

DHSSPS

**Evaluation of the Impact of HSC R&D Funding in Northern
Ireland, Including Benchmarking with other Countries**

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1 EXECUTIVE SUMMARY

RSM McClure Watters were appointed by the Department of Health, Social Services and Public Safety (DHSSPS) to undertake an evaluation of the impact of HSC Research and Development (R&D) funding in Northern Ireland. In the following section we have summarised the methods used to undertake this evaluation and the key findings.

1.1.1 Terms of Reference

The overall aim of the project is to: “evaluate the impact of Health and Social Care (HSC) Research and Development (R&D) funding in Northern Ireland, focusing on three well established areas of research: 1) Cancer; 2) Diabetes; 3) Mental Health, and to benchmark the findings against comparable work in other countries”.

Specifically the terms of reference were to:

- Provide evidence for the development of the next strategy for HSC R&D in Northern Ireland: 2013 – 2018;
- Provide evidence for the development of Policy regarding HSC R&D in Northern Ireland; and
- Provide evidence for the development of Bids to increase the funding allocated to HSC R&D in line with the rest of the UK.

1.1.2 Methodology

The model used for this assignment was based on the Payback Framework. This is a tool designed to measure the impact of health R&D funding and has been used extensively in a number of projects. These include ‘Medical Research: What’s it worth? Estimating the economic benefits of medical research in the UK’¹; ‘Making an Impact: The Economic and Social Benefits of HRB-Funded Research’²; ‘Assessing the impact of England’s National Health Service R&D Health Technology Assessment program using the “payback” approach’³; and ‘Institutional strategies for capturing socio-economic impact of academic research’⁴. The following diagram provides an overview of the Payback Framework’s logic model.

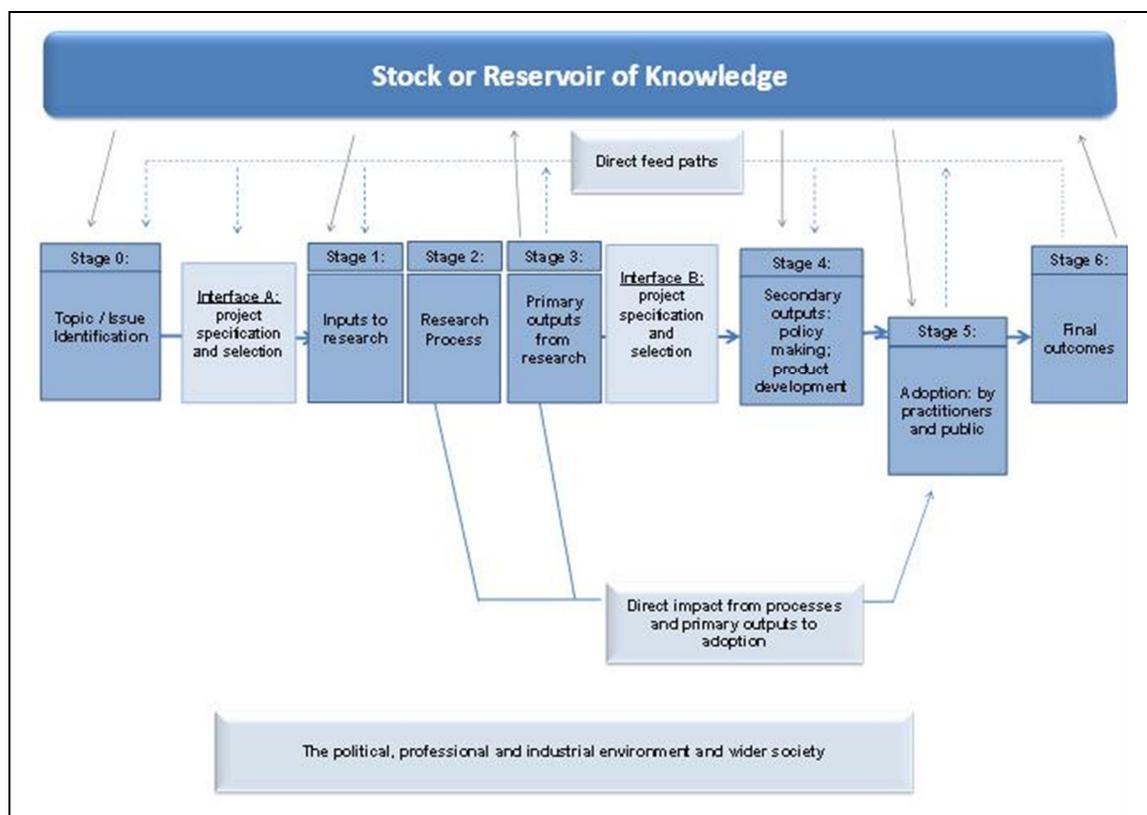
¹ Medical Research: What’s it worth? Estimating the economic benefits from medical research in the UK, *Health Economics Research Group, Office of Health Economics, RAND Europe*, London: UK Evaluation Forum; (2008).

² Making an Impact: The Economic and Social Benefits of HRB –Funded Research, *Health Research Board*, (May 2008).

³ Assessing the impact of England’s National Health Service R&D Health Technology Assessment program using the “payback” approach, *International Journal of Technology Assessment in Health Care*, 25:1-5 (2009).

