http://www.oecd.org/health [Accessed19/05/2011]

²⁵ OECD *Public Management Reviews Ireland - Towards an Integrated Public Service* June 2008.

The role of health informatics, improving patient care by improving the management of health information in clinical decision-making, will increase with the evolving national information infrastructure. Technical advances and investments in medical information systems will make possible the integration of routine data from long-term care, inpatient and ambulatory settings into analysis of quality, cost and access. Furthermore, the advocacy for a decision making process jointly shared by patients and their health care providers, which helps patients play an active role in decisions concerning their health, following appraisal of the best evidence of the risks and benefits of all the available options, will change the nature of the healthcare system.

1.4 Harnessing PHR and HSR to address health care challenges

PHR and HSR have vital roles to play in addressing the complex questions and challenges facing policy makers and health service providers in Ireland. There are many examples internationally, especially in the USA where high-quality data from private health insurers is available, of how these disciplines have contributed to improving the way health care is planned, provided and managed. It is clear that many of the challenges faced in Ireland by health care providers, managers and organisers, policy makers within healthcare administration and the government, and ultimately by the consumers of health care can benefit from, and will create new demands for, PHR and HSR.

1.4.1 Contribution of PHR to solving health care challenges

Studies reporting on descriptive epidemiology of major diseases, injuries and risk factors, and on the measurement of health at the population level - either for monitoring trends in health levels or inequalities, or for measuring broad outcomes of health systems and social interventions - are critical components of the evidence base for health policy.²⁶ PHR bridges a range of currently disconnected fields of inquiry relating to health: biology, demography, epidemiology, health economics, and broader social science disciplines relevant to assessment of health determinants, health state valuations and health inequalities. Changes to the underlying ("upstream") determinants of health prompted by the evidence provided by PHR research, have made a significant contribution to improving the health of the population²⁷, and include:

- Increases in life expectancy
- Control of infectious diseases resulting from clean water, improved sanitation
- Vaccination against common diseases with resultant decreases in childhood morbidity and mortality
- Safer and healthier foods resulting from decreased microbial contamination, increases in nutritional content and establishing food fortification programmes
- Healthier mothers and babies resulting from better hygiene and nutrition, availability of antibiotics, greater access to health care services and technologic advances in neonatal and maternal medicine

11

²⁶ Mathers CD et al. (2003) *Population health metrics: crucial inputs to the development of evidence for health policy.* Population Health Metrics, 1: 6

Achievements in Public Health, 1900-1999: Changes in the Public Health System. (1999). MMWR Weekly, 48(50):1141-7. http://www.cdc.gov/mmwr/preview/mmwrhtml/mm4850a1.htm [Accessed19/05/2011]

- Family planning has altered the social and economic role of women and has resulted in better
 access to planning and contraceptive services, increased counselling and screening services,
 fewer infant/child/maternal deaths and has prevented the transmission of HIV and other STDs
- Fluoridation of water safely and inexpensively benefits both children and adults by effectively
 preventing tooth decay regardless of socioeconomic status or access to care
- Recognition of tobacco use as a hazard has resulted in major public health anti-smoking campaigns, smoking cessation programmes, reduced exposure to environmental tobacco smoke by legislation and other means and reductions in smoking-related deaths

Population-based interventions, for example community-wide health education programmes (e.g. the importance of 'five-a-day' for heart health), policy interventions within particular sub-populations (e.g. higher alcoholic beverage prices to affect changes in drinking behaviours among teenagers), and control of communicable diseases (e.g. screening programmes for sexually transmitted diseases among young adults or community vaccination against annual seasonal influenza) have significant impacts on health in Ireland. PHR can explore the impact of these programmes on the health of a target population over time and can thus be predictive of health service utilisation in the future. Understanding the effects of these public health initiatives, with an associated consideration of their costs, staffing and relationship to demands on health service provision, will be increasingly critical as health services are restructured with a focus on cost containment, and as hard decisions are made about where to make investments of public resources.

1.4.2 Contribution of HSR to solving health care challenges

A 2011 policy brief published by HSR-Europe²⁸ entitled *Health services research: Helping tackle Europe's healthcare challenges*, describes how HSR can help healthcare decision-makers to tackle the challenges they face and provide scientific evidence to inform policies and practices. The strength of HSR lies both in the wide range of disciplines it encompasses and the broad array of factors it addresses in its attempt to understand and evaluate health care. Health services researchers conduct studies designed to improve the quality of health care, reduce its cost, evaluate its effectiveness, improve patient safety, decrease medical errors, and broaden access to essential services. Research studies range from assessment of specific health technologies and approaches to providing care, to the evaluation of health sector reforms and health care interventions. These are underpinned by methodological work which includes developing new instruments for assessing health outcomes, the evaluation of policy options, and reviews of health services research methods. The evidence-based information produced by this research helps healthcare decision-makers to make more informed decisions. As health care costs rise and the quest for value for money increases, the role of HSR becomes more and more crucial.

As far back as 1994 Thaul *et al.*²⁹ described a number of areas in which HSR had provided a strong evidence base on which to effect changes in health care policy and service provision in the USA, including:

Detailed studies of the phenomenon of practice variation—a profound mismatch between the
epidemiology of disease and the epidemiology of health care—which raises significant
questions about the quality of the professional knowledge base and the quality of decisionmaking in medicine.

²⁸ See http://www.healthservicesresearch.eu/ for link to Policy Brief. [Accessed 26/05/2011]

²⁹ Thaul S et al. (eds) (1994) *Health Services Research: Opportunities for an expanding field of enquiry - An interim statement.*Committee on Health Services Research: Training and Workforce Issues. National Academy Press.
http://www.nap.edu/openbook.php?record_id=9242&page=R1 [Accessed19/05/2011]

- Development of tools now widely used in health care financing and reimbursement, including
 the diagnosis-related groups used in the Medicare prospective payment system and the
 resource-based relative value scale for setting physician reimbursements.
- Clarification of concepts of health status and functioning, quality of life, patient satisfaction, and psychosocial determinants of behaviour and outcome; development of methods and measurement instruments; and application of these products in, for example, investigations of the effects of various home therapy interventions on the ability of people to cope with disabilities and on studies of quality-of-life issues as important indicators of successful rehabilitation.
- Medical effectiveness and cost-effectiveness studies, which have led to expanded health insurance for new services (e.g. alcohol treatment and long-term care) and have documented the oral health benefits of fluoridating drinking water.
- Refinement of concepts and methods of risk adjustment for use in studies to: predict the use of services by a population with certain demographic and health characteristics; estimate appropriate reimbursements for patients with certain characteristics; and compare providers or systems of care with outcomes while controlling for patient differences.

Lomas (2003)³⁰ also described significant benefits derived from applying HSR to the operation of two healthcare systems in the USA:

- Between 1995 and 2000 the Veterans' Affairs healthcare system improved diabetes control from 52 per cent to 94 per cent and screening for cervical cancer from 62 per cent to 93 per cent while reducing costs per patient by 25 per cent
- The Kaiser Permanente health system achieved consistently higher quality of care than the NHS, as measured by process and outcome measures, while maintaining costs at the same level as the NHS.

It should be no surprise that both of these health care providers invest heavily in HSR, including quality enhancement research initiatives which 'purposely link research activities ... to clinical care in as close to real time as possible, thereby leading to rapid adoption of best clinical practices and improvement in patient outcomes'.

At the cross-over between HSR and PHR, the Nordic countries provide examples of policy interventions on health care provision that have had significant impacts at a population level:

- A policy that broad-spectrum antimicrobial compounds should be avoided in the treatment of common infections presenting in general practice and acute hospital settings has resulted in greater susceptibility in Nordic countries to commonly used antibiotics than elsewhere in Europe³¹.
- As far back as 1985, the implementation of a national screening programme for cervical cancer in Finland, for women aged between 30 and 60 years, was shown to result in an a decrease in the annual incidence of invasive cervical cancer of over 50%³². Evaluation of the intervention demonstrated that the recommended frequency of screening could be pushed out to five yearly in the same age group, a policy subsequently adopted in many other European countries.

_

³⁰ Lomas J (2003) Health Services Research: More lessons from Kaiser Permanente and Veterans' Affairs health care system. British Medical Journal. 327:1301-2.

³¹ Bergan T (2001) *Antibiotic usage in Nordic countries*. International Journal of antimicrobial Agents. 18(3):279-282. ³² Hakama M (1985) *Effect of population screening for carcinoma of the uterine cervix in Finland*. Maturitas, 7(1):3-10.

• The introduction of a personal identification number system in Finland in 1964 has allowed Finland to develop its health policies on a strong evidence base provided by both population health research studies and evaluation of the impacts of health care interventions on service provision and need³³. Infant and maternal mortality in Finland is one of the lowest in the world and there have been significant improvements in life expectancy, amenable mortality, eradication of communicable diseases, cancer survival and the functional capacity of the population in the last three decades³⁴.

³³ Gissler M and Haukka J (2004) *Finnish health and social welfare registers in epidemiological research*. Norsk Epidemiologi.

³⁴ Vuorenkoski L (2008) Finland: Health System Review. Health Systems in Transition, Vol 10, No. 4. http://www.euro.who.int/en/home/projects/observatory/publications/health-system-profiles-hits/full-list-of-hits/finland-hit-2008 [Accessed19/05/2011]

Chapter 2 Strategic coordination and prioritisation

2.1 Introduction

It is clear from the evidence gathered and the consultations undertaken during this review that there is still a lack of explicit support for PHR and HSR within national strategic initiatives that support health research. Where this exists, it often forms a subsection of a broader health research strategy. For example, the DoH recognises the importance of research as a policy input and a driver of improved health and well-being in the population of Ireland. It does not, however, prioritise the support of high-quality PHR or HSR within its performance framework. Likewise, the stated strategic objective of the HSE to adopt a 'population health' approach to service delivery is not sufficiently supported by any explicit recognition of the importance of PHR and HSR in achieving this aim.

This review acknowledges that there is a sometimes uncomfortable fit between the evidence generated by research and the more immediate economic and political realities with which policy makers must deal. From a political perspective, independent research evidence is only one factor that shapes decisions. Government agendas are also shaped by political commitments, party platforms and the views of key political leaders. There is also the issue of the selective use of research evidence rather than the systematic use of research evidence by policy makers and unless that distinction is clear, Ireland is in danger of moving from a no-evidence basis for policy to a selective evidence basis for policy. That said, the landscape is changing and there have been a number of important strategies published in the past 15 years that have implications for PHR and HSR. These are described in the next section and Figure 2.1 sets out their chronology.

2.2 Strategic support for PHR and HSR

The 1995 publication of the first national health promotion strategy, *Making the healthier choice the easier choice* (Department of Health 1995)³⁵ sought to give effect to a strategic approach to tackling many of the lifestyle factors that contribute to premature illness and death in Ireland. The Strategy recognised that Ireland needed to evolve from an exclusively "topic-based" approach to initiatives tailored to meet the needs of a range of settings conducive to health promotion in its broadest sense. A second strategy in 2000, *The National Health Promotion Strategy 2000-2005* (Department of Health and Children 2000)³⁶ led to the establishment of Health Promotion Units in all health boards, the publication of allied strategies to support the work of these units and the initiation of the first nationally representative surveys of lifestyle practices in Ireland, the *Survey of Lifestyle, Attitudes and Nutrition* (SLÁN)³⁷ and *Health Behaviours in School-aged Children* (HBSC Ireland)³⁸, as inputs to national health-promotion policies. Both of these surveys continue to be carried out in collaboration with academic departments.

Department of Health (1995). *A health promotion strategy: making the healthier choice the easier choice*. Stationary Office, Dublin. http://www.lenus.ie/hse/handle/10147/46380 [Accessed19/05/2011]

³⁶ Department of Health and Children (2000) The National Health Promotion Strategy 2000-2005. http://www.DoHC.ie/publications/national health promotion strategy.html [Accessed19/05/2011]

SLÁN (2006) Survey of lifestyles, attitude and nutrition. http://www.slan06.ie/ [Accessed19/05/2011]

³⁸ Health Behaviours in School-Aged Children. http://www.nuigalway.ie/hbsc/publications_reports.html [Accessed19/05/2011]

The 2001 government blueprint for the reform and long-term development of the health services in Ireland up to 2010, *Quality and Fairness: A Health System for You* (DoHC)³⁹ identified overarching goals to guide planning and activity in the health system and to address some very clear deficiencies around health service provision. A 2001 report by the Chief Medical Officer, *Better Health for Everyone; A Population Health Approach for Ireland*⁴⁰, published in the aftermath of this strategy, set out in detail how the population health approach articulated in the strategy can lead to better health for everyone. While not explicitly describing a research agenda, this document endorsed the role of research in quality health care and identified a need to support health care professionals in carrying out research and applying their findings to improve service delivery. The link between attracting and retaining high-quality professionals and providing them with research opportunities was also recognised.

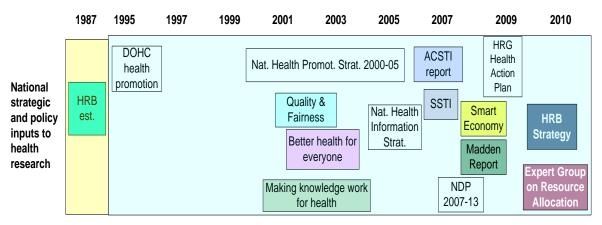


Figure 2.1 Timeline of policy and strategy inputs to health research in Ireland

Other strategic initiatives, including *Making Knowledge Work for Health: A strategy for health research* (DoHC, 2001)⁴¹, *Towards Better Health; Achieving a Step Change in Health Research in Ireland* (Forfás and ACSTI, 2006)⁴² and the *Strategy for Science Technology and Innovation 2006-2013* (SSTI), (DETE, 2006)⁴³ recognised the increasing importance of health research to future economic and social development in Ireland and identified it as a key element in the development of the Irish healthcare system. The *Report of the Commission on Patient Safety and Quality Assurance* (2008)⁴⁴, highlighted the importance of patient safety and quality of care as drivers of reform and improvement in health services, areas where HSR is particularly relevant. The *HSE Transformation Programme* (2008)⁴⁵ adopted a population health approach to deal with the complex array of political, social, economic and environmental factors - and health and social services issues - that affect the health of the people living in Ireland. In June 2009 the HSE published the *Health Status of the Population of*

_

³⁹ Department of Health and Children (2001b) Quality and Fairness: A Health System for You.

http://www.DoHC.ie/publications/pdf/strategy.pdf?direct=1 [Accessed19/05/2011]

40 Chief Medical Officer (2001) Better Health for Everyone; a Population Health Approach for Ireland. Annual Report http://www.DoHC.ie/publications/cmo_2001.html [Accessed19/05/2011]

⁴¹ Department of Health and Children (2001a) Making Knowledge Work for Health: A strategy for health research. http://www.DoHC.ie/publications/making knowledge work for health.html [Accessed19/05/2011]

⁴² Advisory Council for Science, Technology and Innovation (2006) *Towards Better Health. Achieving a step change in health research in Ireland*. https://www.sciencecouncil.ie/publication/ascSearch.jsp?ft=/publications/2006/title,3254,en.php [Accessed19/05/2011]

⁴³ Department of Enterprise, Trade and Employment (2006) *Strategy for Science, Technology and Innovation 2006-013*. http://www.entemp.ie/science/technology/sciencestrategy.htm [Accessed19/05/2011]

Report of the Commission on Patient Safety and Quality Assurance (2008) Building a culture of Patient Safety. Department of Health and Children, Dublin. http://www.dohc.ie/publications/building_culture_patient_safety.html [Accessed19/05/2011]

⁴⁵ Health Services Executive (2008) The Health Service Executive Population Health Strategy. <a href="http://www.hse.ie/eng/staff/FactFile/Health_Status_Reports/Population_Health/Population_Health_Strategy/FactFile/Health_Status_Reports/Population_Health/Population_Health_Strategy/FactFile/Health_Strategy/FactFile

Ireland 2008 report with the aim of informing the development of future health services 46. Finally, the Report of the Expert Group on Resource Allocation and Financing in the Health Sector (2010) sets out a comprehensive and detailed set of recommendations on how resources in the health services might be better allocated in the future and will be an important input to strategic planning of service provision and access to health care in Ireland in the coming years.

