RESEARCH FOR HEALTH & WELLBEING 2007-2012

Supporting research Developing understanding Improving health and wellbeing Making a difference





### making a difference

Enormous advances in health & social care have been made in the last few decades and these are continuing at an accelerating rate.

They have brought great benefits to health and social wellbeing. Despite this there has been no reduction in the demands on the HPSS and the cost of healthcare is steadily increasing. New treatments and systems of care are needed for many conditions, but these can be expensive, and powerful drugs may have harmful as well as beneficial effects. We need to know much more about how best to use new and expensive treatments, and how to obtain the best value, in terms of health and social outcomes, from our investment. Thus the need for research in both health and social care is as great as ever.

The Research & Development Office for the HPSS launched its first Strategy in 1999. This new HPSS R&D Strategy builds on the success of *Research for Health & Wellbeing* and sets the scene for HPSS research & development for the next five years. We can look forward to the Department, through the R&D Office, supporting high quality research in health and social care in the HPSS in collaboration with our partners in the Universities, the health research charities and industry. A major feature is the development of strong collaborative links with researchers and research funding bodies in the rest of the United Kingdom, the Republic of Ireland and the United States. Research & development is an international activity and these collaborations bring new opportunities for Northern Ireland's researchers to participate at the highest level.

The need for research and development in health and social care has never been greater. I believe that the Strategy will allow the HPSS and Northern Ireland to take full part in the exciting opportunities in health and social care research in the coming decades and to be sought after as a place to undertake leading edge research. This is an ambitious strategy which can only be implemented by strong commitment from both funders and researchers, and by working closely with our partners.



Paur Goza

**Paul Goggins, MP** Minister for Health, Social Services and Public Safety oreword

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### knowledge & innovation



Clinical research aims to help improve health & wellbeing by increasing our understanding of the diagnosis, treatment, and prevention of disease. If we are to improve health and social care we need more knowledge and more innovation in the application of that knowledge.

As well as the direct benefits of providing new treatments or interventions and helping drive up the quality of care provision, research can also help motivate our staff to bring about service improvements, and encourage the recruitment and retention of high quality staff.

As one of the largest employers in Northern Ireland, the Health & Personal Social Services (HPSS) needs highly qualified employees with specialist skills, who are motivated to remain at the leading edge of their professions. They operate some of the most technically advanced equipment, for example radiology, laboratories, operating theatres and information technology. They work at the interface of science, technology and the human condition and have a keen interest in the application of new discoveries that may benefit patients and clients. Research helps involve HPSS professionals in national and international professional and scientific networks keeping them abreast of the new knowledge that underpins best practice.

The Research & Development Office for the HPSS (R&D Office) was established in 1998 to support the broad spectrum of HPSS R&D through direct research funding and through less direct mechanisms. We need to balance longer term investment in infrastructure against the more responsive direct support for research grants. We need to focus our support for high quality research in areas of strength, but flexibility should also be built in to allow us to support new investigators or emerging health priorities. We are only one of many funders and much of the funding provided by the R&D Office should be seen as pump priming, helping Northern Ireland researchers to become competitive in applying for funds from other sources such as the Research Councils, research charities, industry and the European Union (EU). The R&D Office must also focus on its specific remit to support research that directly addresses the needs of the HPSS with emphasis on applied and translational research rather than the basic underpinning research that is supported by the Research Councils, the research charities and the EU. Basic research without clinical application will not be supported by the R&D Office; neither will research involving experimentation on animals.

To keep pace with advances in technology and other new developments in health and social care, the new HPSS R&D strategy needs to be flexible and adaptable. This new strategy is therefore necessarily high level and builds on the previous *Research* 

for Health and Wellbeing. It continues to take forward the strategic initiatives that have been introduced in the last seven years, providing continuity and building on our achievements. This new strategy focuses on five strategic priorities against which the R&D Office and HPSS will deliver. We will build infrastructure, build research capacity, build our research portfolio, translate research findings into practice through innovation and build patient and public involvement in HPSS R&D. The HPSS R&D infrastructure will include a new clinical research network helping to secure Northern Ireland's position within the emerging UK Clinical Research Network.