⁴ Institutional strategies for capturing socio-economic impact of academic research, *Journal of Higher Education Policy and Management*, 32: 5, 499— 510, (2010).

Figure 1:1: Logic Model of the Payback Framework



Source: Hanney S, et al. (2004) Proposed methods for reviewing the outcomes of research: the impact of funding by the UK's 'Arthritis Research Campaign'. *Health Research Policy and Systems*, 2:4

The methodology for the assignment had seven distinct stages, as summarised below:

- **Stage 1:** Project Inception: The project commenced with a Project Inception Meeting with the Project Board Group. The main purpose of this meeting was to discuss our approach, establish overall project priorities, agree exact deliverables and confirm the requirements in relation to project monitoring and reporting.
- **Stage 2:** Desk Based Review: This stage involved the analysis of data relating to HSC R&D funded research (1998 – 2011), a review of the strategic context in which the research was undertaken, a review of the current literature relating to the study and a review of the macro level statistics/health indicators associated with the 3 areas of research.
- **Stage 3:** Consultations: This stage involved a suite of consultations with a key range of stakeholders who had a detailed understanding of:
 - the health sector R&D in Northern Ireland;
 - the three areas of research (Cancer, Diabetes and Mental Health);
 - Public Health; and
 - leverage from all sources.

A range of techniques was used at this stage of the assignment including one-to-one interviews and on-line surveys.

- **Stage 4:** Survey of funded researchers: Using the information provided to us by HSC R&D Division, Public Health Agency (HSC R&D), an email was sent to all principal investigators who

had received funding (1998-2011) and who were still working in Northern Ireland. The survey was informed by the Buxton and Hanney Payback Framework⁵, which provided categories of impacts and an assessment of the degree of impact attributable to specific research.

- **Stage 5:** Case Studies: A total of three case studies were developed. Each case study contained information on the origins of the research and the primary outputs such as publications. They also explored the contribution to research training and career development, and the translation of the research findings into product development, policy and practice.
- **Stage 6:** Benchmarking: Three countries were chosen to benchmark against; England, Sweden and Canada. The benchmarking analysis included a high level review of the level and range of government funding provided to Health Care R&D in each country and a desk based review of any evaluations of this funding.
- **Stage 7:** Data Analysis and Reporting: Data from the literature review, the survey and the case studies were categorised into type of benefit/impact using the Payback Framework. This analysis describes the level and range of funding to the three subject areas from 1998-2011, quantifies the level of corresponding consequential funding attached from outside sources and quantifies and describes the employment and support created. It also describes the extent to which research capabilities have been enhanced and describes the improved evidence basis on which to make health policies.

1.1.3 Background and Strategic Context

It is important to consider the policy context in which health and social care research is taking place and the various factors that can impact upon the importance that is placed upon the sector. Over the years there has been a number of key policy and strategy documents that have impacted upon the delivery of health and social care research in the UK, these include:

- Culyer Review (1994⁶);
- Cooksey Review (HMT, 2006);
- A Shared Vision for UK Health Research (Office for Strategic Coordination of Health Research (OSCHR), March 2010); and
- Investing in UK Health and Life Sciences⁷ (Business Innovation and Skills, December 2011).

The HSC R&D strategy for Northern Ireland, Research for Health and Wellbeing 2007-2012, consists of five strategic priorities:

- Develop an infrastructure to support R&D;
- Build research capacity;
- Build research portfolio;
- Translate research findings into practice through innovation; and

⁵ Buxton M, Hanney S, How can payback from health services research be assessed? *Journal of Health Services Research and Policy*, 1(1), (1996), pp35-43.

⁶ Culyer, A J *Supporting Research and Development in the National Health Service: A Report to the Minister for Health by a Research and Development Task Force Chaired by Professor Anthony Culyer*, (1994) London, HMSO.

⁷ Investing in UK Health and Life Sciences, *Department for Business, Innovation and Skills*, (December 2011).

- Build patient and public involvement in R&D.

R&D plays a central role in the planning and delivery of health and social care service, and as such, there are a wide range of policy and strategic documents that are relevant to this assignment. In the following paragraphs we have summarised some of the key, relevant strategies to provide an overview of the broader policy environment in which HSC R&D has operated over the review period. In Northern Ireland these include:

- The Programme for Government (2008 – 2011) sets out the priorities and budgets for the Executive, whilst the PfG (2008 – 2011) did not specifically refer to HSC R&D, there are seven targets relating to Cancer, Diabetes and Mental Health, which could be considered as an indication of the importance of addressing these health and wellbeing concerns in the Northern Ireland population.
- The Programme for Government (PfG) 2011-2015 was published on 12th March 2012 and specifically sets targets for cancer, diabetes and mental health.
- The Service Framework for Cancer Prevention, Treatment and Care outlines the standards which patients, clients, carers and their wider families can expect. It sets standards in relation to the prevention, diagnosis, treatment, care, rehabilitation and palliative care of individuals and communities at a greater risk of developing cancer. The Service Delivery Framework encompasses a wide range of standards which aim to improve the prevention, diagnosis, treatment and care for individuals. Research is a key part of their development and directly links the trajectory of focused research and patient care.
- The Service Framework for Cardiovascular Health and Well-being outlines the standards that patients, clients, carers and their wider families can expect. It sets standards in relation to the prevention, diagnosis, treatment, care, rehabilitation and palliative care of individuals and communities who currently have a greater risk of developing cardiovascular disease, including diabetes. As such, the Service Delivery Framework for Cardiovascular Health and Well-being utilises substantial research to justify each of its overarching standards.
- The Service Framework for Mental Health and Well-being outlines the standards that patients, clients, carers and their wider families can expect. It sets standards in relation to the prevention, assessment, diagnosis, treatment, care, rehabilitation and palliative care of individuals and communities who currently have or are at a greater risk of developing mental illness. As a result of extensive research the Service Delivery Framework for Mental Health and Well-being represents a comprehensive, accurate record of issues facing the mental health sector and as a result of this knowledge can propose realistic and effective standards for the future.