2.2.1 Lessons for Ireland from international experience

How best to ensure appropriate health care for the population is a key challenge for every nation, now far harder to achieve given the global economic downturn⁴⁷. Internationally, there have been sustained attempts to develop both population health policy and to reform health systems to achieve improved population health, equitable access to care, public satisfaction, quality and greater efficiency while controlling costs. While reform of healthcare systems is highly country-specific and dependent on a unique blend of history, politics, economic circumstance and the relative power of key groups, the broad policy strategies and goals share similarities across countries (see Volume 2, Chapter 9 for a fuller description of the PHR and HSR policy context within a number of countries).

Experience from abroad consistently shows that the successful use of PHR and HSR evidence demands the establishment of effective inter-department, inter-government and inter-sectoral mechanisms so that policy initiatives are implemented concurrently and act synergistically, when, and wherever possible. A focused and integrated whole-of-government strategy for action focused on specific targets within realistic timeframes - which can be implemented and monitored - appears to be more successful that an approach that either emanates solely from within the health ministry, or consists of various interventions implemented independently. In the UK the involvement of the Treasury has been important in ensuring adequate funds to support research and policy implementation, but also in maintaining the commitment from other government departments. Successful countries have established national research programs, instituted national arrangements to monitor and report on population health, or have embedded health impact assessment methods in government policy-making processes.

Public organisations, at arm's length from health service providers and charged with assessing the quality of care by providers, are part of the landscape in many countries. HIQA fulfils this role in Ireland, although its scope and powers are less extensive that those of similar organisations in other European countries, such as the National Institute for Health and Clinical Excellence (NICE) in the UK. Many countries have also sought to increase the external challenge on providers by giving the public more influence in shaping local services.

In addition to governmental oversight of service delivery there has been growing engagement of clinical professionals in improving whole services within provider organisations. Health care professionals have taken on management and leadership responsibility for improving quality and efficiency, developing clinical governance and patient safety initiatives, crafting better evidence-based and coordinated pathways of care, and developing incentives to help motivate their peers. In Ireland, the HSE is currently fostering such engagement through its Directorate of Quality Clinical Care, and the development of 22 Clinical Care programmes, each of which is headed by a leading clinician in the

⁴⁶ HSE (2009) Health Status of the Population of Ireland 2008

http://www.lenus.ie/hse/bitstream/10147/69698/1/Health%20Status%20Web%20PDF.pdf [Accessed19/05/2011]
See 2010 Nufield Trust briefing paper by J. Dixon and V. Alakeson for a more in-depth discussion of this topic. http://www.nuffieldtrust.org.uk/publications/detail.aspx?id=145&prID=735 [Accessed19/05/2011]

field, all of whom are tasked with the development of clinical care pathways that engage multidisciplinary teams of health care professionals.

Ireland can also learn much from initiatives elsewhere aimed at the vital issue of bridging the 'knowledge gap' and improving knowledge transfer and exchange (KTE) across the health research system. Key among these is to create a cadre of 'responsive' and research savvy health managers and policy makers, capable of receiving and using the evidence generated in the research community to inform their policy development and practices. In the HSR realm, Canada provides a good example of developing capacity and leadership through the Canadian Health Services Research Foundation's Executive Training for Research Application (EXTRA) programme, which gives health system managers (nurse executives, physician executives, and other health administration executives) across Canada the skills to better use research in their daily work as a way to increase evidence-informed decision-making in the health system⁴⁸.

In relation to PHR KTE, the six Canadian National Collaborating Centres (NCCs)⁴⁹ for Public Health provide a good example of how to promote and improve the use of scientific research and other knowledge to strengthen public health practices and policies. Established in 2005 and funded through the Public Health Agency of Canada, the NCCs produce information to help health care professionals improve their response to public health threats, chronic disease and injury, infectious diseases and health disparities. They identify knowledge gaps and work with practitioners, policy makers and researchers to foster networks and translate existing knowledge to produce and exchange relevant, accessible, and evidence-informed products.

Closer to home, the Scottish Collaboration for Public Health Research and Policy (SCPHRP)⁵⁰, supported by the Chief Scientist Office, is a public health consortium with members drawn from research, policy and practice, that aims to tackle Scotland's poor health record by strengthening the evidence base for improving health. SCPHRP fosters collaboration between the Scottish Government, researchers and the public health community to develop a national programme of intervention development, large-scale implementation and robust evaluation. The Collaboration has an overarching structure that is supported by a small core team of full-time staff. It draws on the expertise of its contributors through Working Groups, public consultations, and a small number of feasibility and pilot projects that develop and evaluate novel public health interventions. SCPHRP is also tasked with building capacity within the public health community for collaborative research with maximum impact on Scottish policies, programmes and practice.

2.3 Coordination of health research

The Irish health research system is a complex mix of many groups including relevant governmental departments, the HSE, HIQA, the funding agencies, academia, medical charities, patient advocacy groups and the healthcare industry, whose strategies, although interlinked, are not integrated at present. International experience demonstrates that integrated strategic support and planning for health research are vital, that the respective roles of the key stakeholders in the health research system need to be clear, and that appropriate emphasis needs to be placed on coordination across the system.

⁴⁸ http://www.chsrf.ca/Programs/EXTRA.aspx for details of the Canadian Health Services Research Foundation (CHSRF) Executive Training for Research Application (EXTRA) programme. [Accessed19/05/2011]

⁴⁹ See http://www.nccph.ca/en/home.aspx for more information [Accessed19/05/2011]

⁵⁰ See https://www.scphrp.ac.uk/ for more information [Accessed19/05/2011]

The establishment of the Health Research Group (HRG) in Ireland to coordinate strategic engagement of all relevant organisations at national level and to address some of the fragmentation currently prevalent in the system has been a significant step forward in terms of coordination. Figure 2.2 outlines the current national coordinating structure for research and policy and the place of the HRG within this structure. The purpose of the HRG is to ensure that health research in Ireland is coordinated, prioritised and focused, and that national policies and strategies for health research are framed strategically in the context of the wider science, technology and innovation agenda. The HRG is chaired by the DoH and includes representatives from the government departments primarily involved in formulating policy in relation to health research (DoH, Enterprise, Jobs and Innovation [DEJI], Education and Science [DES], Environment, Heritage and Local Government [DEHLG], Marine and Natural Resources [DMNR], and Agriculture, Food and Fisheries [DAFF].) These are supported by their agencies, including the HRB, the HSE, HIQA, Science Foundation Ireland (SFI), Enterprise Ireland (EI), the Industrial Development Authority (IDA), the Environmental Protection Agency (EPA), the Marine Institute and Forfás.

A key output of the HRG has been the development of an *Action Plan for Health Research 2009-2013* (2009)⁵¹. The Action Plan is integrated into the government's programme for economy recovery to maximise the strategic outcomes of all applicable health research expenditures, and addresses the entire spectrum of health research, including those shortcomings amplified in PHR and HSR. Many of the actions identified in the HRG *Action Plan for Health Research* address the challenges of creating an integrated and focused health research system that can effectively translate and apply research to the development of new diagnostics, treatments or therapies, to improving patient outcomes, to changing the way in which health care is practised and delivered, and ultimately to improving the nations' health and well-being.

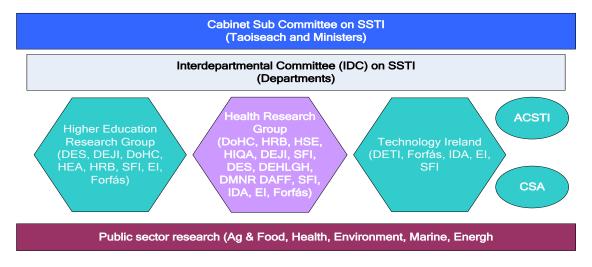


Figure 2.2 National coordinating structures for research and policy

The establishment of the HRG will be important for coordination of overall health research activity and priorities at a national level. That said, the critical importance of PHR and HSR in providing the evidence base on which improvements in the efficacy and effectiveness of the Irish health system can be build are not explicitly recognised or prioritised in the HRG Action Plan. Therefore, there is a need for an additional mechanism focused specifically on the needs of PHR and HSR and enabling

-

⁵¹ Health Research Group (2009) Action Plan for Health Research 2009-2013. http://www.DoHC.ie/publications/pdf/action_plan_health_research.pdf?direct=1 [Accessed19/05/2011]

infrastructure, which brings together relevant stakeholders, in particular, the HRB, the DoH, the HSE, HIQA and the Irish Research Council for Humanities and Social Sciences (IRCHSS). Such a grouping is the most appropriate one to look at the broader issues of how PHR and HSR can work in an Irish context. This includes developing a national PHR and HSR strategic agenda that clearly identifies the respective roles of the relevant stakeholders in the health research system. There is a need to determine agreed priorities within this agenda between the different agencies and to place appropriate emphasis on coordination across these agencies, as well as between cognate government departments and other funding and health service provision agencies. The process of agreement should ensure clarity in the distinct roles of the different agencies while supporting joint cooperation where appropriate, for example in planning the objectives and target audience for funding schemes and sequencing the release of funding calls to the health research system. Establishing a PHR and HSR Work Stream under the auspices of the HRG might provide a mechanism for pulling the appropriate stakeholders together while ensuring integration with the broader national health research agenda.

2.4 Identifying priorities for PHR and HSR in Ireland

Developing national research priorities is an essential aspect of good governance and management in both the general and health research systems. Credibly set (using a robust methodology; encouraging an inclusive approach; allowing sufficient time for debate) and regularly updated research priorities ensure that national health research investments balance the needs and interests of these using, designing, delivering and managing health services with the needs of the health research system to achieve short, medium and long term health objectives⁵². Setting health research priorities also provides opportunities to co-ordinate and to communicate among the relevant stakeholders, to increase the scope for interdisciplinary and cross-agency approaches and ultimately to foster enhanced utilisation of research evidence. Clearly articulated research priorities allow researchers and funders to align their activities and expertise with national requirements and provide a clear framework for government to measure the impact of national health research. Gibson et al. (2005)⁵³, has also emphasised the importance of ensuring that decisions on health services priorities are ethically sound (fair and publically accountable), especially where the demand for health services exceeds available resources.

To date there has been little nationally coordinated priority setting for health research in Ireland although a number of key health stakeholders, including the DoH, HRB, HSE, HEA and HIQA, have identified high-level priorities to drive their own strategies, There has been even less nationally coordinated priority setting in the specific areas of PHR and HSR. This is partly because of the absence of a clear vision and a common set of values underpinning the Irish health system, but also, as noted by the Expert Group on *Resource Allocation and Financing in the Health Sector* (2010), because of the mixed public-private delivery of health care and the fragmented nature of service provision in Ireland.

In the absence of nationally set priorities, the focus of health research in Ireland has typically been driven by research producers, thereby creating a situation of 'inadequate knowledge pull' from the user communities in the health system, a situation that is common in the early stage of developing effective

Montorzi G et al(2010) *Priority setting for health research: A management process for countries.* Council on Health Research Development (COHRED): http://www.cohred.ch/prioritysetting [Accessed19/05/2011]

Gibson JL et al. (2005) Evidence, economics and ethics: Resource allocation in health service organizations. Healthcare Quarterly, 8(2):50-59.

knowledge transfer and exchange in all countries⁵⁴. At present, the principle of evidence-informed policy and practice is not embedded in the Irish healthcare system. Consequently, the demand for PHR and HSR is weak and often poorly articulated by policy-makers and service providers, in particular the HSE, the DoH and the Department of Finance. This hampers the development of good-quality research in PHR and HSR, and the identification of priorities in a short- and medium-term research agenda.

There is, however, a strong push to move towards a more priority-driven health research system in Ireland. In late 2010 a National Research Priority Steering Group, established by the Department of Enterprise, Jobs and Innovation (DEJI)⁵⁵ and assisted in data collection by Forfás, began developing a five-year prioritisation plan for Government investment in research and 'smart' jobs. Within this exercise 'Health, Well-Being and Ageing', has been identified as one of the four pillars of national investment. This will provide a framework for health research investment in Ireland in the coming years and is an important acknowledgement of the importance of research for the health, well-being and economic advancement of the Irish population.

However, from the perspective of PHR and HSR, any attempt to identify priorities that link research to economic gain and job creation may fail to appreciate the important downstream benefits of health research in general and PHR and HSR in particular. A report commissioned by the UK Evaluation Forum (2008)⁵⁶, noted that estimating the returns on investment in health research is notoriously difficult, because of the time it takes for much of this research to filter into measurable health and economic gain. The Forum argued that in thinking about the value of health research, not only should the gains in terms of health and quality of life, with consequent savings on health care, be considered but that the wider impact on GDP from so-called 'research spill-overs' must be taken into account. Research spill-overs include the production of skilled graduates, ideas generated by academic and clinical researchers, networking opportunities, high-quality libraries and so on, that encourage high-tech firms to locate themselves near centres of excellence in higher education.