The culture of innovation that is required to exploit and apply new ideas and new knowledge emerging from HPSS R&D must extend to potential commercial exploitation. The R&D Office will work both locally and nationally to ensure industrial partnerships provide opportunities for HPSS R&D to benefit the Northern Ireland economy.

By the end of the five year period of the strategy, Northern Ireland should have a well developed network for clinical research supporting clinical trials in all sectors including primary, community and social care. Associated support structures will be in place, along with a well-trained HPSS research workforce, excellent local, national and international collaborations, enhanced external research income and a pipeline of products for commercial exploitation. This will allow the HPSS and Northern Ireland to take their full part in the exciting opportunities in health and social care research in the coming decades, and to be sought after as a place to undertake excellent research. This is an ambitious strategy, which can only be implemented by strong commitment from both funders and researchers, in partnership with other key stakeholders, and by seeking patient and public involvement at each stage of research.



**Professor Robert Stout** Director of Research & Development for the Northern Ireland Health & Personal Social Services.

ntroduction



### partnerships

The R&D Office will continue to work closely with its partner organisations including: All Ireland Institute of Public Health • Atlantic Philanthropies • Biobusiness Northern Ireland • Cancer Research UK • Department of Enterprise, Trade & Investment • Economic & Social Research Council • Health Research Board (Dublin) • Health & Social Services Authority • Health & Social Services Trusts • Invest Northern Ireland • Medical Research Council • National Cancer Institute (USA) • Northern Ireland Practice & Education Council for Nursing & Midwifery • National Institutes for Health (USA) • Northern Ireland • Queen's & Research Agency • Office for Research Ethics Committees Northern Ireland • Queen's University Belfast • Royal College of Nursing • UK Departments of Health • UK Clinical Research Collaboration • UK Cochrane Collaboration • University of Ulster • Wellcome Trust • Wolfson Trust

# HPSS R&D needs effective partnership

Health & social care research is becoming more dependent on local, national and international collaborations, which provide access to a wider pool of skills, facilities and resources.

HPSS R&D will increasingly work in this wider context, requiring partnerships that bridge: organisational boundaries within the HPSS; sectoral boundaries within Northern Ireland; and geographical boundaries within and without the island of Ireland. The R&D Office will continue to forge strategic links with key organisations like the Health Research Board (HRB) in Dublin. We will help HPSS R&D exploit these partnership opportunities and facilitate alliances and collaborative arrangements - allowing access to new funding opportunities and helping HPSS R&D develop in an all-Ireland, UK and international context.

The context of HPSS R&D will also be characterised by constant change. The UK Clinical Research Collaboration (UKCRC)<sup>1</sup> is and will continue to be one of the most significant drivers of change. Industry involvement is a key aspect of the UKCRC giving patients and researchers early access to new therapies and technologies. The R&D Office and HPSS R&D are fully engaged with all aspects of the UKCRC and its ambitious forward agenda to make the UK the best place in the world for health research and innovation. In the local context the establishment of a Northern Ireland Clinical Research Network (NICRN) will be a significant challenge for health & social care

research and help link HPSS R&D to the wider context of the new UK Clinical Research Networks. The NICRN will extend the opportunity for involvement in high quality clinical research throughout Northern Ireland.