1.1.4 Statistical indicators of Health and well-being in Northern Ireland

High-level population statistics relating to the three research interest areas demonstrate the on-going need for further work in these areas. The importance of research relating to Cancer prevention, treatment and care is clearly evident. A review of the high levels of statistics has shown that the rate of diagnosis of many cancers has increased but that the survival rates have also improved. Clinical trials and other clinical research studies such as those that have led to changes in clinical care and improvements in surgery techniques have been integral to the latter being achieved.

There is also evidence to support the need for enhanced research in the field of diabetes. It is widely recognised that obesity continues to be a common problem in modern society and considering the relationship between being overweight and the increased risk of developing type 2 diabetes, the need

for further research into prevention and treatment will only increase as obesity levels escalate. Moreover, it will play an important part if the aim set out in the Obesity Prevention Framework (2011 – 2021) of reducing the level of obesity in Northern Ireland to 2005/06 levels by 2021, is to be achieved and maintained.

Mental illness continues to be an issue in Northern Ireland, over the last five years, the total number of admissions to hospital under the mental health programme of care increased by 2.4%. The NI suicide rate also increased from 10.4 (deaths per 100,000) in 2000/02 to 15.9 (deaths per 100,000) in 2008/10. Furthermore, projections relating to dementia suggest a 41% increase in the number of diagnoses by 2021.

1.1.5 HSC Funding

Between 1998 and 2011, a total of £40,700,749 HSC R&D funding was issued to undertake research in the fields of cancer, diabetes and mental health.

HSC R&D has supported 184 cancer, diabetes or mental health research projects since 1998 at an average of £221,199 per project.

The total amount of funding available through the single regional HSC R&D Fund reached its peak of £13.5 million in 2008 and declined subsequently. Currently the level of research spend per capita is less than 50% of that in England (£6.57 compared to £15.12) and 53% of the funding per capita in Scotland.

1.1.6 Survey Findings

Given the relatively long period of time which this evaluation covers (14 years), it is not realistic to expect a 100% response rate, as researchers have retired, moved on, died or, were otherwise non-contactable. Surveys were returned for 50% of projects which were deliverable, representing 52% of the total amount of funding issued to the three research areas.

Overall the results relating to the economic impact of the funded research were very positive in that 110 jobs were supported and an additional £53 million was leveraged. The amount of leverage generated by the projects equates to around £4.14 per £1 invested. 60% of respondents noted that the HSC R&D support had a considerable influence of the acquisition of further funding.

The funding helped to support 57 post graduate qualifications (32 of which were PhDs) and 81 individuals to progress further in their careers. This is important as it contributes to the development of research capacity within Northern Ireland and workforce development.

As is noted in other studies⁸ the impacts of the funding to HSC R&D on health outcomes and health sector impacts can be difficult to quantify. 20% of respondents to the survey noted that one of the health impacts of the research was an increased length or quality of life for patients. In addition, 17% of respondents noted that their research indicated better targeting and accessibility of services.

⁸ For example; Frank, C. and Nason, E. 2009. *CMAJ*, March, 3, 180 (5)

1.1.7 Consultations

There was generally high regard for the HSC R&D funding and the staff within HSC R&D. All consultees noted the high levels of leverage that was gained from the HSC R&D funding and its importance in 'pump priming' HSC research. It was also recognised that the level of support that HSC R&D can provide to the sector is constrained due to its limited budget and that the sector itself is further constrained due to the inability of Northern Ireland to participate in highly-relevant funding streams that are available to the rest of the UK.

HSC R&D has fully or partially funded a relatively large number of high quality research posts within Northern Ireland. In addition to the economic benefits associated with these posts, the funding has allowed universities, HSC Trusts and research centres to maintain and attract a body of highly experienced and qualified staff, which is crucial to the continued development of the sector.

There have been a relatively large number of high quality posts that have been supported through the HSC R&D funding directly and indirectly. This has been through posts that have been fully funded or research projects which have been part funded and have been able to attract more funding. These posts are for experienced and highly qualified researchers.

It was recognised among a number of consultees that high quality research should be at the core of policy development and that research is needed to evaluate the effectiveness of policies.

Most consultees agreed that there appeared to be a 'bottle neck' from research to the translation of findings into policy or services.

It was generally recognised that not all health sector organisations have a strong research culture and that more needs to be done to ensure that research becomes embedded within organisations, while some consultees suggested that HSCTs should have targets relating to research. A few consultees noted that they were concerned that R&D generally has a low profile across the health and social services in Northern Ireland and there should be stronger links between R&D and those responsible for the development of policies within the Trusts and the DHSSPS.