The National Research Priority Steering Group is unlikely to develop a set of clear priorities within the specific areas of PHR and HSR, and the priorities that it identifies for the broader health research system may not serve a PHR and HSR agenda well. The impacts of PHR and HSR often take the form of public good in cases where the social benefits of the research are high but the private benefits are low, i.e. where there is little incentive for commercialisation. These are exactly the situations where public funding for research is essential and ought to be given priority. Radical demographic change, an ageing population, increases in the number of people living with chronic disease, the spiralling cost of providing healthcare facilities and medication, greater demand from citizens for higher quality and more personalised care and greater needs for shifting investment from acute to primary, community and self-managed care are just some of the social challenge facing the Government and the health services. This underlines the importance of identifying a mechanism that can bring together the appropriate stakeholders to identify the gaps and needs in these areas, and articulate clear and appropriate priorities for PHR and HSR.

⁵⁴ Pers. Comm. Prof. John Frank.

⁵⁵ See http://www.deti.ie/press/2010/20100927.htm for more information on this activity. [Accessed 14/12/2010]

Health Economics Research Group, Office of Health Economics and RAND Europe (2008). *Medical Research: What's it worth? Estimating the economic benefits from medical research in the UK*. London: UK Evaluation Forum. http://www.wellcome.ac.uk/About-us/Publications/Reports/Biomedical-science/WTX052113.htm

2.4.1 HSR priorities from a European perspective

In Europe, there is a growing interest in understanding how health services and systems work and can be improved. The 2011 HSR-Europe Policy Brief⁵⁷ describes three levels at which such systems can be examined:

- 1. at care provision level (micro), for example, assessing which interventions are most effective from both a cost and health outcome perspective
- 2. at organisational level (meso), for example examination of efficiencies in service provision, shortening of waiting times and so on
- 3. at system level (macro), for example health care policy challenges such as how care should be financed

The Policy Briefing describes the major areas of research that each of these levels will need to further develop, including cross-cutting themes of measuring the quality of performance of health care. The report looks at priorities for analysing health care systems, for studying the organisation and delivery of services, for better assessing health technologies, for improving performance indicators and their use in benchmarking, and for linking research to policy. Key directions in which future research needs to be developed include research into:

- the effects of health care reforms on major health outcomes, such as changing the funding of health insurance or privitisation of care
- improved understanding of the complex interactions and relationship between acute hospital
 and primary and community care, in order to ensure service provision that is safer, of higher
 quality and more patient-centred
- new approaches to Health Technology Assessment and to the economic and organisational consequences of introducing new health technologies
- the need for improved effectiveness and efficiency of performance indicators and their linkage to other governance policies

By gaining a better understanding of how HSR is being undertaken and used in different countries, Ireland will also be addressing challenges being experienced nationally. It is likely that the priorities emerging from European discussion will also be shared by Ireland and we have, therefore, much to gain by engaging at a European as well as a national level in priority-setting exercises areound HSR and PHR.

2.5 Shaping the Irish PHR and HSR agenda

A number of key stakeholders will have a critical role in ensuring that PHR and HSR are considered in any priority setting process, and in setting and executing a PHR and HSR agenda over the coming years, in particular the HRB, DoH, HSE and HIQA. The individual roles of these key players in ensuring that PHR and HSR take their rightful place in the broader health research agenda are examined below.

⁵⁷ Health Services Research Europe (2011) *Health services research: Helping tackle Europe's healthcare challenges.* http://www.healthservicesresearch.eu/ [Accessed 26.05.2011]

2.5.1 Role of the DoH in shaping the PHR and HSR agenda

The DoH determines the policy for health research and health care provision in Ireland. While the DoH can influence the strategic direction of health research through the HRB, the extent to which it can influence research engagement and policy implementation in the HSE is limited by the fact that the Department of Finance holds the 'vote' for the HSE at present. Changes in this arrangement in the future might provide the DoH with an opportunity to ensure that health research is more fully aligned with health care policy.

In its *Statement of Strategy 2008-2010* ⁵⁸ the DoH identified seven high level objectives around implementing policies and practices that improves the health and well-being of Irish people. These are:

- the provision of policy and corporate support to ensure the delivery of high quality and effective health and social services within available resources
- promotion and protection of the health and well-being of children and families
- the provision of a broad spectrum of integrated, locally-based services
- reduction of the incidence, morbidity and mortality from cancer and provision of quality assured cancer services by the HSE
- rapid, appropriate and safe access to acute hospital care with optimum outcomes for each patient
- the promotion of mental health through appropriate support and interventions, and help people with disabilities to achieve their fully provide
- enhancement of the quality of life of older people, through home and community support where possible, with access to appropriate residential care where necessary

These objectives are a mixture of upstream changes in determinants of health with downstream improvements in post-disease-onset access to and quality of curative care. In order to achieve this blend of objectives, the DoH has recognised that it needs the capacity to access and analyse the relevant existing evidence base and to identify where new evidence needs to be generated. Many of these evidence needs are in areas relevant to PHR and HSR.

Within the performance framework for the health system laid out in the DoH Strategy Statement, there is explicit policy support for the role of PHR in keeping people healthy thought increasing healthy behaviours, focusing on prevention and early detection of disease, reducing health inequalities and promoting the health and well-being of vulnerable groups. Research-led activities within the DoH relevant to PHR and HSR centre on continued support for national longitudinal and cross-sectional surveys as inputs to policy. These include the National Longitudinal Study on Children (Growing Up in Ireland) and the National Children's Research Programme, the SLÁN Survey of Lifestyle and Health Behaviour, the Health Behaviour in School-aged Children (HBSC) survey of health behaviours among teens and the Irish Longitudinal Study on Ageing (TILDA). However, while the outcomes of these surveys provide important evidence to policy formation for the DoH public health programme, the Expert Group on *Resource Allocation and Financing in the Health Sector* (2010) has observed that there is little evidence that these policies are being delivered into the health system.

Department of Health and Children (2008b) Statement of Strategy 2008-2010. http://www.DoHC.ie/publications/pdf/en_strategy08.pdf?direct=1 [Accessed19/05/2011]

2.5.2 Role of the HRB in shaping the PHR and HSR agenda

The HRB is the primary health research funding agency in Ireland, distributing its funding through open-calls to applicants of high quality, as assessed by international peer review. The HRB Board has been given a mandate by its parent department, the Department of Health, to develop funding strategy that can best address identified gaps in health research capacity and infrastructure, and enable high-quality research across the health research system. While it is not the role of the HRB to set national policy in health research, it can shape and drive the PHR and HSR agenda through the research that it supports and the funding models that it uses.

In 2009, the HRB and its Board undertook a significant review of its strategy, to ensure that its investments and effort continue to serve the Irish health agenda into the future. In developing its *Strategic Business Plan*, the HRB was guided by the DoH on the appropriateness of these strategic changes to satisfy the needs of national health policy. As a result, the HRB strategy sets out investments in a number of areas that have the greatest potential for translation into impacts and benefits for health, in particular patient-orientated, applied biomedical, clinical, PHR and HSR,

Among Irish public funding agencies, the HRB is unique in funding both theoretical and applied research across the spectrum of health from clinical, HSR, PHR and practice-based disciplines such as nursing and midwifery, primary care and therapies, as well as supporting research in the applied biomedical space. HRB support for these areas is not new and its' focus will continue to be on building capacity for PHR and HSR, to address the gaps highlighted by this review. In the longer term however, support for these areas will also need to be provided by other stakeholders. The HRB is ideally positioned to nurture such links between academia and the health service. In addition, PHR and HSR are starting to be viewed by the enterprise agencies as 'enabling' activities for economic development, creating opportunities for collaborative engagement by the HRB research community with this sector.

As a HRG member, the HRB is well placed to articulate the needs of both the health research community and strategic stakeholders, and to broker knowledge transfer and exchange between these different interest groups. This role is captured as a strategic goal within the HRB's strategy. The HRB also has the requisite expertise to drive the development of an evaluation framework for health research investment (as set out in the HRG Action Plan). In the current economic climate there are numerous competing pressures for funding and stakeholders may need continuous persuasion to invest time and resources in research. Robust evaluation will be vital in providing a strong international benchmark of the quality of research and a basis on which to refine programmes and drive the need for sustainable funding. In terms of PHR and HSR research, such an evaluation framework should aim to reward the total impact of research by ensuring that, in addition to usual econometric indicators, measures of the impact on quality of services, policy and the lives of patients and communities are included.

2.5.3 Role of the HSE in shaping the PHR and HSR agenda

In 2006 the Population Health Directorate of the HSE prepared a discussion document setting out broad principles that would underpin research in the HSE. This document highlighted the importance of collaboration, both internally and externally, for the promotion of health research, the development of a research culture in the HSE and the need to increase research capacity and funding for research in the HSE. The HSE's *Corporate Plan 2005-2008*⁵⁹ highlighted the importance of linking research with

http://www.hse.ie/eng/services/Publications/corporate/HSE_Corporate_Plan_2005-2008.html [Accessed19/05/2011]

⁵⁹ HSE Corporate Plan 2005-2008.

evidence-based services, leading to better health outcomes. The plan undertook to "develop our research capability, putting evidence into practice, thus leading to better health outcomes", to agree and implement a research governance framework and to develop a HSE research strategy.

Despite these aspirations, there has been little subsequent progress in developing or implementing a research strategy for the HSE, no research priorities (other than very high level objectives) have been identified nor has any discreet research budget been identified within the HSE to support these objectives. More notably, the HSE's *Corporate Plan 2008-2011*⁶⁰ makes no mention of these plans. This suggests that while the HSE recognises the crucial importance of developing health-services embedded research, it is currently unable to address the challenges of doing so, and of building meaningful links between clinical, PHR and HSR and improved patient care and service delivery.

However, this review acknowledges that the complexity and difficulty of developing an R&D culture and supporting infrastructure in the HSE cannot be underestimated, especially in the context of the immediate clinical and service delivery pressures that it faces. In developing a research strategy and identifying research priorities, the HSE will have to address a very underdeveloped infrastructure for research and research governance in the Irish health services, which includes considerable financial constraints and organisational and analytical capacity deficits. Since research has not traditionally been seen as a front-line activity that can underpin high-quality health care, there have been few incentivise for front-line staff to become involved in research and to use research evidence to inform their practices.

At a practical level, a considerable constraint to advancing a research agenda has been the absence of any one unit within the HSE with overall responsibility for R&D and any structural mechanisms to carry this through. The HSE *Medical Education, Training and Research Strategy* (2007)⁶¹ identified the appointment of a Director of Research as crucial in this regard. The 2009 HSE report, *Education, Training and Research; Principles and Recommendations*⁶², reiterated the urgency of progressing this appointment in order to bring the appropriate leadership, coordination and direction to the HSE's key role in the national health research agenda. However to date this position has not been filled. In addition, the moratorium on recruitment of research staff, the absence of a clearly articulated research strategy for PHR and HSR within the HSE, and the absence of a research budget or any formal system to account for research expenditure within HSE agencies has made it difficult for the HRB and others agencies such as SFI and the enterprise agencies to engage with the HSE on research.

Some progress has been made by the HSE in working to identify and shape a clinical research agenda and research priorities for the programmes within the recently formed Directorate of Quality and Clinical Care (DQCC). This Directorate has been given the task of identifying R&D needs with a specific focus on clinical and service delivery across its 22 clinical programmes, although its focus will primarily be on quality improvement and audit, and will exclude much vital PHR and HSR research. Nonetheless, this initiative presents an opportunity to advance research in the HSE, particularly if they are willing to work collaboratively with research partners such as the HRB, as recommended in their 2009 Education, Training and Research report. It is also critical that the process by which identified research gaps are addressed by the HSE must be based on the core principles of independence and excellence endorsed as best practice by the international research community and the HRB.

⁶⁰ HSE Corporate Plan 2008-2011.

http://www.hse.ie/eng/services/Publications/corporate/HSE_Corporate_Plan_2008-2011.html [Accessed19/05/2011]

⁶¹ See http://www.hse.ie/eng/services/Publications/corporate/etr/mededucationtrainingresearch.html for the full report [Accessed19/05/2011]

⁶² See

http://www.hse.ie/eng/services/Publications/corporate/etr/education%20training%20research%20principles%20recommendations.html [Accessed 26.05.2011]

The disconnect between the funders of health research and health services providers is not unique to Ireland. Recognition of the difficulties of translating research findings into health and economic benefits in the health services led the UK Departments of Health and Trade and Industry to establish the Office for Strategic Coordination of Health Research (OSCHR)⁶³ in 2007, as a central coordinating body. OSCHR facilitates the Medical Research Council, the National Institutes of Health Research and the National Health Services to work together to maximise the benefits of publicly funded health research. The proposed changes to the structure and governance of the health services in Ireland in the coming years may present the DoH with an opportunity to put in place a similar entity in Ireland that could facilitate engagement and mutually beneficial cooperation between the HSE and funding agencies with a health focus.

2.5.4 Role of HIQA in shaping the PHR and HSR agenda

Internationally, there are many agencies that support evidence-based decision-making regarding the introduction of effective innovations and the efficient use of resources in health care provision. These include the Canadian Agency for Drugs and Technologies in Health⁶⁴, the Swedish Council on HTA⁶⁵, the Finnish Office for HTA⁶⁶, and the Pharmaceutical Benefits Advisory Committee and Medical Services Advisory Committee in Australia⁶⁷. The National Institute for Health and Clinical Excellence (NICE) in the UK has a decision-making role, so that recommendations from technology assessments conducted by NICE essentially represent national policy decisions⁶⁸.

Until recently, Ireland was one of the few developed countries with no systematic processes for evaluating the clinical and cost effectiveness of its health services. However, the role of Health Technology Assessment (HTA) in informing decision-making (at both a local and a national level) has now been strongly endorsed by the DoH, particularly in the context of the constrained budgets within which the policy-makers and those charged with providing health services have to operate. The Health Information and Quality Authority (HIQA), in setting up Ireland's first HTA function, is responsible for making sure that the resources in the Irish health services are used in a way that ensures the best and most cost-effective outcome for the patient or service user.