This new HPSS R&D Strategy will therefore span a period of significant change driven by:

- political developments within Northern Ireland
- organisational reform across the HPSS leading to profound changes in the way health & social care is delivered
- professional initiatives such as Modernising Medical Careers and Modernising Nursing Careers
- national developments such as the implementation of the Cooksey Review and the establishment of the Office for the Scientific Co-ordination of Health Research, impacting on the management and organisation of UK health research
- international developments including new EU directives

Within Northern Ireland the current Review of Public Administration creates various degrees of uncertainty about the local context for HPSS R&D but it also presents potentially important opportunities for improving how we support and manage research. The HPSS R&D Strategy must be capable of adapting to this context of constant change if we are to gain full advantage of new opportunities and new possibilities.

context

<sup>1</sup> Information on the UKCRC can be found at www.ukcrc.org

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HPSS R&D should be an integral part of health & social care providing new ways to identify, prevent and treat disease and new ways to promote health & wellbeing.

#### strategic plan 2007-2012

# improving health & wellbeing through high quality HPSS R&D

Over the next five years the R&D Office will encourage, support and invest in high quality R&D with the aim of developing Northern Ireland as a national and international centre for research & development in health & social care.

#### Our five strategic priorities are:

- developing an enabling infrastructure to support HPSS R&D
- building research capacity for HPSS R&D
- funding HPSS R&D
- supporting innovation as a means of transferring HPSS R&D findings into practice
- ensuring patient and public involvement in HPSS R&D

We are committed to ensuring HPSS R&D meets the needs of the HPSS and helps build the evidence base that informs decisions about both existing and new health & social care interventions and services. HPSS research will help: patients and the public understand health issues and make informed decisions about health behaviour and health & social services; front-line health & social care professionals make informed decisions about the clinical effectiveness of care interventions; and policy makers draw on an evidence base that supports policy development.

The original HPSS R&D Strategy was built around nine strands of interlinked activity implemented through a variety of schemes and initiatives. Although these strands of activity will continue they will adapt to support the delivery of our five strategic priorities.

Education & Training			
Career Development			
Recognised Research Groups		Pa	
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Special Iniatives			
Support for UK Schemes			

A cross-cutting activity - **Strategic Links** - emerged after the publication of the 1999 Strategy as an important enabling activity that generated national & international collaboration and alliances which support all our other strands. This will continue and is joined by a new cross-cutting activity -**Patient and Public Involvement (PPI)** which will become a feature of most aspects of HPSS R&D.

purpose

Existing HPSS Infrastructure includes: • All Ireland Co-operative Oncology Research Group • Clinical RAMAN Microscopy Centre • Clinical Research Support Centre • Northern Ireland Cancer Clinical Trials Unit • Northern Ireland Longitudinal Study • Nucleic Acid Extraction Centre • Research Governance Framework for Health & Social Care

# developing an enabling infrastructure

The R&D Office has an important role in building an infrastructure that can support, enable and facilitate HPSS R&D.

That infrastructure ranges from datasets like the Northern Ireland Longitudinal Study (NILS) which links demographic and health & social care information, to the Clinical Research Support Centre (CRSC) providing advice, training, consultancy and a range of services that include data management, research monitoring and intellectual property management. It also includes the policy infrastructure that governs the conduct of HPSS R&D and protects the rights and safety of all those involved in research.

When investing in infrastructure we look to partner organisations for assistance and to maximise the return on our investment. Recent successes of our partnership investments include the new Clinical Research Facility, which will facilitate the testing of novel hypotheses, treatments and products in small scale investigator initiated clinical trials, and the Centre for Ageing Research & Development in Ireland. The balance between infrastructure and direct research support is likely to change and if the NICRN realises its full potential that balance will shift towards infrastructure. This shift of emphasis will come with the expectation of more external funding and an increase in the overall level of HPSS R&D activity.