1.1.8 Case Studies

Whilst it is recognised that three case studies cannot be fully representative of all the HSC R&D funded projects, they provide good examples of the incremental nature of the impacts associated with research within the Health and Social Care field, as well as the diversity of activities that are supported by HSC R&D. The case studies provide an example of the funded activities and impacts associated with:

- Research infrastructure;
- Health and Social Care Trust Research; and
- Clinical research.

A summary of key findings from the case studies included:

- The case studies demonstrate how the initial research, funded by HSC R&D helps to target future research, which, as noted in section seven is often funded by other funders who are external to Northern Ireland;

- HSC R&D supports the Northern Ireland Clinical Research Network (NICRN) which in turn facilitates the delivery of high quality clinical trials and other clinical research across the Trusts in Northern Ireland;
- Since 2008 NICRN has facilitated 30 clinical trials in the five HSC Trusts in the field of diabetes which has generated over £1.2 million additional income and benefited over 2,000 patients;
- HSC R&D support R&D offices within each of the 5 HSC Trusts. In addition to core funding the Trusts can apply for discretionary funding to address local research needs;
- HSC R&D supported research has led to Trust staff being involved in the development of National Guidelines relating to the care of patients with diabetes;
- Support from HSC R&D and NICRN has allowed the individual Trusts to participate in clinical trials and to attract funding;
- Exploratory research funded by HSC R&D led to the development of new treatments for breast cancer;
- Follow-on research from the exploratory studies attracted over £1.5 million of funding from sources outside of Northern Ireland (including MRC and cancer Research UK); and
- Findings from each stage of the research have been widely published in journals such as the Lancet and the Oncologist.

1.1.9 Benchmarking

There is not a consistent approach to assessing research impacts, within a country, or across them. There are also complications across disease types, where data may be routinely collected on funding (although by no means everywhere) but impact data is not assessed by disease area. Even where economic data exists, based on payback-style studies, the findings may not be comparable if the methods of identifying what an economic impact is are different.

This evaluation identified a return of 4.14:1 on research funding provided by HSC R&D in Northern Ireland. While the structure of economic evaluations in other countries does not allow a direct comparison of this ratio with existing findings, we can see that the leveraged funding return is higher than the return on clinical research identified using a net health benefits and GDP approach (that did not include leveraged research funds) in both England (1.37/1.39:1) and Sweden (1.08:1). It is also larger than the leveraged funding data available in England (where the MRC leveraged funding at 1.27:1) and Canada (where a specific program by the INMD leveraged private sector funding at 2:1). Whilst these numbers are based on different methods and can only be used as an indication that in Northern Ireland, health research funding is successful in generating additional research income for the region, they compare very favourably to the economic success of research funding in England, Sweden and Canada. The full comparison benchmark report can be found in Appendix 6.

1.1.10 Conclusions and Recommendations

Conclusions

The review of the relevant literature demonstrated the need for continuing to build up health sector R&D, its overall importance to the economy and the key role that R&D plays in the planning and delivery of health and social services.

High-level population statistics relating to the three research interest areas demonstrate the on-going need for further work in these areas.

Between 1998 and 2011, just over £40 million HSC R&D funding was issued to 108 Principal Investigators to undertake research in the fields of cancer, diabetes and mental health.

The total health and social care R&D budget is significantly less in Northern Ireland per capita than the rest of the UK. Even at its peak in 2008 the total HSC R&D budget in Northern Ireland equated to around £7.63 per capita, less than 50% of what is available in England (an estimated £15.12).

Based on responses to the survey of PIs, that additional and follow-on funding was secured for the HSC R&D supported project totalling over £53 million. This equates to in the region of £4.14 generated for every £1 of HSC R&D funding.

Whilst the low level of funding available is a significant issue amongst those consulted with the standard of supports and the quality assurance provided by HSC R&D Division was well regarded.

Many PIs noted that their research activities were restricted due to the lack of access to larger funds such as the National Institute of Health Research (NIHR).

A number of consultees noted that R&D within the health sector across Northern Ireland should have a higher profile.

Recommendations

In the following paragraphs we have summarised the main recommendation emanating from the evaluation:

- Consultations for a new strategy for HSC R&D should include policy makers and those responsible for planning and delivering services. The new strategy could then indicate research requirements for Northern Ireland so that funding might be considered for each. Important considerations would include the need for research and the potential to deliver outputs and outcomes against the payback framework. Subsequently, when project funding is provided, the payback framework elements should be referenced in the letter of offer of grant support.
- The DHSSPS should urgently consider (in close consultation with the research community) contributing to NIHR. This would enable NI researchers to participate in the NETS programmes of the NIHR. **As part of this a cost/benefit analysis should consider the impact of the funding over a five to ten year period with interim reviews to ensure its continued benefit to Northern Ireland.**
- The evident success in leveraging of the annual HSC R&D budget should be built upon. Strategies might include direct bi-lateral partnerships with other research funders; continuing to work within funding consortia to enable projects of a larger scale than would be possible locally; ensuring the timely development of local funding opportunities so that research findings, capabilities etc. would enhance the competitiveness of NI based researchers in UK, EU or other significant funding opportunities.