HIQA is working with the HSE to develop HTA in line with international practice, through research groups such as the National Centre for Pharmacoeconomics, which is jointly funded by the DoH and HSE, and conducts economic assessments of pharmaceuticals. HIQA also commissions research from a variety of organisations on elements of HTA. Within the higher education sector HTA has started to build up capacity, with the appointment in 2008 of a Professor in Health Technology Assessment at NUI Galway, the development of new Health Economics courses in University College Cork (UCC) and the provision of Health Economics Fellowships by the HRB. This incremental increase in capacity to conduct high-quality HTAs, while welcome, is fragmented at present and in a small system like Ireland there is a need to integrate existing and emerging capacity, to achieve critical mass,

For more information on OSCHR see http://www.ukcrc.org/aboutus/keyorganisations/oschr/ [Accessed19/05/2011]

⁶⁴ See http://www.cadth.ca/index.php/en/home for details of the Canadian Agency for Drugs and Technologies in Health [Accessed19/05/2011]

⁶⁵ See http://www.sbu.se/en/Home/ for details of the Swedish Council of HTA [Accessed19/05/2011]

^{68*} See http://www.nice.org.uk/ for details of the UK National Institute for Health and Clinical Excellence (NICE) [Accessed19/05/2011]

HIQA also has an important role to play in ensuring that high quality health and social care information is available to support the delivery, planning and monitoring of services. Their work in this area will focus on establishing standards for all aspects of health and social care information, developing guidelines for the collection and use of information in health and social care, identifying gaps in health information and making recommendations on how fill them. Since accurate, timely and accessible health information is the life-blood of researchers in PHR and HSR, this role is critical in improving the quality and applicability of outputs from these research areas over the coming years.

Chapter 3 Key observations and implications of mapping study

3.1 Introduction

From the data and opinions gathered during this review it is clear that PHR and HSR require a flexible array of skills and competencies in both research producers and consumers, appropriate models of funding and infrastructure to support PHR and HSR, mechanisms to ensure that PHR and HSR evidence can influence policy and practice, and networking of all stakeholders to enhance the efficacy and efficiency of the health system. This chapter draws on the learning of the Mapping Study (Volume 2) conducted for this review, with regard to the inputs (capacity, funding, infrastructure) and outputs (publications, policy impacts, networks) to identify any significant gaps that remain in the PHR and HSR system in Ireland, but also to draw out opportunities for strengthening PHR and HSR in Ireland across these interrelated requirements and to indicate some steps that could capitalise on these opportunities.

Arising from this review, and in line with the objectives stated in its strategy, the HRB will develop an implementation plan in 2011 setting out its priorities in PHR and HSR from now until 2014 and beyond. It is also hoped that the evidence and analysis provided by this review will contribute to a wider priority setting exercise for health research in Ireland and will assist other stakeholders with a role to play in developing PHR and HSR (research funding providers, research performers and policymakers) in developing specific and collaborative actions to ensure that there is organised and sustained support for PHR and HSR similar to other leaders internationally.

3.2 Building and developing capacity for PHR and HSR

A strong PHR and HSR system in Ireland will require an adequate cohort of high quality researchers at all levels of the career path to sustain and develop these areas. Research on PHR and HSR-relevant topics requires the expertise of a broad range of disciplines. This is reflected in the breadth of academic units that undertake this type of research, and in particular the interdisciplinary nature of academic units that have made this type of research their core focus.

This review looked at the current capacity to conduct PHR and HSR in Ireland and at training opportunities for those engaged in, or wishing to be engaged in, PHR or HSR. Data was collected through three surveys conducted during this review of (i) research-funding providers, (ii) heads of academic units and (iii) PHR and HSR researchers, as well as through mining of HEI web pages. Survey findings are described in full in Volume 2, Chapters 2 and 3, and the survey instruments used to collect data are provided in Volume 2, Appendices 4.1 - 4.3.

3.2.1 Key findings - building and developing capacity

- The bulk of health-related research is conducted in higher education institutions (HEIs), teaching hospitals or in research centres affiliated with them, although a number of independent research organisations and statutory agencies are active in these research areas.
- A wide range of disciplines undertake some PHR and HSR and there is a strong interdisciplinary focus in academic units whose principle research activities are in PHR and HSR.
- An imbalance between experienced and inexperienced researchers was identified in all academic disciplines undertaking PHR and HSR. The lack of experienced academic staff impacts on post-graduate supervision and the provision of the taught elements of graduate programmes.
- It would appear that there is a 'branding' issue with HSR in particular, since many clinicians either have difficulty recognising or do not acknowledge that their research has PHR and/or HSR orientation or relevance, perhaps considering it of lesser quality than clinical research.
- Areas in which skills deficits were identified include health economics, biostatistics, epidemiology, qualitative skills, randomised control trials and intervention research⁶⁹, and health technology assessment.
- There are limited opportunities for early stage training in PHR and HSR at present, with the HRB being the primary funder of capacity building initiatives in this area. The proliferation of short-term contracts for research staff is also concern.
- A clear career structure and strategy for staff development is lacking in the higher education sector and in the HSE, worsened by the current capping of staff recruitment and promotion.

The mapping study carried out for this review demonstrated that there are clearly pockets of excellence in PHR and HSR in Ireland, a wide range of academic units undertake some PHR and HSR and there is a strong interdisciplinary focus in academic units that have made PHR and HSR their core academic focus (see Volume 2, Sections 2.4 and 2.5). However, in the health system as a whole PHR and HSR capacity remain low. Chesley *et al.* (2002)⁷⁰ has observed that in order to build the knowledge base that will allow healthcare decision makers to improve health care access, cost, and quality in a meaningful way, there needs to be a critical mass of individuals skilled in the methods of PHR and HSR working in both academia and the health services.

In the higher education sector, little consideration has been given to how to embed the concepts of PHR and HSR into the undergraduate curricula of relevant academic disciplines and to pump prime graduates for a career in either PHR or HSR. Furthermore, the lack of experienced academic staff working within PHR and HSR observed by the mapping study is an issue that hampers the provision of high quality research in these areas, but also impacts the ability of academic units to provide adequate post-graduate supervision and the taught elements of graduate programmes. Therefore, there is an urgent need for more mid-career and senior PHR and HSR researchers in academia and investment in research leaders in the health system.

The imbalance of non-tenured to tenured staff in higher education institutes (HEIs) may be exacerbated as research capacity in relevant disciplines is subject to shrinkage in the current

-

⁶⁹ **Intervention research** is an emerging field of research in the social sciences that integrates approaches to research which seek to yield results that can be put to practical use by practitioners, administrators and policy makers (see Rothman J and Thomas EJ (1994)). It focuses on the development of knowledge about interventions, the design and adaption of new and existing interventions and packaging and disseminating knowledge about innovative interventions.

The Chesley FD et al. (2000) Building a community of health services research and training. Health Services Research. 35:11-17.

economic climate. The proliferation of short-term contracts in these units is a worrying factor and lack of reasonable duration salary support for early career researchers will limit their ability to consolidate research skills and develop an academic career. The current legislative and economic climate and the employment control framework in the university sector may also have serious implications for maintaining current numbers in non-medical disciplines with relevant skill sets for PHR and HSR, in particular in the social sciences and humanities. It is unlikely that there will be an increase in tenured academic posts in these areas in the coming years to absorb existing non-tenured staff, and as a result the opportunities for PhD students to move into contract research posts could be diminished considerably.

3.2.1 Implications of findings for capacity building and development

Each of the topics introduced in this review will require building new theories, methods and tools. To do so will require the creation of a cadre of researchers of sufficient number, education, disciplinary mix and experience to move the fields of PHR and HSR forward (in both academic and health services settings). However, ensuring such a cohort of researchers presupposes the existence of educational and employment structures through which to pursue appropriate training and a relevant career path. The mapping study showed clearly that this is not, in general, the case, although there are notable exceptions such as the HRB PhD Scholars Programmes.

In its *Action Plan for Health Research*, the HRG sets out a prominent role for the HSE, as the national provider of public health and social services, in facilitating the workforce needs of PHR and HSR training into the future and in driving a number of key actions such as priority setting, research capacity building linked to health service needs and the development of research career frameworks in all health disciplines. The establishment of the interdisciplinary Medical Education and Training (MET) unit represents an important development for the HSE in this regard and has the potential to provide a focus for the agenda set by the HRG.

This ambitious agenda will require both young health care professionals whose training incorporates research skills, and investment in mid-career and senior level in researchers in professions and disciplines vital to PHR and HSR, in both the health services and the higher education sectors. Integrating research and clinical training, and encouraging the formation of multi-skilled teams of clinicians and academics to a common research purpose, would bring together academics with crosscutting skill-sets and clinicians with expertise in a particular disease area to deliver research solutions to health care problems and contribute to the development of health research as a core activity of the Irish health services. Supporting the hiring or training of a small number of multi-skilled individuals will also be vital to addressing this capacity deficit.

Any capacity building and development initiatives adopted will require careful demographic planning and analysis of PHR and HSR units and the disciplines that feed into them. Capacity building and development initiatives will also need to be coupled with a commitment by the HSE and the university medical and other cognate departments to ensure that mid- and senior-level researchers have the potential to enter a clear career path with an opportunity for tenure. There is, therefore, a need to consider the development of a career ladder in any manpower planning strategy that seeks to increase capacity in specific fields within PHR and HSR.

Capacity building initiatives also need to be supported by facilitative actions in the health services, such as the provision of protected time and the facilitation of locum arrangements, that will support health care professionals to continue their research in the areas of PHR and HSR, In the absence such

commitments to support these research leaders during and beyond the period of their initial research programme, investment in such schemes could be wasted. The HRB is currently developing a model for the sustainability of its Clinician Scientist Award, in which it is seeking a commitment over the longer term from both the HSE and the affiliated university to support the research programme of the clinician scientist, subject to satisfactory progress. This not only insures the sustainability of HRB investment, but also allows both the university and HSE to focus their workforce planning in areas of strategic importance to them. Such a model might serve as a template for other funding schemes.

Box 1: Some next steps for capacity building and development

Early stage training

- Taking an interdisciplinary approach to education in PHR and HSR will produce graduates with the ability to work across academia and health services settings and to provide cohesion between academic disciplines.
- In addition to health economics and epidemiology, other areas in which research capacity is
 particularly under-developed, and which will require investment in the future include
 biostatistics, qualitative research and intervention research.
- Provision of opportunities to build awareness of PHR and HSR methodology among trainee clinicians and other health care professionals through incorporation of relevant modules in their clinical training programmes. Developing these skills would enable them to work within multidisciplinary teams and would serve to increase their capacity to contribute to PHR and HSR research.
- Engagement by the HSE and the university sector at an early stage of the health professional career pathway would serve to add value to such training and enhance the skill sets of those individuals.

Capacity development

- Increased participation by disciplines not traditionally associated with PHR and HSR, for
 example business and economics, ITC, mathematics, and medicine would serve to attract
 'hidden capacity' into the national PHR and HSR arena and to integrate and enrich available
 capacity within the higher education sector.
- Innovative solutions to addressing the capacity gap at mid-career and senior level, in both the HSE and the university sector need to be considered.
- Encouraging those who already have health professional roles to work collaboratively with academic researchers would contribute to the development of health research as a core activity of health care professionals in the health services.
- Investment in skills development needs to be set in the context of career development and
 further opportunities to apply skills to practice. Research training initiatives need to be aligned
 with the needs and opportunities within the HSE and other health agencies.
- The HSE, as part of its changing R&D focus will need to giver consideration to enablers for its staff to apply research skills to practice.
- Collaboration between health care professionals and academic researchers in multi-disciplinary teams will have a vital role in helping to fill the capacity gaps in the HSE.

3.3 Funding of PHR and HSR in Ireland

In the absence of funding support only very limited PHR and HSR can take place. This review examined the current funding environment for PHR and HSR by mapping the organisations in Ireland that invest in health-related research and development, and looked at the level and type of support for PHR and HSR within the overall health research budget. The outcomes of the mapping study are described in full in Volume 2, Chapter 4. Research expenditure data was collected through a survey of research funding providers described in full in Volume 2, Appendix 4.1 and up-dated in 2009 and 2010 by email and phone.

3.3.1 Key findings - funding of PHR and HSR

- In line with most other countries, health research funding in Ireland exists within a multi-funder environment. Most funding agencies support some research activities within the broad areas of medical and health sciences, with the bulk of health-related research funding in 2008 and 2009 being in the medical biotechnology⁷¹ sub-field.
- Investment in PHR and HSR remains low, and accounted for 9.2 and 8.8 per cent of total health research investment in 2008 and 2009, respectively, including national surveys supported by the DoH.
- The HRB and DoH were the primary funders of PHR and HSR. Other agencies with roles in supporting these areas included the EPA, DAFF, HEA, HIQA, IRCHSS, philanthropy and the voluntary sector, in particular the MRCG, although the scope of their funding was limited by the statutory remit of the agency or charity.
- Within the HSE there is PHR and HSR activity, led mostly at local and project-specific or disease-specific level and often not peer-reviewed, but there is no way to quantify this expenditure in the absence of a specific research budget or research support structure.
- Much research that is funded by the enterprise agencies (El and the IDA) and described by them as 'health-related' would not fit within the WHO definition of health. However, there is significant scope for the industry sector to engage in PHR and HSR research through the development of ehealth, connected health and assistive living technologies initiatives such as TRIL, TILDA and the Ageing Network.
- Current funding models for PHR and HSR do not accommodate the multi-disciplinary nature of these areas in many cases and do not incentivise linkages between the research community, policy-makers and other potential users of research evidence.

The importance of PHR and HSR research as a driver for quality, efficacy and efficiency in health care delivery and improvement of the health of the population is not always understood at governmental level or by the public, as exemplified by the lack of strategic support for these areas of endeavour. This deficit can be partly traced to the historic lack of a research culture in the Irish health sector. This review found that, despite concerted government efforts over the past decade to develop overall research capacity in Ireland, there is still significant underinvestment in PHR and HSR. Ireland is unusual in that the HSE is funded directly by the Department of Finance and not by the DoH as would be the case in most other countries, adding another layer of complexity to its governance, the lines of accountability and legislative arrangements. The engagement of the Department of Finance is,

Medical biotechnology: Health-related biotechnology; Technologies involving the manipulation of cells, tissues, organs or the whole organism (assisted reproduction); Technologies involving identifying the functioning of DNA, proteins and enzymes and how they influence the onset of disease and maintenance of well-being (gene-based diagnostics and therapeutic interventions (pharmacogenomics, gene-based therapeutics); Biomaterials (as related to medical implants, devices, sensors); Medical biotechnology related ethics.

therefore, key to ensuring adequate funds to support research and policy implementation, but also in maintaining the commitment from other government departments to health research.

Prioritisation of PHR and HSR within the national health research budget will require a shift away from the current dominance of expenditure on biomedical research. At present much more is spent on understanding disease and developing treatments than on how these treatments are delivered and services effectively organised to maximise benefits for the populations' health. A better balance will help both the implementation of proven treatments and establishment of change in the health system. The HRG Action Plan for Health Research recognises that the flow of funding to health research needs to support the overall strategic direction of the health system and that the priorities identified will require both greater coordination in funding management between agencies and a potential rebalancing of funding flow so that investment is made along the full continuum of health research.