#### Approach

To improve the HPSS R&D infrastructure we will:

- develop research governance in a way that: facilitates R&D integration with patient care; removes unnecessary barriers to research in the HPSS; helps service users participate in and benefit from HPSS R&D; and protects the rights and safety of all those involved in HPSS R&D
- develop the NICRN concept to provide managed research networks enhancing the capacity of the HPSS R&D community to engage with the larger UK research networks and with researchers in the Republic of Ireland. The NICRN will also generate high quality local clinical research and support population sciences, translational research, experimental medicine, clinical trials and health & social care services research
- work with the new Health & Social Services (HSS) Trusts to put in place research offices that can promote and support high quality research
- review our current research support centres, research units and other infrastructure elements to ensure they meet the needs of HPSS R&D
- support new initiatives which enhance the research infrastructure, provide new opportunities for HPSS researchers, and help attract research funds into Northern Ireland



## infrastructure

#### Deliverables

#### Over the next five years we will:

- provide a comprehensive set of research governance policies and procedures for adoption by individual HSS bodies
- develop unified, co-ordinated and streamlined research governance systems in the areas of regulation, approvals, management and reporting that minimise bureaucracy and maximise effectiveness
- establish research offices in each of the five new HSS Trusts that can deliver an effective and consistent research approvals function, proper research management and high quality research support
- establish a vibrant inclusive NICRN that becomes a cornerstone of HPSS R&D infrastructure:
  - improving patient care
  - decreasing research start-up times
  - improving research quality
  - increasing research participation
  - strengthening collaboration with industry
- work with our partner organisations to establish a fully operational Clinical Research Facility based in the new Phase 2b of the Royal Victoria Hospital redevelopment
- work towards a functional NILS dataset to help inform the development of public health policy
- establish in partnership with HRB, GeneLibrary Ireland holding 10,000 anonymised DNA and blood samples together with lifestyle, environment and medical information

delivery





# building research capacity

The HPSS needs a research literate workforce that can provide the best health and social care informed by a growing evidence base.

We also need a core of active skilled researchers contributing to the evidence base and pursuing research and development that is directly relevant to the HPSS. In Northern Ireland we have consistently spent more of our HPSS R&D budget on capacity building than other regions of the UK. This investment in our future researchers will continue.

#### Approach

To build research capacity we will:

- maintain a comprehensive set of schemes to develop health and social care research capacity, covering the range from those starting research to advanced training (including participation in UK Schemes)
- engage with the current initiatives to modernise academic research careers amongst the HPSS professions, and identify opportunities to develop new schemes to support them
- consider how trained researchers in career HPSS posts can be provided with the opportunity to continue in active research, to help ensure the ongoing availability of sufficient, highly skilled research professionals

- continue to provide specific support to those HPSS professions which have traditionally had a low R&D base, including Allied Health Professionals, Nursing, Pharmacy and Social Care
- encourage collaborations between health and social care professions taking advantage of the unique contribution of each, and creating multidisciplinary research teams led by researchers from all health and social care professional backgrounds.



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Deliverables

#### Over the next five years we will:

- work with the HPSS and both universities to develop clearly defined, flexible and accepted career pathways for the emerging concept of clinical academic researchers facilitating the combination of research and clinical practice
- work innovatively to address particular issues such as continuity by developing new schemes to provide post-doctoral research opportunities for HPSS researchers
- regularly review our portfolio of research capacity development support to ensure our schemes are focused most appropriately to meet the needs of the HPSS

delivery





The R&D Office will fund a wide range of health & social care research in all disciplines and all sectors and welcomes qualitative as well as quantitative research paradigms. However funded research must be directly relevant to the HPSS and basic underpinning research in the biomedical, behavioural and social sciences will not be supported unless there is a clear translational path relevant to the needs of the HPSS. Experiments on animals will not be supported although it is recognised that some work involving animals may be an inherent requirement for some clinical research eg raising antibodies for diagnostic or treatment purposes.