The need for enhanced flexibility in the allocation of HSC R&D funding was mentioned by some consultees. Consultations with the Trusts noted that the annual budget provided to Trust R&D Directors by HSC R&D did alleviate this to some degree. It was felt that more of the funding might be

discretionary or set aside to deal with emerging research needs. However it is recognised that this would need to be balanced with maintaining the supportive research infrastructure across the province that was put in place during the current 5 year strategy period with the intention that it would assist researchers to attract funding from elsewhere.

Our consultations highlighted the opportunity to enhance the profile of research within Trusts and among policy-makers and service planners in the DHSSPS and across HSC organisations. For example, the reporting structures between those responsible for managing R&D and senior management within each organisation might be reviewed.

It was the perception among many of those consulted with from Trusts that research was not sufficiently high up the agenda of the executive committees. Consideration should be given to the most appropriate way of ensuring that research is embedded and becomes more central to decision-making processes within HSC organisations. In addition to benefits for each organisation, this would enhance further the effectiveness of the HSC R&D Strategic Advisory Committee on which all of the organisations are represented and provides very valuable input to major HSC R&D activities.

It was also evident through our consultation exercise that research generally and HSC R&D had a low profile within the HSC sector. This creates even greater difficulty in raising awareness of the benefits that research can provide for health or social care policy or service delivery. We recommend that this lack of visibility be addressed and steps taken to rectify it. **Any action in that direction would help to ensure that HSC R&D can have the greatest possible impact on the development of health and social care.**

Research funders elsewhere in the UK are now developing tools for ongoing measurement and monitoring of the impact of health research. All of the three major funders of health research (MRC, NIHR and Wellcome Trust) have developed such systems. We feel that such ongoing monitoring is essential as it can provide reassurance that the projects are on schedule, especially given the length of time it can take impacts to emerge. **For these reasons we would recommend that HSC R&D adopts a similar online approach for monitoring its funded projects. The survey should allow easy quantitative analysis consistent with the domains of the payback framework used in the current study.**

All HSC Trusts should have access to evidence on the impact of the R&D that they support, including appropriate financial information on the income generated through clinical research (including clinical trials). **It is recommended that each Trust ensures that any surplus it generates is reinvested to support further research.**

Health professionals who have been awarded Doctoral Fellowships usually return to full-time clinical roles. The learning and experience they have gained through the Fellowship is well known to enhance their practice, their future career prospects and overall contribution to their organisation. However, in addition we recommend that a structured approach is taken to ensuring that, as far as possible, they are supported to continue to undertake high quality research. This would, for example, allow them to investigate specific and 'live' health and health service delivery issues that they have identified through their clinical work and ensure that robust findings are rapidly implemented in practice.

There was a widely recognised bottle neck for the implementation of research findings. Whilst this is not unique to Northern Ireland⁹, consideration should be given to the most appropriate mechanisms to increase translational and implementation activities. These could include extending the timescales and budgets of research projects to allow direct dissemination to relevant health service delivery organisations or ensuring that funded projects include, and achieve, appropriate dissemination targets. A more radical example of how this is achieved elsewhere includes the Department of Health's (England), Policy Research Programme (PRP). Through this programme high quality research is commissioned to provide evidence necessary for the Department's policy remit. The PRP works alongside other NIHR research programmes and allocates a multi-million pound budget annually. In Northern Ireland it would be highly appropriate to consider additional funding to enable such policy-relevant research. In addition, given that the majority of policy / strategy documents originating with DHSSPS now highlight what research is necessary, applications for HSC R&D funding should include an indication of their local policy relevance.

- The Northern Ireland Programme for Government and current Economic Strategy all emphasise the central role of R&D. Research in health and social care is an extremely valuable element of the total R&D capacity of a region. While the primary focus of HSC R&D is to provide high quality research evidence to support policy and practice, it is recommended that further engagement with Invest Northern Ireland be pursued, e.g. joint funding initiatives enabling direct academic, clinical and business collaboration in pursuit of shared goals of value to all three sectors.
- Results from the survey and additional data received from individual HSC Trusts showed that R&D can generate substantial income in the form of research grants and income from clinical trials, in addition to meeting the full cost of undertaking the research. As well as capturing this financial information by Trusts, it is recommended that reports are compiled to indicate the impact of each study with regard to the domains of the payback framework (i.e. IP income, jobs created etc). This information would be of value in demonstrating the essential nature of R&D and also to underpin any future study on the spillover impacts into the wider local economy.

⁹ A recent study (*Tracking the impact of research on policy and Practice: investigating the feasibility of using citations in clinical guidelines for research evaluation*. Kryl, D. et al *BMJ Open* 2012, 2. Noted that the research community as a whole could be better at translating the findings of medical research into tangible health and healthcare benefits.

2 INTRODUCTION AND METHODOLOGY

The following paragraphs provide an overview of the terms of reference for this assignment and the methodology used.

2.1 Terms of Reference

The overall aim of the project is to: “evaluate the impact of Health and Social Care (HSC) Research and Development (R&D) funding in Northern Ireland, focusing on three well established areas of research: 1) Cancer; 2) Diabetes; 3) Mental Health, and to benchmark the findings against comparable work in other countries”.