3.3.2 Funding support for PHR and HSR

The main funders of PHR and HSR in Ireland are the HRB and the DoH (longitudinal studies) with other agencies providing some funding in niche areas. With a commitment to refocus even more of its budget on PHR and HSR, the HRB will continue to dominate in these areas for some time to come. It was also clear from discussion with HSE personnel that there is significant PHR and HSR activity within the HSE at local level although the extent of this activity not possible to quantify. Volume 2, Chapter 4 provides a full description of the types of funding support provided by Irish funding agencies for PHR and HSR, with only a summary being provided here.

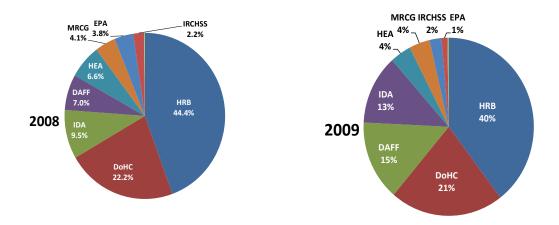


Figure 3.1 Contribution of major funding agencies to 2008 and 2009 expenditure on PHR/HSR research (€22.13M and €23.35M respectively)

The dominance of the HRB and the DoH as funders of PHR and HSR is illustrated by Figure 1.1, which shows the percentage share, by agency, of the total estimated expenditure on PHR and HSR in Ireland for 2008 of €22.1 million and for 2009 of €23.3 million.

In terms of research expenditure:

None of these agencies, with the exception of the HRB and the DoH, fund HSR.

- The HRB is the primary funder of research in PHR and HSR, through a range of fellowships, projects and programmes that represent approximately 24 per cent of its current funding commitments.
- In both 2008 and 2009 a strong focus of DoH funding was on child health, in particular the National Longitudinal Study of Children in Ireland (Growing Up in Ireland) and a number of projects around social care issues for children. In 2009, the DoH provided support for The Irish Longitudinal Study on Ageing (TILDA), based at TCD, which is a collaboration with an interdisciplinary panel of scientific researchers, with expertise in various fields of ageing from higher education institutes across Ireland, and with the ESRI.
- For DAFF, research in the area of PHR is focused primarily on dietary impacts on health, development of functional foods that improve health and food quality and safety research. DAFF co-funds a number of projects in this area with the HRB.
- The EPA share is primarily focused on environmental health impacts, for example pollutants, while HEA support is predominantly capital expenditure on the infrastructure underpinning PHR. As an example, the Environmental Change Institute at NUI Galway, established through PRTLI funding, supports projects in environmental and sociological health impacts.
- Funding in this area provided by medical charities through the MRCG is focused on the evaluation of health-promotion interventions.
- Some PHR and HSR also take place within the HSE. However, it is not currently possible to quantify the investments in these areas in the absence of any mechanisms within the HSE for capturing research expenditure or activity.

The HSE has an important role to play in supporting PHR and HSR, not only by facilitating research by its employees and supporting research collaborations between health practitioners and academics, as recommended in its 2009 Education, Training and Research Report⁷², but in focusing some of its considerable resources in these areas, as is being done in the UK through the National Institute for Health Research (NIHR) within the National Health Service (see Volume 2, Section 9.2.2 for a fuller description of the NIHR).

Finally, PHR and HSR researchers need to be cognisant of the opportunities provided by European research funding programmes such as the Public Health Programme and Framework 7 (FP7.) The HRB recognises the importance of these funding streams to Irish health research by hosting both the National Delegate and National Contact Point for the FP7 Health Theme; and the National Focal Point for the Public Health Programme. Beyond the issue of funding, these programmes underline the increasing internationalisation of PHR and HSR research and provide many opportunities for Irish PHR and HSR researchers to engage in European-level initiatives. Examples include the European Health Interview Survey⁷³ which will replace a number of existing funded surveys in Ireland including the SLÁN survey and the HBSC Survey. It will be conducted every 5 years for 15 years starting in 2012 and the microdata will be available to researchers and policymakers. Other European PHR and HSR initiatives, in which there is already Irish participation include;

in the PHR realm, the Strengthening Public Health in Europe (SPHERE) Project⁷⁴, which aims to describe public health research at European level, including support by national governments, and advise how it can be strengthened and most effectively integrated with European health policy

HSE (2009) Education, Training and Research: Principles and Recommendations. HSE Print & Design. http://www.hse.ie/eng/services/Publications/corporate/etr/education%20training%20research%20principles%20recommendati ons.html [Accessed 26/05/2011]

The seminary one of the seminary of the semina

⁷⁴ See http://www.ucl.ac.uk/public-health/sphere for more information [Accessed 26/05/2011]

• in the HSR realm, HSR-Europe⁷⁵ which aims to identify, evaluate and improve the contribution of HSR to the health policy process in Europe through linkage and exchange initiatives that bridge the 'knowledge' gap by strengthening the research-policy infrastructure Europe-wide

3.3.3 Funding models for PHR and HSR

Current funding models employed by Ireland's agencies to support research in the biological and social sciences may not be appropriate for PHR and HSR. Irish funding agencies have relied heavily on models developed for laboratory- and specialism-based biomedical and clinical research. For example, the model of support for PhD training has tended to focus on a single supervisor/mentor, a narrow range of specialisms and full-time participation. Likewise, much project and programme support is targeted at peer-reviewed outputs, to the exclusion of other methods of knowledge dissemination, The research findings of PHR and HSR need to be disseminated to members of a wide variety of professional and management groups and traditional models of dissemination do not incentivise knowledge transfer and exchange to this broader constituency.

It is imperative that the scope and breadth of current health-research funding, both recurrent and capital, is expanded to explicitly include interdisciplinary research and to facilitate appropriate models for PHR and HSR. In a situation of limited capacity and resources, there is a need to think innovatively about what models might be most appropriate to the needs of PHR and HSR. For example, taking a 'graduate school' approach to training, such as the *HRB PhD Scholars Programme*, acknowledges that the blend of research skills required for PHR and HSR is broad and that the emphasis needs to be on a flexible multi- and inter-disciplinary approach. In addition, establishment of 'shared' models for funding, whereby research providers and the users of research evidence both have a role to play in the development of research ideas would help to ensure the relevance and usefulness of research outcomes for policy and practice.

Other areas that will require continued support, not just at a project level but in terms of building research capacity to utilise emerging data, include funding of randomised control trials, cohort studies, longitudinal studies, interventional research, practice-based research, support of translation of results into policy, and partnership funding with relevant agencies and organisations for maximum impact. The current dearth of funding for these areas belies the fact that the methodologies required to conduct research in these fields is often more costly than appreciated e.g. population sampling, telephone interviewing, qualitative surveys, and so on. Where funding is provided, the scope of this funding is often limited by the remit of the funding provider.

Research funding and governmental agencies need to explore opportunities to support the creation of multi-disciplinary teams, networks and collaborations that can bring together an array of academic and clinical perspectives and skills, to help to address specific skills deficits, especially in areas such as economics, mathematics and statistics. Mining the hidden capacity of such non-traditional academic departments might help to overcome the challenges posed by overstretching of the small number of people with these skills who are currently engaged in PHR and HSR research. The HRB has recognised this deficit and is prepared to invest in initiatives that will develop and improve methodological skills among PHR and HSR researchers in Ireland. For example, the HRB has funded a pilot initiative, the Research Methodology Support Centre (CSTAR) to provide support for statistics and experimental design in health services, primary care and clinical research on a national basis, and will continue to explore appropriate models in this space. The recent establishment by the UK MRC of

 $^{^{75}}$ See http://www.healthservicesresearch.eu/ for more details. [Accessed 26/05/2011]

an All-Ireland Hub for Trials Methodology Research⁷⁶ also provides an opportunity for those interested in methodological work to network on an all-island basis and to access other MRC hubs across the UK.

Where strategically appropriate, a co-funding model presents the HRB with a means to leverage matching funding in areas of mutual benefit to its agenda and that of other agencies. Such an approach should be based on shared budgetary responsibility, to ensure a real commitment from all parties to support and facilitate high-quality research. The HRB already co-funds projects with SFI (Translational Research Award), DAFF (Health Research Centre for Diet and Health) and the MRCG. In terms of partnering with the HSE, the issue of immaturity in HSE research support structures and the difficulties posed by the lack of mechanisms in the HSE to manage and facilitate research present considerable challenges for the HRB and others. However, the success of the National SpR/SR Academic Fellowship Programme (NSAFP), which is run in partnership with the HSE, the Forum of Irish Postgraduate Medical Training Bodies and the university academic medical departments demonstrates that such co-funding can be productive for all parties. The success of this scheme is also due in large part to the engagement of the Education, Training and Research Unit of the HSE in facilitating recipients of awards in these schemes, and demonstrates the importance of having research champions within the HSE.

Other agencies that have potential as partners in collaborative PHR and HSR projects and programmes include the DoH (longitudinal studies), HIQA (HTAs), the Irish Research Council for Humanities and Social Sciences (for example, studies relevant to health demography and geography), the Environmental Protection Agency (environmental health), the HEA (targeted PRTLI funding of infrastructure to support PHR and HSR projects), philanthropy, medical insurance companies and the enterprise agencies (EI and the IDA.) However, in exploring such models of collaboration it will be vital that the HRB maintains its independent position as a funder of high-quality, peer-reviewed health research.

Box 2: Next steps for appropriate funding of PHR and HSR

- Innovative funding models need to be developed that accommodate the needs of PHR and HSR in terms of its multi- and inter-disciplinary inputs and non-traditional outputs.
- The scope and breadth of funding schemes needs to incentivise applicants to include more interdisciplinary research in PHR and HSR within their programmes.
- Mining the hidden capacity of non-traditional academic departments might help to overcome the challenges posed current skills deficits.
- Mutually beneficial models of partnering and 'co-funding' between agencies with an interest in PHR and/or HSR, and of 'shared funding' between policy stakeholders and research providers would help to enhance the value of HRB research investment.
- Areas that will require continued support include the funding of longitudinal studies, qualitative research, economic evaluations, programme evaluation, practice-based research, systematic reviews, randomised control trials and intervention research.
- Continued support and encouragement of Irish PHR and HSR researchers to participate in European initiatives and to seek European funding partnerships would improve their access to additional research funding but more importantly link them into the broader European PHR and HSR research agenda.

⁷⁶ See http://www.methodologyhubs.mrc.ac.uk/about_us/hubs/all-ireland_hub.aspx for more information on this initiative from the MRC.

3.4 Infrastructure supports for PHR and HSR

This review looked at the current infrastructure supports of particular relevance to PHR and HSR in Ireland, and examined the gaps in this area that are hampering research. The results of this mapping study are described in Volume 2, Chapter 5. Data for the study was collected in part through a survey of research funding providers, the survey instrument for which is provided in Volume 2, Appendix 4.1.

For the purpose of this review, infrastructure refers not only to capital buildings, specialist facilities and equipment but also to information systems, database access, libraries, specialist technical expertise and other resources that are required to facilitate and underpin PHR and HSR research.

3.4.1 Key findings - infrastructure supports for PHR and HSR

- Despite the large investments that have been made nationally in buildings and facilities with a
 health focus, little has been targeted towards the specific needs of PHR and HSR, and has been
 primarily confined to support that the HRB has been able to provide.
- There are many gaps in supporting infrastructures that will need to be addressed over the coming years. Specific weaknesses identified include quality, access to, linkage of, and permissible use of health information data; and a fragmented research ethics committees (RECs) structure in Ireland.
- Development of data repositories where researchers can both lodge and access datasets generated through many local, regional and national surveys has been slow.
- There is little support available for maintenance of established cohorts, for which bio-data, biospecimens and medical history have been collected, and which represent a valuable national asset.
- Outside the higher education sector, access to published literature and research material can be difficult, although there is increased awareness of the importance of facilitating open access to research material and published literature.

The environment in which PHR and HSR takes place and the ICT and health information systems and supports available to researchers will have a significant influence on the nature and quality of PHR and HSR that can be undertaken in Ireland into the future. This mapping study found that much of the 'soft' infrastructure that underpins PHR and HSR in Ireland is either underdeveloped or lacking, and is hampered by legislative weaknesses at present, especially for PHR and HSR being conducted in the HSE and other public sector organisations. In addition, in a small system like Ireland, it will not be possible to fund everything and Ireland needs to tap into resources already developed by our nearest neighbours in Northern Ireland and the UK. For example, there needs to be a robust system for testing and evaluating PHR and HSR interventions in the health services but Ireland currently has no supporting infrastructure for Randomised Control Trials (RCTs) or dedicated resources to fund and support research teams conducting RCTs. Developing linkages with UK partners, who have such structures in place might provide a cost-effective solution to this issue in the short-term⁷⁷.

The availability of quality data is a critical enabler of PHR and HSR. There are many sources from which to draw, including the national information infrastructure of health service datasets (mortality

.

A number of UK organisations provide support for, registration of, advice on and free publication of randomised control trials, for example Current Control Trials Ltd (http://www.controlled-trials.com/isrctn/introduction), Cancer Research UK (http://www.cancerhelp.org.uk/trials/types-of-trials/about-randomised-trials) and the NIHR Health Technology Assessment Programme (http://www.htta.ac.uk/about/index.shtml) [Accessed19/05/2011]

statistics, registry data, administrative databases and patient records) and other data sources (such as the Census and patient and population surveys). Volume 2, Chapter 5 identifies a number of issues in this area, including lack of UPIs, and core weaknesses in national health information systems, the lack of linkage and comparability of available datasets, limited or no Irish research data in many areas (cost databases, various patient registries etc.), a lack of access to information on private health care and difficulties in accessing existing data sets in the public system. Development of data repositories where researchers can both lodge and access datasets generated through many local, regional and national surveys has been very slow. ISSDA provides a repository for social sciences and social care data and the Institute of Public Health (IPH) Population Health Observatory includes a collection of health-related datasets, but for much health-related data, the options are very limited.

This review also identified a lack of capacity to conduct qualitative and quantitative analysis on existing datasets, Enhancement of this capacity could be achieved in a number of ways, for example through the development of/input into flexible modules in existing academic programmes and professional training programmes; initiatives to foster cooperation between social sciences and mathematical/statistics disciplines; and the provision of training through workshops, summer/winter schools on the use and analysis of key datasets. In addition, there is little support available for maintenance of established cohorts, for which bio-data, bio-specimens and medical history have been collected, and which represent a valuable national asset. There is also a lack of clarity regarding the secondary use of patient data in health research and the provisions of the Data Protection Acts 1998 and 2003 in this regard Although efforts are being made by the DoH, HIQA, the HSE, the HRB and others to address these issues it is likely that these deficits will continue to hamper PHR and HSR for a number of years to come.