#### Approach

To support a vibrant, cohesive and relevant portfolio of HPSS R&D we will:

- continue to support the Recognised Research Groups (RRGs) for at least a further five year period, re-investing funds in new projects to complement the ongoing programmes and focusing on areas of research strength and relevance to HPSS needs
- carry out further review of the RRGs to ensure the ongoing relevance of the research and the appropriate investment of funds
- encourage researchers, teams or entire RRGs to apply for funding from Research Councils and major charities

- seek advice from the Department of Health, Social Services and Public Safety (DHSSPS) and HPSS to identify areas for commissioning research to support policy and service developments
- identify emerging areas of clinical and social need outside the RRGs and commissioned programmes and devise suitable mechanisms to support research in these areas

#### Deliverables

Over the next five years we will:

- continue to issue calls for research proposals through the vehicle of the RRGs, timed to coincide with the availability of funds, and with consideration of issues such as the continuity of existing research teams
- schedule and organise a further review of the RRGs
- support researchers in their pursuit of funding from external sources
- commission a series of research programmes, in line with policy and service developments, in priority areas of health and social care

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# supporting innovation

HPSS employees and the wider HPSS R&D community produce highly innovative research.

The outcomes of this research must be disseminated and exploited to help ensure that the potential benefits to patients/clients are realised. Such technology transfer may happen directly through changes in practice within health & social care or may require investment from the private sector to develop new products that can be subsequently purchased by the HPSS.

#### Approach

To promote and capitalise on innovation we will:

- continue to disseminate relevant information through promotional material, website and distribution lists
- provide ongoing support for relevant conferences and workshops to facilitate networking and dissemination of research outputs

- contribute to the generation of evidence-based systematic reviews through our partnership with HRB (Dublin) in the UK Cochrane Collaboration
- support researchers in their efforts to transfer their research findings into practice
- ensure increased awareness of the importance and benefits of innovation amongst the research community
- support the identification, assessment and management of intellectual property, with the aim of generating improved technologies and treatments for service users



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delivery

### innovation

#### Deliverables

Over the next five years we will:

- identify research funding opportunities, courses and events of particular relevance to the HPSS research community
- schedule a biennial R&D Office conference starting in 2007, and a programme of other relevant events
- promote the uptake of Cochrane courses and fellowships to help increase the contribution of our researchers to evidence-based systematic reviews
- explore, along with other funders, participation and investment in initiatives such as knowledge brokering that help translate research findings into practice
- develop our partnerships with development agencies and industry to help transfer research outputs to practice and to promote economic growth in the region
- support the ongoing development of HPSS Innovations, to raise awareness, provide incentives for innovative researchers, and to pursue the potential of intellectual property assets to generate revenue streams that will ultimately benefit service users in the HPSS and beyond



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# ensuring patient and public involvement

It is important that research participants or their representatives should be involved, wherever possible, in the design, conduct, analysis and reporting of research.

Such involvement should increase and positively influence public awareness around health & social care research, and enhance its overall quality and relevance, which will ultimately lead to better treatment and care for service users.

#### Approach

To increase PPI we will:

- further promote public awareness of health and social care research and increase the level of PPI in HPSS R&D
- promote awareness amongst the clinical research community of the benefits of PPI, and encourage researchers to liaise with users, carers and advocacy groups at the earliest possible stage in the planning and development of their research projects
- participate in developing a strategy and systems for PPI that help:
  - identify research that is important and relevant
  - researchers ask the right questions in the right way
  - researchers design research studies
  - interpret research results
  - promote good research
- facilitate access to patient and public input for those undertaking research in health and social care

#### Deliverables

Over the next five years we will:

- organise and participate in education and training workshops to raise awareness of the mutual benefits of patient and public involvement in clinical research
- seek further representation of service users and carers at committee and forum meetings
- increase contact with local and national consumer advocacy groups
- participate in UKCRC-led PPI activities, attend working group meetings, distribute information resources and encourage local consumer representation on research panels



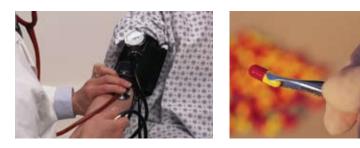
The most challenging aspect is recognising the incremental nature of the research process and the time lags between discovery and application.