Specifically the terms of reference were to:

- Provide evidence for the development of the next strategy for HSC R&D in Northern Ireland: 2013 – 2018;
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The model used for this assignment was based on the Payback Framework. This is a tool designed to measure the impact of health R&D funding and has been used extensively in a number of projects. These include ‘Medical Research: What’s it worth? Estimating the economic benefits of medical research in the UK’¹⁰; ‘Making an Impact: The Economic and Social Benefits of HRB-Funded Research’¹¹; ‘Assessing the impact of England’s National Health Service R&D Health Technology Assessment program using the “payback” approach’¹²; and ‘Institutional strategies for capturing socio-economic impact of academic research’¹³. The following diagram provides an overview of the Payback Framework’s logic model.

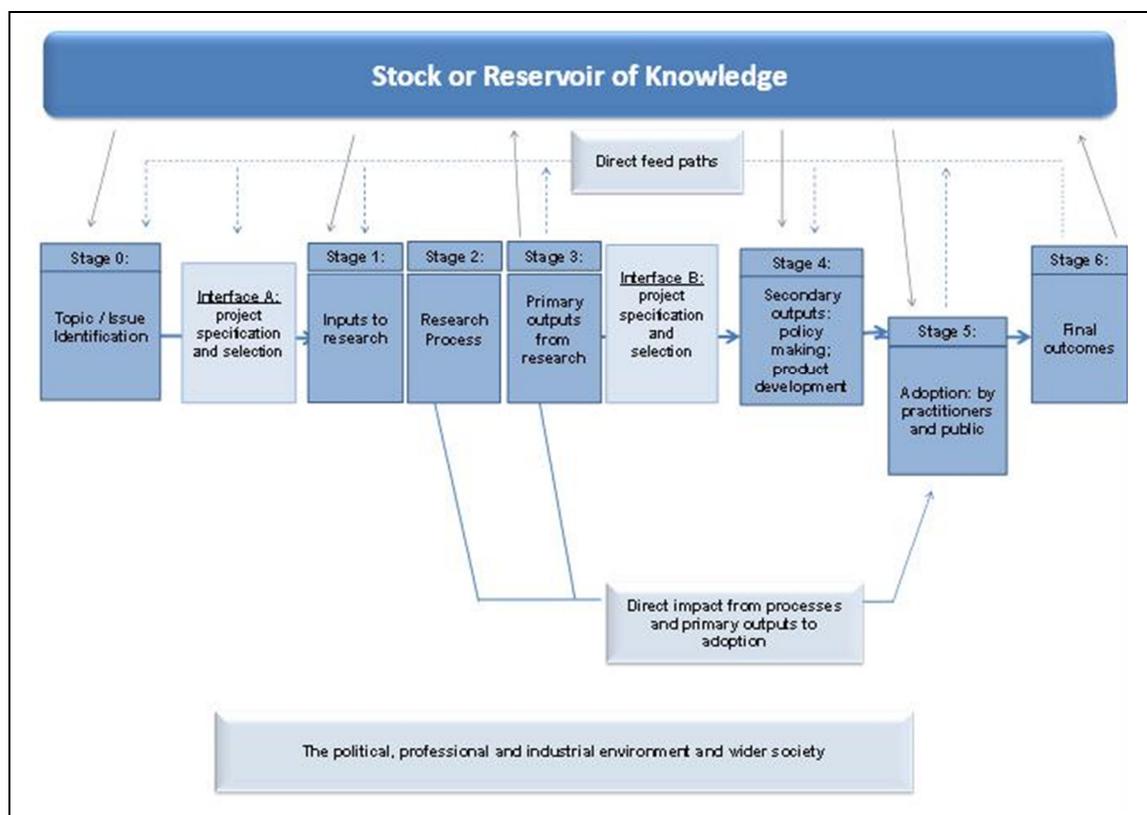
¹⁰ Medical Research: What’s it worth? Estimating the economic benefits from medical research in the UK, *Health Economics Research Group, Office of Health Economics, RAND Europe*, London: UK Evaluation Forum; (2008).

¹¹ Making an Impact: The Economic and Social Benefits of HRB –Funded Research, *Health Research Board*, (May 2008).

¹² Assessing the impact of England’s National Health Service R&D Health Technology Assessment program using the “payback” approach, *International Journal of Technology Assessment in Health Care*, 25:1-5 (2009).

¹³ Institutional strategies for capturing socio-economic impact of academic research, *Journal of Higher Education Policy and Management*, 32: 5, 499— 510, (2010).

Figure 2:1: Logic Model of the Payback Framework



Source: Hanney S, et al. (2004) Proposed methods for reviewing the outcomes of research: the impact of funding by the UK's 'Arthritis Research Campaign'. *Health Research Policy and Systems*, 2:4

The methodology for the assignment had seven distinct stages, as summarised below:

- **Stage 1:** Project Inception: The project commenced with a Project Inception Meeting with the Project Board Group. The main purpose of this meeting was to discuss our approach, establish overall project priorities, agree exact deliverables and confirm the requirements in relation to project monitoring and reporting.
- **Stage 2:** Desk Based Review: This stage involved the analysis of data relating to HSC R&D funded research (1998 – 2011), a review of the strategic context in which the research was undertaken, a review of the current literature relating to the study and a review of the macro level statistics/health indicators associated with the 3 areas of research.
- **Stage 3:** Consultations: This stage involved a suite of consultations with a key range of stakeholders who had a detailed understanding of:
 - the health sector R&D in Northern Ireland;
 - the three areas of research (Cancer, Diabetes and Mental Health);
 - Public Health; and
 - leverage from all sources.