The weak investment in infrastructure that is targeted towards the specific needs of PHR and HSR is not a situation unique to Ireland, and was a key observation of the Wellcome Trust assessment of public health sciences in the UK⁷⁸, where they highlighted "the extraordinary disparity between, on the one hand, the overriding importance of the public health sciences for public protection, service provision and health improvement and, on the other, the limited strategic interest that is taken in their infrastructure and conduct".

The life of Irish PHR and HSR practitioners is further complicated by the fragmentation of RECs. A pragmatic initiative by Molecular Medicine Ireland has been the development and promotion of a common research ethics application form. This is currently being piloted by three hospital ethics committees and the Irish Council for General Practice ethics committee, and should address delays in the approval of multi-centre studies. A further 25 ethics committees across the country will adopt this application form, once it is finalised. At a governmental level, HIQA has been tasked with addressing the fragmented nature of research ethics committees across the country. The 2011 appointment of a person with specific responsibility for implementing a national ethics committee structure is a very positive step in moving this issue forward.

3.4.2 Next steps - infrastructure supports for PHR and HSR

The keenly awaited publication of the Health Information Bill in 2011 should address some of the legislative issues identified by the mapping study. Access to health data, improving the Irish research ethics committee structure and provision of a legislative basis for the development of a UPI would all

Wellcome Trust (2004) Public health sciences: Challenges and opportunities. Report of the Public Health Sciences Working Group of the Wellcome Trust. http://www.wellcome.ac.uk/About-us/Publications/Reports/Biomedical-science/WTD003192.htm [Accessed19/05/2011]

have significant impacts on the number, linkage and quality of data sets available to PHR and HSR researchers. The on-going efforts of HIQA to ensure a coherent and consistent approach to the development of standards for all aspects of health and social care information, based on international best practice, will also assist in improving linkage of existing datasets, and development of new data sets.

Box 3: Next steps for enhancing the infrastructure for PHR and HSR

- Targeting of infrastructure investment towards the needs of PHR and HSR activities would greatly improve the capacity of researchers to conduct high-quality research. There is, however, work to be done in identifying the most pressing infrastructure needs of PHS and HSR, to ensure that infrastructure investment is targeted where it can have most impact.
- There is a need to streamline research governance and regulation regarding collection and use
 of data, including the possibility of linking datasets. Initiatives that facilitate data access, usage,
 linkage and quality need to be considered legislatively and by all agencies concerned and can
 be achieved only through collaboration across the system.
- There is a need to develop initiatives that increase the capacity to perform quantitative and qualitative research on existing datasets and to conduct research in the complex area of intervention research.

3.5 Outputs from current PHR and HSR

The outputs of PHR and HSR provide the evidence base on which improvements in the health of the population and health services management, organisation and provision can be advanced. This review looked at the outputs from academic units conducting research on PHR and HSR, in both the Republic of Ireland (RoI) and Northern Ireland (NI). Publication output, both peer reviewed and non-peer reviewed was the primary unit of measurement of research activity and the quality of peer reviewed output was measured by bibliometric analysis against a number of international comparator countries. This review also looked at the diverse body of PHR and HSR-relevant grey literature that is produced within, or for, the public sector⁷⁹. Data was collected through (i) a survey of heads of academic units, (ii) a bibliometric analysis of Irish PHR and HSR publications and (iii) PHR and HSR researchers, as well as through mining of higher education institution web pages. Survey findings are described in full in Volume 2, Chapter 6 and the survey instrument used to collect data on publications from academic units is provided in Appendix 4.2.

3.5.1 Key findings - outputs from PHR and HSR

 Research that focused on the determinants, risk factors and protective factors for health, health status and distribution of ill-health in the population accounted for almost half of all publications between 2003 and 2008 from Irish academic units whose core focus is PHR and/or HSR. This data could provide important evidence for the formulation and change of policy and practice although current weaknesses in the KTE system will hamper this.

⁷⁹ Grey Literature is the term used for documents and ephemeral material issued in limited amounts outside the formal channels of publication and distribution. Examples of Grey Literature include: scientific and technical reports, government documents, theses, patent documents etc.

- The level of publications in international peer-reviewed journals varies greatly between academic units. Units with a higher usage of Irish journals had close ties with primary care research. Units in which reports and other publications (letters, editorials, commentary, factsheets, rapid response articles, journal abstracts, fact sheets and guidelines) accounted for a significant proportion of overall publications also described themselves as having a policy-focused ethos.
- International comparison found that the Rol produced a relatively small output of peerreviewed publications compared to countries of a broadly similar population; however, this
 output has the third highest impact among the selected countries indicating that the quality of
 the research was high. The ratio of field output to citations for Rol compared to overall Rol
 scientific output to citations ranks second highest with Denmark, and the visibility of Rol
 among the most highly cited publications is relatively strong.
- Taken together, the findings paint a picture of Rol producing a steadily improving bibliometric
 output in PHR and HSR, with output rate in the latter field now approaching that of the top
 European countries. It should be born in mind however, that while peer-reviewed publications
 are important for the career advancement of academic researchers and the development of
 the two fields, their policy impacts are likely to be low.
- The amount of grey literature on PHR and HSR would suggest that there is considerable
 research activity taking place within departments or being commissioned in response to local
 or national strategic needs, that is not being channelled through peer reviewed publications.
 The quality of this output is, however, highly variable.

The mapping study conducted for this review (see Volume 2, Chapter 6) found that publications (both peer reviewed and non-peer reviewed) produced by Irish academic departments whose core focus is PHR and/or HSR were primarily in the areas of aetiology/incident (45 per cent), development and evaluation of interventions (26 per cent) and policy for health (20 per cent), with theory/methods accounting for the remaining 29 per cent. The types of publications and the dissemination methods chosen by individual academic units reflected both the pressure to publish in international peer-reviewed journals on the one hand, especially in the case of QUB and UU which are subject to the UK Research Assessment Exercise, but also a desire to engage with policy makers through the production of policy briefing papers, reports, systematic reviews and fact sheets. This analysis of the types of publications produced by Irish academic departments could not, however, give any indication of the quality of these publications or their international standing and a bibliometric analysis of PHR and HSR output was undertaken for this review, in order to explore this aspect.

Peer-reviewed publication outputs

In identifying appropriate comparator countries for Irish PHR and HSR output, the ideal metric would have been spend on PHR and HSR. However, since this metric was not available the metric chosen was country population size, for which there is reliable data, and countries with a broadly similar population size were used (Belgium, Denmark, Finland, New Zealand, Northern Ireland and Scotland). It is acknowledged that this metric is inadequate and has the potential to introduce bias into the findings. Nonetheless, it does provide some indications of relative activity and international standing of Irish PHR and HSR peer-reviewed publications. Analysis across the comparator countries showed that Republic of Ireland (RoI) peer reviewed publication output, while relatively small in relation to the comparator countries, had the third highest impact among the selected countries, outranked only by Belgium and Denmark, but with a higher impact than Finland, Scotland, New Zealand and Northern Ireland. In addition, the ratio of field output to citations for RoI ranked second highest with Denmark, behind Belgium. Furthermore, the visibility of RoI among the most highly cited publications is relatively strong, with only Denmark and Belgium having a higher share of the top 2 per cent. However, this is

tempered by Rol performing relatively poorly among the top 1 per cent most highly cited publications, ranking last among the selected countries, with a noticeably better performance of NI in this segment. A further analysis of the PHR/HSR sub-fields shows that Rol compares less favourably to the comparator countries for output and impact in the main sub-field of *Public, environmental and occupational health,* while the Rol impact in *Health care policy & services* is significantly lower than both the world field average and the comparator country average. For the sub-field of *General Medicine,* the top medical journals selected for this analysis (New England Journal of Medicine, British Medical Journal, Journal of the American Medical Association and The Lancet) is prominent, resulting in a very high impact score for this sub-field compared to the field-normalised impact level for each country. Notwithstanding this, when the actual impact for Rol was compared to the average impact of the journal set, Rol was the top ranking country.

The findings from this analysis can be broadly compared with those of a bibliometric analysis commissioned by the HRB in 2007, which examined the overall performance of Irish health-research output in the period 1999-2005⁸⁰. In that study, the field of *Health Sciences* included most of the subfields of PHR and HSR defined for this analysis, with the notable exception that the general medical journals were not included in the 2007 *Health Sciences* field. In line with the findings of this review, the 2007 analysis showed an increasing trend in output for Rol in health sciences, while the total output of Rol was significantly lower than comparator countries such as Finland, the US and the UK when the data was adjusted for population size. Furthermore, although the impact of Rol *Health Sciences* output was performing similarly to the EU-25 average, the impact was lower than both the world field average and the impact of comparator countries (including Finland, which Rol outperforms in the 2009 analysis). Therefore, while the selective inclusion of journals for the 2009 analysis demands caution when comparing to the 2007 analysis, a picture of improving output and impact of Irish PHR and HSR can be observed.

The findings are also comparable to two recent EU-wide bibliometric analyses - one analysis focusing on public health sciences undertaken as part of the collaborative EU-funded SPHERE study described in earlier chapters of this report⁸¹; the other analysis focusing on health services research undertaken as part of the ongoing 'Health Services Research in Europe' project, funded through FP7⁸². The SPHERE study analysed publications across all EU countries in the ten-year period 1995-2004. The methods used differed to our analysis in that a more elaborate publication search strategy or 'filter', based on a range of criteria, was employed to interrogate the Web of Science databases. In summary, the SPHERE analysis showed that Rol was a medium-low output producer in PHR, relative to population size, GDP and health burden (i.e. DALYS), although it had a higher than average relative output in PHR compared to biomedical research. These findings are broadly in line with the results of our analysis.

The HSR Europe bibliometric analysis examined publications in health services/systems research across all EU countries for the period 2004-2009. The findings were very positive for Rol as a producer of HSR - it ranked twelfth overall (out of 53 countries) in terms of absolute output of publications, outperforming comparators such as Belgium, Finland and Denmark. Moreover, this ranking rose to fifth and seventh when the output was adjusted for population size and GDP respectively. Of further interest was that the Rol output doubled between 2004 and 2008, which along with the Norwegian

-

⁸⁰ Health Research Board (2007) A Bibliometric Study of Irish Health Research in an International Context. http://www.hrb.ie/research-strategy-funding/publications/rsf-publication/publications//278/ [Accessed19/05/2011]

⁸¹ Strengthening Public Health Research in Europe (SPHERE). http://www.ucl.ac.uk/public-health/sphere/spherehome.htm [Accessed 19/05/2011]

⁸² Garrido MV and Busse R (2010) Health Systems Research in Europe. Draft assessment report prepared for the Working Conference 'Health Services Research in Europe' (The Hague, April 2010)

output represented the largest relative increase in HSR output across all 53 EU and associated countries included in the analysis. Taken together, the findings of the three bibliometric studies described in this section, including our own, paint a picture of Rol producing a steadily improving bibliometric output in PHR and HSR, with output rate in the latter field now approaching that of the top European countries.

Grey literature outputs

The amount of grey literature on PHR and HSR would suggest that there is considerable research (primarily secondary research) activity taking place across government, local authority and health sector departments and units to provide evidence for policy. This quality of this output is, however, highly variable and is not being channelled through peer reviewed publications. The overall picture for the generation of grey literature, funded in the main by government departments, NGOs, the HSE and advocacy organisations and medical charities, is one that is highly fragmented, comprising a mass of individual outputs commissioned in response to pressing local issues or the particular interests of units. With obvious exceptions, it appears, superficially at least, to lack any strategic, sustained thinking across a sector about issues which are relevant to a whole-of-government approach and to the impact of central policies on PHR or HSR. The current process of setting agendas and prioritising themes appears to be one that takes place at the level of individual departments/organisations. There is a need to ensure that this agenda is set within a wider integrated national strategic context and that the existing knowledge base is available to inform the development of future policy and research programmes.

3.6 Enhancing the use of PHR and HSR evidence

This review attempted to assess the extent of influence of Irish PHR and HSR on health policy and practice in Ireland and to identify dissemination strategies employed by researchers to mediate this influence. The results of the mapping study are described in full in Volume 2, Chapter 7. Data for this study was obtained through a survey of research performers, described in full in Volume 2, Appendix 4.3. On the basis of this survey, a follow-up of selected respondents was undertaken to gain further understanding of the barriers and facilitators to knowledge transfer and policy/practice impact. Volume 2, Chapter 7 also describes the outcome of a consultation with DoH personnel on their use of research evidence in policy formulation.

3.6.1 Key findings - use of PHR and HSR evidence

- Irish PHR and HSR researchers rate themselves as being quite active in engaging end-users
 of research and influencing national health policy and practice. Respondents reported a
 consistently high positive response in engaging key stakeholders and end-users of research,
 both informally and formally, throughout the research process.
- A significant minority of respondents reported an influence of their research on health policy, while over half of all respondents reported an influence of their research on clinical practice or health-service provision. The dissemination strategies used by researchers varied from the traditional academic outputs of peer-reviewed publications and scientific presentations to informal and formal linkages with stakeholders in the health policy and service provision sectors.
- In contrast to the above findings, consultation with the primary policy-maker (DoH) suggested that the linkages between academic research and policy remains poor, with few academics capable of packaging their research outcomes in a form amenable to policy makers.

- Factors considered important enablers of policy impact included timing of research, contextual
 relevance in addressing a key knowledge gap, development of on-going relationships with
 stakeholders, commitment of resources in dissemination processes and structures, and
 responsiveness of stakeholders to the research.
- Factors identified as barriers to effective knowledge transfer included a lack of organisational support for dissemination activities, lack of incentives for such activity, unwillingness or inability by researchers to invest time in wider dissemination activities and to present research in an appropriate format for decision-makers, and a lack of strategic leadership, time and resources in the policy and health service sectors to engage research providers.

Current Irish PHR and HSR research knowledge is under-utilised in policy development. This knowledge arises from 'traditional' scholarly and scientific research activity and through the commissioning activities of government departments, statutory agencies, and NGOs. Reasons for the lack of effective connection between the generation of high-quality research evidence and its use in policy formation and implementation in the health system are complex. Black (2001) points to issues such as the fact that policy-makers and researchers often inhabit very different worlds, with different sets of incentives, constraints and pressures that shape their work, and different contexts for knowledge production and use. Elliott and Popay (2000)⁸³ noted that researchers are often convinced that policymaking is a linear process which is driven by empirical evidence.