### monitoring our performance

If we are to maximise the benefits of investing in HPSS R&D it is important to be able to evaluate the outcomes of our strategy and our research.

The R&D Office is therefore committed to monitoring performance against this five-year strategy.

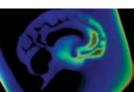
The impact of research can be evaluated in different ways with performance judged against improvements in health & wellbeing at an individual or population level, and improvements in service delivery and policy development. Performance can also be measured by using assessments of academic output or health economics concepts. However, developing appropriate metrics and performance indicators for health & social care research outcomes is difficult and remains a challenge for funding organisations.



The most challenging aspect is recognising the incremental nature of the research process and the time lags between discovery and application. Over the next five years the R&D Office will work with other funders of health & social care research to develop an improved system of metrics and performance indicators that will provide robust monitoring mechanisms.



performance





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Standardising the classification of research activity is an important prerequisite for monitoring and performance measurement. In 2006 the UKCRC developed a bespoke two dimensional analytical framework – the Health Research Classification System (HRCS) enabling research to be classified according to the type of research activity taking place (Research Activity Codes) and according to the area of health or disease under investigation (Health Categories). The R&D Office in common with other UKCRC partner organisations is adopting the HRCS as its main classification system encompassing both past and future research portfolios. The adoption of this single classification system will enable comparisons to be made within and between different research portfolios and to monitor trends over time.

#### Exemplars of HPSS R&D successes

A commissioned study which described and compared coronary event case fatality and out of hospital coronary care in two defined populations, has enabled the Northern Board and the Causeway Trust to focus on effective processes of care and on timeliness of delivery. This work was highly commended in the International Journal of Epidemiology. Research using the Single Photon Emission Computed Tomography (SPECT) brain imaging system, funded under the Neurosciences Recognised Research Group, has resulted in the establishment of a brain SPECT service at Belfast City Hospital, which is used for diagnosis of dementia.



- Research in the Child Health & Welfare RRG has developed a simple non-invasive test for meningococcal meningitis, and an Infectious Diseases RRG project has led to the introduction of real-time Polymerase Chain Reaction (PCR) assays for microbial detection into clinical practice. These rapid diagnostics will improve the response times that are critical to delivering the appropriate treatments to patients affected by life threatening infections.
- Patents have already been granted in the area of cardiac defibrillation and body surface mapping technology from research that was funded by the R&D Office leading to the subsequent commercialisation of this technology by a number of both local/regional and international companies.
- The Institute for Child Care Research examined the cost to children and to Social Services of using the courts to resolve disputes between Social Services and families. The findings highlighted the hidden costs of providing social services, and have major implications for social work practice in Northern Ireland. Consideration is currently being given to how courts can operate more efficiently and how procedures might be improved to ensure that social workers of all grades spend less time on care order work and more in providing for the children and young people in their care.

- Researchers funded by the R&D Office have won Proof of Concept Funding from Invest Northern Ireland to develop novel, highly sensitive predictors for cardiovascular disease. This will exploit the ability to use ultrasound technology as a non-invasive, sensitive, reproducible measure of the microcirculation of the eye.
- A Fellowship project undertook extensive investigations to show that measuring exhaled nitric oxide (ENO) in breath can indicate allergic airways inflammation in childhood asthma. Manufacturers have since developed a small hand held device for measuring ENO which can be used in General Practice. Measuring airway inflammation routinely at asthma clinics improves diagnosis and treatment.
- Research in the Neuroscience RRG is analysing the Northern Ireland Retinitis Pigmentosa (RP) population, and is pioneering the use of microarray genetic screening technology in the field of Ophthalmology. This research has the potential to form the basis of a commercial screening programme for this genetic cause of blindness. The research has already identified the causative mutation in several families with RP and these patients benefit from a firm diagnosis and an improved prognosis.