A range of techniques was used at this stage of the assignment including one-to-one interviews and on-line surveys.

- **Stage 4:** Survey of funded researchers: Using the information provided to us by HSC R&D Division, Public Health Agency (HSC R&D) we sent an e-mail to all principal investigators who received funding (1998-2011) and who were still working in Northern Ireland. The survey was informed by the Buxton and Hanney Payback Framework¹⁴, which provided categories of impacts and an assessment of the degree of impact attributable to specific research.
- **Stage 5:** Case Studies: A total of three case studies were developed. Each case study contained information on the origins of the research and the primary outputs such as publications. They also explored the contribution to research training and career development, and the translation of the research findings into product development, policy and practice.
- **Stage 6:** Benchmarking: Three countries were chosen to benchmark against; England, Sweden and Canada. The benchmarking analysis included a high level review of the level and range of government funding provided to Health Care R&D in each country and a desk based review of any evaluations of this funding.
- **Stage 7:** Data Analysis and Reporting: Data from the literature review, the survey and the case studies were categorised into type of benefit/impact using the Payback Framework. This analysis describes the level and range of funding to the three subject areas from 1998-2011, quantifies the level of corresponding consequential funding attached from outside sources and quantifies and describes the employment and support created. It also describes the extent to which research capabilities have been enhanced and describes the improved evidence basis on which to make health policies.

In the rest of this report we have completed the following sections:

- Section 2: Introduction and Methodology.
- Section 3: Background and Strategic Context.
- Section 4: Statistical indicators of Health and well-being in Northern Ireland.
- Section 5: **Error! Reference source not found..**
- Section 6: Survey Findings.
- Section 7: Consultations.
- Section 8: Case Studies.
- Section 9: Benchmarking.
- Section 10: Conclusions and Recommendations.

¹⁴ Buxton M, Hanney S, How can payback from health services research be assessed? *Journal of Health Services Research and Policy*, 1(1), (1996), pp35-43.

3 BACKGROUND AND STRATEGIC CONTEXT

3.1 Introduction

This section examines the key strategic and policy documents relevant to Research and Development (R&D) within the Department of Health and Social Services and Personal Safety (DHSSPS) in Northern Ireland. It sets out the background to this evaluation as well as key contextual information and an overview of the policy context in which Health and Social Care (HSC) R&D in Northern Ireland operates.

3.2 Background to examining the benefits of HSC R&D funding

Understanding the nature, extent and processes involved in the return on investment in medical research has become an increasingly important area of study. In the early 1990s the National Health Service (NHS) in England embarked on an ambitious new R&D programme and as a result the Research Payback Framework was established to ascertain how the research funded delivered socio-economic benefits. Its designated categories for the range of payback that can arise from research create a systematic assessment of the impact that publically funded research has on the economy and society.

The importance of capturing information about when and how health research makes an impact on policy is emphasised in the article 'Yes, research can inform health policy; but can we bridge the 'Do-Knowing It's Been Done' gap?'¹⁵ It recognises the significance of health research and the need for robust techniques to assess this, citing the Payback Framework as an effective method that considers impact on policy as part of a multi-dimensional categorisation of benefits which also includes health and health equity benefits as well as broader economic benefits.

A number of recent publications¹⁶ have provided an overview of the benefits of the Payback Framework and how its application continues to be successfully utilised. A review of recent papers using this method has shown that¹⁷:

- Research leads to a wide range of benefits or types of 'payback';
- Much research leads, by subsequent application of the knowledge it generates, to significant benefits for society beyond that which the knowledge itself brings to science;
- It is difficult to understand, even looking back with the wisdom of hindsight, the ways and extent to which any individual project or researcher or programme of research does this; and
- It is even more difficult to predict, looking forward without the wisdom of hindsight, the characteristics of projects or researchers or programmes that are likely to be associated with the greatest payback or impact.

There is already established research in the UK and Republic of Ireland which has attempted to assess the issue of returns to investment in medical research. The report 'Medical Research: What's

¹⁵ Yes, research can inform health policy; but can we bridge the 'Do-Knowing It's Been Done' gap?, *Health Research Policy and Systems*, 9:23 (2011).

¹⁶ For example: The impact of Payback research: developing and using evidence in policy, *Research Evaluation*, 20(3), (September 2011) pp257-258.

¹⁷ The impact of Payback research: developing and using evidence in policy, *Research Evaluation*, 20(3), (September 2011) pp257-258

it worth? Estimating the economic benefits of medical research in the UK¹⁸ details the analysis of important research-based changes that have taken place in the treatment of particular disease areas (cardiovascular disease and mental health). It addresses the questions of economic returns to the UK population and economy from UK medical research by estimating the two main elements of economic returns; the value of health gains and the impact on Gross Domestic Product (GDP). As a result it demonstrates, through best/central estimates, that there are significant benefits from investing in UK health research. Overall the total value of the health gains and the GDP gains to public/charitable cardiovascular disease research in the UK in the years 1975-1992 gave a total internal rate of return (IRR) of around 39%, meaning a £1.00 investment in public/charitable research produced a stream of benefits thereafter that is equivalent to earning £0.39 a year in perpetuity. For mental health the rate of return to the public/charitable research investment is 37%. This report also raises the important issue that estimated rates of return are very sensitive to the assumed lag between the years when the research expenditure occurs and the years when the ultimate health benefit arises. For cardiovascular disease treatments it is suggested that the mean lag time between research and impact ranged from 10 to 25 years, with a central lag of 17 years. This is significant when considering the impact of HSC R&D, aspects of which may not be evident for a number of years.