However, in reality, development or change in policy tends to be incremental and based on compromise between competing agendas (Harries *et al*, 1999)⁸⁴. In addition, from a political perspective, evidence is only one factor that shapes government decisions. Policy agendas are shaped in part by political commitments, party platforms, and the views of key political leaders. They are also influenced by external political pressures, changing circumstances, unexpected events and crises. Research impact is also affected by the degree of structure that already exists in a given area of policy or practice. Therefore, ensuring the relevance, applicability and eventual impact of PHR and HSR research will involve effecting changes in the way that both researchers and the end-users of that research approach the generation, dissemination and utilisation of, and place value on, high-quality evidence.

3.6.2 Dissemination of research evidence

Successful dissemination of research findings requires both an appreciation of the realities of decision and policy-making in the healthcare system and the skills to package and place evidence where it can be best used. Strengthening capacity in this area will require focused support from all stakeholders. Some countries have put specific mechanisms in place to promote dissemination of research to make it more accessible to managers and policy-makers. Examples include the NIHR-funded Centre for Reviews and Dissemination, the Health Services Clearinghouse in Germany and the Norwegian Knowledge Centre for Health Services.

There are a number of initiatives beyond traditional peer-reviewed journal publications that would facilitate effective dissemination of research evidence to key stakeholders, including commissioned reports, research reports, new datasets/databases, media engagement, informal relations with policy-

⁸⁴ Harries U et al. (1999) Evidence-based policy-making in the NHS: exploring the interface between research and the commissioning process. Journal of Public Health Medicine. 21(1): 29-36.

⁸³ Elliott H and Popay J (2000) *How are policy makers using evidence? Models of research utilisation and local NHS policy making.* Journal of Epidemiology and Community Health, 54:461-468.

makers, membership of policy advisory group, and presentations to policy-makers and interest groups. For academic researchers in particular, involvement in knowledge transfer and exchange work is not particularly attractive - it is slow, difficult to publish, and often does not conform to traditional metrics of success. The Canadian Institute for Work and Health⁸⁵ provides a number of examples of how to build 'protected environments' for KTE work, that include cross-disciplinary academics, post-graduate students and research user organisations, who part fund the initiative. In addition, supporting international KTE experts to spend time in Ireland mentoring/advising policy-makers/researchers wanting to move into this field would also present a cost-effective mechanism for increasing capacity in this area.

Researchers surveyed during this review identified a skills gap on their part in effectively packaging and placing their research with relevant end-users. Of concern also is the fact that traditional metrics for assessing the quality and impact of research do not incentivise the application of research or the translation of research. If academic units are to be encouraged to link their research to health system needs, then universities need to recognise guidelines, evidence summaries and policy briefings as valid output metrics and as an element of the pro bono activity of academics, which would count towards promotion. This issue warrants dialogue and a joined-up approach between the Department of Health (DoH), the Department of Education and Science (DES) and their respective agencies.

3.6.3 Use of research evidence by the health system

The considerable value of building capacity for PHR and HSR will be diminished if research outputs remain unused. However, regardless of how persuasive the research message might be, its targets are individuals and organisations with their own policy context, a context that has not historically been aware of or receptive to research evidence. Organisations are often not incentivised to incorporate research evidence as a routine part of day-to-day or even strategic decision-making. In addition, the average health system manager will not necessarily be well versed in where to find, access, and employ research evidence. Such skills need to be accepted as a core competency of a health services manager (indeed, of any professional public servant), alongside the traditionally accepted skills such as financial management, people management and project management.

In Ireland, the HRB couples provision of free national access to the Cochrane Library with half-day introductory training, two-day training on systematic reviews, workshops on protocol writing and metaanalysis, and train-the-trainer modules for health care professionals, decision-makers and educators wishing to understand and/or undertake systematic reviews. In addition to being the first country in the world to provide free national access to the Cochrane Library, the HRB along with its partner research funding agency in Northern Ireland, the HSC R&D Division, was also the first to offer a number of HRB Cochrane Fellowships annually, to build capacity in conducting systematic reviews in the health and social care field in Ireland. These fellowships pay for protected time for applicants of up to two days per week for two years to conduct a Cochrane systematic review in any topic of their choice. Developments and progress in this area might represent a potential model for further knowledgeappraisal initiatives. Internationally, the Canadian Health Services Research Foundation's (CHSRF) Executive Training for Research Application (EXTRA) programme might also provide a workable model for Ireland86.

 ⁸⁵ See http://www.iwh.on.ca/knowledge-transfer-exchange for more information [Accessed19/05/2011]
 86 See http://www.chsrf.ca/Programs/EXTRA.aspx for details of the Canadian Health Services Research Foundation (CHSRF) Executive Training for Research Application (EXTRA) programme. [Accessed19/05/2011]

The survey of policy impacts undertaken for this review, while limited in scope, did underline that closer collaboration between researchers and decision-makers and an improved understanding of each other's working contexts is needed to improve knowledge exchange and research utilisation in the Irish context. With some notable exceptions, for example in the field of illicit substance abuse research and policy, formal structures and systematic processes to link researchers and decision-makers are not established in Ireland. As such, Ireland can draw on the experiences of international agencies that have sought to facilitate such structures, as well as linkage strategies elucidated in the literature. For example, Hanney *et al.* (2003) have described a comprehensive set of effective linkage mechanisms to improve 'permeability at the interfaces' of researcher and policy-maker communities, with their distinct values, interests and time-frames⁸⁷. These include participation as members of government advisory groups and/or task forces and short-term placements of researchers within policy organisations.

The CHSRF in Canada, the SCPHRP in Scotland and the Sax Institute in Australia are organisations at the forefront in attempting to bridge the knowledge gap and foster knowledge transfer and exchange (KTE). The CHSRF and the SCPHRP run programmes that focus on the formal interaction, collaboration, and exchange of ideas and information between health researchers and health decision-makers so that they are able to better understand each other's goals and professional cultures, influence each other's work, forge new partnerships, thus promoting the use of research-based evidence in decision-making. The overall experience in Canada suggests that adopting a knowledge brokering approach improves the culture for evidence-informed decision-making and attracts the attention, resources, and engagement of these decision-makers to the research agenda⁸⁸. Other studies have shown that research funded under such a 'shared agenda' model is four times more likely than that funded by traditional means to be subject to active efforts at dissemination and implementation (as referenced in Lomas (2007).

Box 4: Next steps for enhancing the use of research evidence

- Initiatives are needed encourage closer collaboration between researchers and decision-makers and an improved understanding of each other's working contexts.
- Funding agencies can contribute to knowledge dissemination by asking researchers, as part of their deliverables, to provide lay summaries/implications for policy/practice.
- Identification and training of knowledge brokers could ensure that research evidence can be presented and placed in a policy context.
- Encouraging universities to consider non-traditional publications as an important part of a researcher's track-record and as an element of their pro bono academic activity, might incentivise researchers to disseminate their outputs in more user-friendly formats.
- Traditional bibliometric measures of research are biased against KTE-impactful PHR and HSR. A meaningful way of assessing the impact of PHR and HSR outputs could be the use of international expert panels to assess evidence and the use of health system decision-maker or policy maker testimonials of impact in a more holistic way.

⁸⁷ Hanney S et al. (2003) *The utilisation of health research in policy-making: concepts, examples and methods of assessment.*Health Res Policy and Syst 1:2 (1-28)

Health Res Policy and Syst, 1:2 (1-28).

88 Lomas J (2007) *The in-between world of knowledge brokering*. British Medical Journal, 334:129-132.

3.7 Linkage and exchange

The considerable value of building capacity for PHR and HSR will be diminished if research outputs remain unused. Networks are a vital mechanism in building capacity to use, exchange and translate research evidence into health and healthcare system improvement. Building networks, partnerships and collaborations is, therefore, integral to building and further developing capacity in PHR and HSR in Ireland and ensuring that the outputs can be translated into policy and practice. Volume 2, Chapter 8 describes the current PHR and HSR networks and collaborations that exist in Ireland, and also examines some international models that may have application here in the future.

3.7.1 Key findings - networks, partnerships and collaborations

- There are few Irish networks specific to PHR and HSR and there is a need to look at innovative approaches to drive and incentivise the use of research through instruments such as networks, collaborative fora and working groups, and the use of knowledge 'brokers' who understand the context of both the research producer and user.
- All-island partnerships with Northern Ireland could present Ireland with opportunities to learn from the more advanced UK health-research system.

Linkage between research producers and the end-users who can implement changes in policy and practice would facilitate the translation of health care needs to researchable questions. This in turn would increase the relevance, applicability and eventual impact of research, and would provide an evidence base on which to develop health care priorities. However, Ireland has not been strong in this area to date. We need to look at innovative approaches to drive and incentivise the use of research through instruments such as networks, collaborative fora and working groups. While no country has fully resolved the knowledge-transfer challenge, many have developed models from which Ireland could learn and on which it could build. Building partnerships and collaborations is integral to building and further developing capacity in PHR and HSR in Ireland and ensuring that the outputs can be translated into policy and practice.

One of the main challenges in health services research is to overcome the structural and professional boundaries restricting the opportunities for cooperation between researchers, clinicians, and practitioners in designing and conducting applied research. In our view, two steps are necessary to strengthen linkage and exchange between organizations and bodies interested in health services research. First, reconnecting the different scientific disciplines and researchers working in the field of health services research is essential. Second, it is necessary to bring both researchers and the users and funders of research together in order to ensure that the research agenda is pursuing the right questions and to foster the translation of the data generated into valuable information for practical decisions⁸⁹.

In her review of the international literature on mechanisms to promote research use in policy and practice Buckley⁹⁰ suggests that the fostering of networks and partnerships between organisations and research producers, and the establishment of intra- and inter-organisational forums would provide opportunities to identify policy relevant issues. It is the mechanism by which research skills and knowledge are exchanged, developed and enhanced and it is the only way to address complex health problems. While there are few networks relevant to PHR and HSR Ireland, the landscape is not

⁸⁹ See http://www.ncbi.nlm.nih.gov/pubmed/17175756 for more information. [Accessed19/05/2011]

⁹⁰ Buckley H (2009) Putting research evidence to work: key issues for research utilisation in Irish Children's Services. CAAB Research: Report No. 2. http://www.caab.ie/getdoc/59565377-3b78-435e-8204-92508019fb1b/PREW-Full-Report.aspx [Accessed19/05/2011]

completely blank and Volume 2, Annex 8 describes a number of these networks. Some international models that could be adapted to the Irish landscape are also identified.

3.7.2 Importance of PHR and HSR networks for Ireland

The benefits of networks and partnerships include increased efficiencies through sharing of resources and facilities information and knowledge exchange and innovation. This is particularly important for PHR and HSR, given the multiagency and interdisciplinary nature of these areas. There are a number of areas where networks and partnerships could facilitate PHR and HSR in Ireland. These include:

- Identification of priority themes for research
- Creation of evidence that requires multiagency working
- Facilitation of the design and execution of complex interventions that are delivered in complex environments
- Implementation of research findings into health services and practice and the implementation of population health interventions.

Recent national documents have highlighted the need for development of HSR in terms of information sharing, co-funding mechanisms, strategic partnerships and interdisciplinary working. The *HRB Strategic Business Plan 2010 - 2014* advocates for "the establishment of research clusters and/or networks to accelerate and scale up the delivery of high-quality outcomes in targeted population health research and health services research". The HRG Action Plan has identified the importance of establishing research networks between researchers, practitioners and policy makers in priority areas in the health services.

3.7.3 Next steps - Enhancing linkage and exchange

While specific networks in PHR and HSR may be lacking, a number of formal academic networks and alliances are already in place in Ireland (see Volume 2, Chapter 8) that could be built upon and developed further. We now need to look at innovative approaches to drive and incentivise the use of research through instruments such as networks, collaborative fora, communities of practice and working groups. Stronger links between research and policy are possible only if there is greater understanding of the realities of each context, the links that can exist between them and the opportunities for accessing and influencing existing policy-making structures. The use of knowledge 'brokers' who understand the context of both the research producer and user can also help to bridge this gap. Researchers, policy-makers and funders need to think strategically about where the chances are greatest to influence policy, and to focus on those areas where 'policy windows' open. While our experience is that no country has fully resolved the knowledge-transfer challenge, many have developed models from which Ireland could learn and on which it could build.

Box 6: Next steps in enhancing linkage and exchange

- It is important that Irish practitioners participate in, and learn from, more mature networks internationally, many of whom welcome Irish membership. For example, Ireland should capitalise on its closeness to the UK by developing networks on an all-island basis which would seek to transfer learning and best practice and jointly leverage the sharing of research capacity, infrastructure and funding from the wider UK systems.
- Resources invested in the development of Irish networks of practitioners and researchers, and in the development of 'communities of practice' will stimulate innovative thinking and practice.
- Seeking mechanisms to enhance linkage and exchange between researchers, services
 providers and policy makers will be key to be vital to capitalising on, and informing, current and
 future PHR and HSR investment in Ireland

3.8 Conclusions

Current health care practices are becoming increasingly unsustainable with Ireland's growing and ageing population, the rise in consumer expectations and the increase in the use of expensive technology and therapies in health care. A significant reconfiguration of services is needed, including a shift in care from acute hospitals to the community and primary care. The importance of health promotion interventions in preventing ill-health and promoting healthy lifestyle habits needs to be recognised more fully as a key component of the health research system. The past decade has seen very significant increases in public expenditure on health but with very little research and evidence particularly on effectiveness and evaluations of interventions. There is agreement and clarity over the major shortcomings in research funding, capacity, infrastructure, governance, support and use. There is also a consensus over the greater role for research in improving the health of the Irish population and the manner in which the Irish healthcare system functions, manifested in the widespread movement towards addressing these gaps.

While Ireland has many unique features and deficits that will necessitate a bespoke approach to PHR and HSR, it is not unique in grappling with the challenges of how best to build up a strong PHR and HSR system that is supported at a national strategic level and the outputs of which are used by policy makers, health services managers and health care professionals to inform, guide and improve their practice. Therefore, there is much that Ireland can learn from the experience of other countries that have successfully developed robust PHR and HSR systems.

Strengthening the current PHR and HSR landscape will require both innovative and flexible thinking, and working within a crowded system that is adjusting to severe economic constraints by becoming increasingly risk adverse. While the obstacles to success are formidable, there are many possible mechanisms for effecting change. The existence of the HRG and a working *Action Plan for Health Research*, the on-going reconfiguration of the health services and higher education sectors, the government's 'Smart Economy' strategy, and the planned reform of national scientific research funding, all represent opportunities to raise the profile of PHR and HSR by highlighting the critical role that research-informed health policy and practice can play in modern Ireland.