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**erformance** 

# HPSS R&D fund

The work of the R&D Office and the research it supports is funded by the HPSS R&D Fund. This Fund is allocated annually by the DHSSPS with no provision for carry forward. In 2005-06 the HPSS R&D Fund totalled £12 million. An analysis of the spend in 2005-06 across the nine strands of R&D activity is presented in Figure 1.

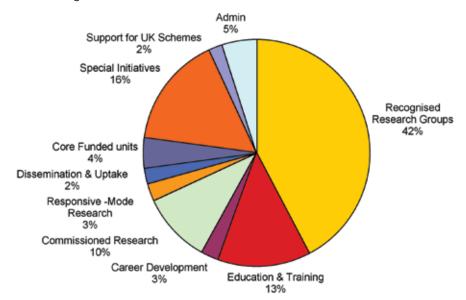
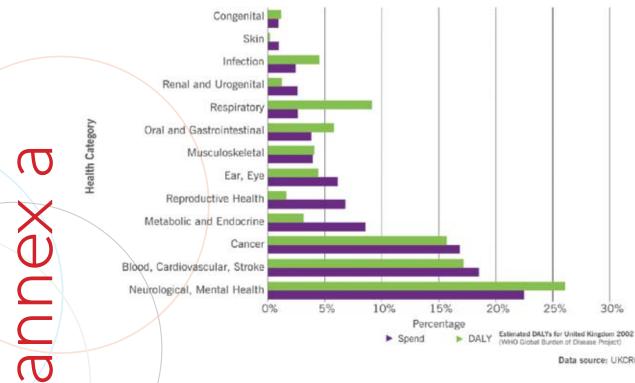


Figure 2 presents the HPSS R&D Fund spend analysed by HRCS Health Categories compared to a measure of UK Disability Adjusted Life Years (DALY) rates.



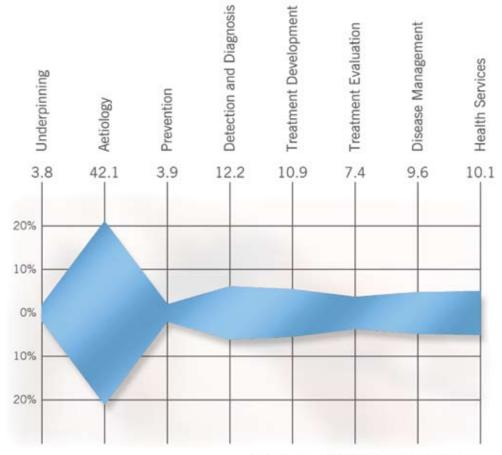


Figure 3 presents the HPSS R&D Fund spend analysed by HRCS Research Activity.

Data source: UKCRC Health Research Analysis

Figure 3 shows a significant concentration on Aetiology, a low level of spend on underpinning and prevention research and a uniform spread across the other research activities. This pattern is different from the other UK Health Departments which spend much less on Aetiology and much more on Treatment Evaluation and Health Services research. The research activity profiles for the Research Councils and research charities demonstrates that the majority of their research spend is directed to underpinning research and aetiology. The R&D Office will continue to retain its particular emphasis on clinical research. 23

# glossary

CRSC	Clinical Research Support Centre
DALY	Disability Adjusted Life Years
DHSSPS	Department of Health, Social Services and Public Safety
EU	European Union
HPSS	Health & Personal Social Services
HRB	Health Research Board
HRCS	Health Research Classification System
HSS	Health and Social Services
NICRN	Northern Ireland Clinical Research Network
NILS	Northern Ireland Longitudinal Study
PCR	Polymerase Chain Reaction
PPI	Patient and Public Involvement
R&D Office	The Research & Development Office
	for the Health & Personal Social Services
RRGs	Recognised Research Groups
SPECT	Single Photon Emission Computed Tomography
UKCRC	United Kingdom Clinical Research Collaboration

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glossary



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