Progression in PHR and HSR will depend on a strong ethos of partnership involving many services, disciplines, organisations and individuals. It is imperative that action is not left to the major public

sector players but that the research agendas and outputs of other smaller and often very effective public agencies, private sector, and voluntary and community sector groups are synergised. Linkages and collaboration should cover the distance between the designers of policy and those tasked with delivering it on the ground, and filtrate across boundaries within and between government departments. Linkages and collaboration should also be nurtured across jurisdictional borders so that we can learn from and work in unison with our neighbours.

In the words of Henry Ford:

'Coming together is a beginning, keeping together is progress, working together is success'

References

Advisory Council for Science, Technology and Innovation (2006) *Towards Better Health. Achieving a Step Change in Health Research in Ireland.*

http://www.sciencecouncil.ie/publication/ascSearch.jsp?ft=/publications/2006/title,3254,en.php

Bergan T (2001) *Antibiotic usage in Nordic countries*. International Journal of antimicrobial Agents. 18(3):279-282.

Black N (2001) Evidence based policy: proceed with care. British Medical Journal, 232: 275-9.

Brick A, Nolan A, O'Reilly J and Smith S (2010) Resource Allocation, Financing and Sustainability in Health: Evidence for the Expert Group on Resource Allocation and Financing in the Health Sector. Economic and Social Research Institute, 596p.

http://www.dohc.ie/publications/resource_allocation_financing_health_sector.html

Buckley H (2009) *Putting research evidence to work: key issues for research utilisation in Irish Children's Services.* CAAB Research: Report No. 2. http://www.caab.ie/getdoc/59565377-3b78-435e-8204-92508019fb1b/PREW-Full-Report.aspx

Chief Medical Officer (2001) *Better health for everyone; a population health approach for Ireland.* Annual Report. http://www.DoHC.ie/publications/cmo_2001.html

Chesley FD, Rudinski KA, Eisenberg JM (2000) *Building a community of health services research and training.* Health Services Research. 35:11-17.

CHPI (2004) Improving the Health of Canadians. Canadian Population Health Initiative, Ottawa;

CSO (2006) Principal Demographic Results.

http://www.cso.ie/census/documents/Amended%20Final%20Principal%20Demographic%20Results% 202006.pdf

CSO (2008) Population and labour force projections, 2011-2041.

http://www.cso.ie/releasespublications/po_lab_project.htm

Dash P, Gowman N, Traynor M (2003) *Increasing impact of health services research*. British Medical Journal, 327:1339-41.

Department of Enterprise, Trade and Employment (2006) *Strategy for Science, Technology and Innovation 2006-2013*. http://www.entemp.ie/science/technology/sciencestrategy.htm

Department of Health (1995) *A health promotion strategy: making the healthier choice the easier choice.* Stationary Office, Dublin. http://www.lenus.ie/hse/handle/10147/46380 [Accessed 14/12/2010].

Department of Health and Children (2000) *National Health Promotion Strategy 2000-2005*. Government Publications. Dublin.

http://www.DoHC.ie/publications/national health promotion strategy.html

Department of Health and Children (2001a) *Making Knowledge Work for Health: A strategy for health research*. Government Publications. Dublin.

http://www.DoHC.ie/publications/making knowledge work for health.html

Department of Health and Children (2001b) *Quality and Fairness: A health system for you.*Government Publications. Dublin. http://www.DoHC.ie/publications/pdf/strategy.pdf?direct=1

Department of Health and Children (2008) *Statement of Strategy 2008-2010*. Government Publications. Dublin. http://www.DoHC.ie/publications/pdf/en_strategy08.pdf?direct=1

Department of the Taoiseach (2008) *Building Irelands Smart Economy: a framework for sustainable economic renewal.* Government Publications. Dublin.

Dixon J and Alakeson V (2010) Reforming health care: why we need to learn from international experience. Nuffield Trust. http://www.nuffieldtrust.org.uk/publications/detail.aspx?id=145&prID=735

Elliott H and Popay J (2000) How are policy makers using evidence? Models of research utilisation and local NHS policy making. Journal of Epidemiology and Community Health, 54:461-468.

Farrell C, McAvoy H and Wilde J (2008) *Tackling health inequalities. An All-Ireland approach to social determinants*. Institute of Public Health in Ireland.

http://www.iph.ie/publications/tacklinghealthinequalitiesanallirelandapproachtosocialdeterminants

Forfás/HEA Mapping Study (2010) Profile of public research activity and research and development activity in Ireland and the linkages between the public research base and the enterprise sector. In preparation.

Garrido MV and Busse R (2010) *Health Systems Research in Europe*. Draft assessment report prepared for the Working Conference 'Health Services Research in Europe' (The Hague, April 2010).

Gibson JL, Martin DK and Singer PA (2005) Evidence, economics and ethics: Resource allocation in health service organizations. Healthcare Quarterly, 8(2):50-59.

Gissler M and Haukka J (2004) *Finnish health and social welfare registers in epidemiological research.* Norsk Epidemiologi. 14(1):113-120.

Hakama M (1985) Effect of population screening for carcinoma of the uterine cervix in Finland. Maturitas, 7(1):3-10.

Hanney S, Gonzalez-Block M, Buxton M and Kogan M (2003) *The utilisation of health research in policy-making: concepts, examples and methods of assessment.* Health Research Policy and Systems, 1(2): 1-28.

Harries U, Elliot H and Higgins A (1999) *Evidence-based policy-making in the NHS: exploring the interface between research and the commissioning process.* Journal of Public Health Medicine. 21(1): 29-36.

Health Behaviours in School-Aged Children. http://www.nuigalway.ie/hbsc/publications_reports.html

Health Economics Research Group, Office of Health Economics and RAND Europe (2008). *Medical Research: What's it worth? Estimating the economic benefits from medical research in the UK.*London: UK Evaluation Forum. http://www.wellcome.ac.uk/About-us/Publications/Reports/Biomedical-science/WTX052113.htm

Health Research Board (2007) A Bibliometric Study of Irish Health Research in an International Context. http://www.hrb.ie/research-strategy-funding/publications/rsf-publication/publications//278/

Health Research Board (2009) *Strategic Business Plan 2010-2014; the future of Irish health research.* Dublin. http://www.hrb.ie/publications/hrb-publication/publications/hrb-publicatio

Health Research Group (2009) *Action Plan for Health Research 2009-2013*. Government Publications, Dublin. http://www.DoHC.ie/publications/pdf/action_plan_health_research.pdf?direct=1

Health Services Executive (2006) *Transformation Programme 2007-2010*. http://www.hse.ie/eng/services/Publications/corporate/transformation.pdf

Health Services Executive (2009) *Activity in Acute Public Hospitals in Ireland, 2007.* Health Research and Information Division Annual Report.

http://www.esri.ie/health_information/latest_hipe_nprs_reports/2007/

Health Services Executive (2008) *The Health Service Executive Population Health Strategy*. http://www.hse.ie/eng/staff/FactFile/Health-Status Reports/Population Health/Population Health Strategy/

Health Service Executive (2009) *Health Status of the Population of Ireland 2008 in Republic of Ireland.* http://www.hse.ie/eng/services/Publications/HealthProtection/Public Health /Health Status of the P opulation of Ireland 2008.html

Health Service Executive (2009) Education, Training and Research: Principles and Recommendations. Dec 2009, HSE Print and Design.

http://www.hse.ie/eng/services/Publications/corporate/etr/education%20training%20research%20princ iples%20recommendations.html

Health Services Research Europe (2011) *Health services research: Helping tackle Europe's healthcare challenges.* http://www.healthservicesresearch.eu/

HSE Corporate Plan 2005-2008.

http://www.hse.ie/eng/services/publications/corporate/hse_corporate_plan_2005-2008.html

HSE Corporate Plan 2008-2011.

http://www.hse.ie/eng/services/Publications/corporate/HSE Corporate Plan 2008-2011.html

Layte R, Barry M, Bennett K, Brick A, Morgenroth E, Normand C, O'Reilly J, Thomas S, Tilson L, Wiley M and Wren M-A (2009) *Projecting the impact of demographic change on the demand for and delivery of health care in Ireland*. ESRI. http://www.esri.ie/UserFiles/publications/20091023164031/RS013.pdf

Lomas J (2003) *Health Services Research: More lessons from Kaiser Permanente and Veterans' Affairs health care system.* British Medical Journal. 327:1301-2.

Lomas J (2007) The in-between world of knowledge brokering. British Medical Journal, 334:129-132.

Mathers CD, Murray CJL, Ezzati M, Gakidou E, Salomon JA and Stein C (2003) *Population health metrics: crucial inputs to the development of evidence for health policy.* Population Health Metrics, 1: 6

Montorzi G, de Haan S and Ijsselmuiden C (2010) *Priority setting for health research: A management process for countries*. Council on Health Research Development (COHRED): http://www.cohred.ch/prioritysetting

Morgan K, McGee H, Watson D, Perry I, Barry M, Shelley E, Harrington J, Lolcho M, Layte R, Tully N, van Lente E, Ward M, Lutomski J, Controy R and Brugha R (2008) *SLÁN 2007: Survey of Lifestyle, Attitudes and Nutrition in Ireland.* Main report. Department of Health & Children, Dublin.

OECD Health Spending and the Economic Crisis. See www.oecd.org/health

OECD (2008) *Public Management Reviews Ireland - Towards an Integrated Public Service*. http://www.oecd.org/document/31/0,3343,en 2649 33735 40529119 1 1 1 1,00.html

Oxley H (2009) Policies for healthy ageing: an overview. OECD Health Working Papers No. 42

Report of the Commission on Patient Safety and Quality Assurance (2008) *Building a culture of Patient Safety. Department of Health and Children*, Dublin.

http://www.dohc.ie/publications/building_culture_patient_safety.html

Report of the Expert Group on Resource Allocation and Financing in the Health Sector (2010). Chaired by Prof Frances Ruane and published by Department of Health and Children, Dublin. http://www.dohc.ie/publications/resource_allocation_financing_health_sector.html

Rothman J and Thomas EJ (eds) (1994) Intervention Research: Design and Development for Human Services. Haworth Press, 469p.

SLÁN (2006) Survey of lifestyles, attitude and nutrition. http://www.slan06.ie/

Smith S (2009) *The Irish 'health basket': a basket case?*. European Journal of Health Economics. DOI 10.1007/s10198-009-0171-4.

Strengthening Public Health Research in Europe (SPHERE) http://www.ucl.ac.uk/public-health/sphere/spherehome.htm

Thaul S. Lohr KN and Tranquada RE (eds) (1994) *Health Services Research: Opportunities for an expanding field of enquiry - An interim statement.* Committee on Health Services Research: Training and Workforce Issues. National Academy Press.

http://www.nap.edu/openbook.php?record_id=9242&page=R1

UK Clinical Research Collaboration (2006) *UK health research analysis*. London: UK Clinical Research Collaboration.

Vuorenkoski L (2008) *Finland: Health System Review.* Health Systems in Transition, Vol 10, No. 4. http://www.euro.who.int/en/home/projects/observatory/publications/health-system-profiles-hits/full-list-of-hits/finland-hit-2008

Wellcome Trust (2004) *Public health sciences: Challenges and opportunities.* Report of the Public Health Sciences Working Group of the Wellcome Trust. http://www.wellcome.ac.uk/About-us/Publications/Reports/Biomedical-science/WTD003192.htm

World Health Organization (2006) *Gaining Health - The European Strategy for the Prevention and Control of Noncommunicable Diseases.* www.euro.who.int

Abbreviations and Acronyms

ACSTI Advisory Council for Science, Technology and Innovation

BMJ British Medical Journal

CIHR Canadian Institutes of Health Research

CRF Clinical Research Facility

CWTS Centre for Science and Technology Studies, Leiden
DAFF Department of Agriculture, Food and Fisheries

DALY Disability Adjusted Life Years

DCU Dublin City University

DES Department of Education and Science

DEJI Department of Enterprise, Jobs and Innovation

DoHC Department of Health and Children

DoH Department of Health
EC European Commission
El Enterprise Ireland
EU European Union

EPA Environmental Protection Agency
ESRI Economic and Social Research Institute
ETR Education, Training and Research

FÁS Foras Áiseanna Saothair (Training and Employment Authority)

FP7 7th Framework Programme of EU

FTE Full Time Equivalent

HBSC Health Behaviours in School-aged Children

HDA Health Development Authority UK

HEA Higher Education Authority
HE(I) Higher Education (Institution)
HIPE Hospital Enquiry System

HIQA Health Information and Quality Authority

HRB Health Research Board
HRG Health Research Group
HSE Health Services Executive
HSR Health Services Research

ICRIN Irish Clinical Research Infrastructure Network

ICSTI Irish Council for Science, Technology and Innovation

IDA Industrial Development Authority

INIsPHO Ireland and Northern Ireland Population Health Observatory

IPH Institute of Public Health in Ireland

IRCSET Irish Research Council for Science, Engineering and Technology IRCHSS Irish Research Council for Humanities and Social Sciences

IUA Irish Universities Association

JAMA Journal of the American Medical Society

MET Medical Education and Training
MRCG Medical Research Charities Group
NCRI National Cancer Registry of Ireland

NDP National Development Plan
NEJM New England Journal of Medicine
NGO Non-Governmental Organisation

NHMRC National Health and Medical Research Council (Australia)

NHS National Health Services (UK)

NI Northern Ireland

NIH National Institutes for Health

NIHR National Institute for Health Research (UK)
NPIRS National Psychiatric Inpatient Reporting System

NUI Galway National University of Ireland Galway NUI Maynooth National University of Ireland Maynooth

OECD Organisation for Economic Cooperation and Development

OMC Office of the Minister for Children

OSCHR Office for the Strategic Coordination of Health Research

PHIS Public Health Information System

PHL/SNOMED Public Health Language/ Systematised Nomenclature of Medicine Clinical Terms

PHR Population Health Research
PPS Personal Public Service Number

PRTLI Programme for Research in Third Level Institutions

QUB Queens University Belfast

RCSI Royal College of Surgeons in Ireland

ROI Republic of Ireland

RCT Randomised Control Trial
SFI Science Foundation Ireland

SLÁN Survey of Lifestyle, Attitudes and Nutrition

SPHERE Strengthening Public Health Research in Europe
SSTI Strategy for Science, Technology and Innovation
SWOT Strengths, Weaknesses, Opportunities and Threats

TCD Trinity College Dublin
UCC University College Cork
UCD University College Dublin
UL University of Limerick
UPI Unique Personal Identifier

UU University of Ulster

WHO World Health Organisation