The impact of investing in the health research sector has also been considered in the Republic of Ireland. In its report 'Making an Impact: The Economic and Social Benefits of HRB – Funded Research'¹⁹ the Health Research Board (HRB) stresses that the need for robust evaluation methods and the ability to demonstrate research outcomes are vital to provide evidence of value for money. Using the Payback Framework it examines the wider impact of eight funded grants from the early and mid-1990s. It uses the four broad areas of economic returns set out by the UK Evaluation Forum;

- Direct cost savings to the health system;
- Evaluating benefits to the economy from a healthy workforce;
- Value to society; and
- Commercial development.

In turn this found that:

- Several of the projects studied produced impacts that can be felt in the organisation of the health system. This is important as by creating a more cost-effective health system the Irish government can more effectively allocate its resources;
- A healthy workforce means a reduced number of days lost through illness, alternatively it is possible to consider the gains in terms of the intrinsic value of health;
- A number of researchers attracted significant funding from international sources including the European Union and international projects;
- Building and maintaining a highly skilled workforce of skilled researchers was important for building an international reputation; and
- The research described in several case studies has gone on to interact strongly with industry and commercialise research findings.

¹⁸ *Medical Research: What's it worth? Estimating the economic benefits from medical research in the UK*, Health Economics Research Group, Office of Health Economics, RAND Europe, (2008).

¹⁹ *Making an Impact: The Economic and Social Benefits of HRB –Funded Research*, Health Research Board, (May 2008).

Thus it is evident that there has been significant interest in promoting the benefits of medical research, with the UK Evaluation Forum stating “UK research stakeholders should be more active in demonstrating the benefits that arise from medical research and making the case for continued investment”²⁰. This appears even more pressing when considering the comments of the Director of Research Strategy and Funding, HRB, who stated that “today’s health research is tomorrow’s health care”²¹. Thus it is evident that the benefits of HSC R&D in Northern Ireland not only need to be recognised, but are part of, and contribute to, a wider overall process.

3.3 United Kingdom strategic and policy documents

It is also important to consider the policy context in which health and social care research is taking place and the various factors that can impact upon the importance that is placed upon the sector. The following paragraphs summarise a few of the key policy and strategy documents that have impacted upon the delivery of health and social care research in the UK.

3.3.1 Culyer Review (1994²²)

The remit of this review was to consider whether to recommend changes in the conduct and support of R&D in and by the NHS, and if so to advise on alternative funding and support mechanisms for R&D, including transitional measures, within available resources. The review group made a range of recommendations to create a new framework ‘of managed competition for NHS resources associated with R&D’.

Implementation of Culyer in Northern Ireland led to declarations by each hospital of its research funding. This was subsequently transferred over a period of some 5 years to create a single R&D Fund. The (then) R&D Office was established in 1997 to manage and oversee the Fund.

This activity of that Office has seen two 5-year strategic plans and a third is now in preparation.

3.3.2 Cooksey Review (HMT, 2006)

The Cooksey Review was commissioned in the UK to establish the best institutional arrangements for a new single fund for health research in the Treasury Budget. The review concluded that although good progress had been made in some areas further work was needed to ensure that publicly funded health research was carried out in the most effective and efficient way, and to facilitate the translation of findings into health and economic benefits. It stated that although the UK is a leader in basic research, it is not as successful as it could be at taking the results of that research along the pathway to new innovations, products or health care practices. It identified two gaps in translation:

- The first gap arises in the translation of basic and clinical research into ideas and products; and

²⁰ *View of the UK Evaluation Forum underpinning its report Medical Research: Assessing the benefits, May 2006, as quoted in What’s it worth? Estimating the economic benefits from medical research in the UK, Health Economics Research Group, Office of Health Economics, RAND Europe. Medical Research, (2008).*

²¹ *Making an Impact: The Economic and Social Benefits of HRB –Funded Research, Health Research Board, (May 2008).*

²² *Culyer, A J Supporting Research and Development in the National Health Service: A Report to the Minister for Health by a Research and Development Task Force Chaired by Professor Anthony Culyer, (1994) London, HMSO.*

- The second relates to introducing those ideas and products into clinical practice.

The first gap in translation relates to the process of taking ideas developed either by basic scientists working in the laboratory or by clinician-scientists working in a clinical environment, or, increasingly, by a mix of the two, and developing them into products that can either be commercialised or in some other way disseminated into wider healthcare practice. The key issues raised during the consultation process for this review include:

At a national level:

- Achieving more effective strategic coordination of efforts to translate health research to a stage where it can be commercialised and / or generate health benefits for patients;
- Ensuring that the skills base needed to ensure that health research in the UK continues to be world-class, and that we have the skills to translate it into greater health and economic benefits;
- The availability of capital for SMEs in the healthcare sciences sector that are looking to commercialise ideas developed in healthcare research, especially in the biotech sector; and
- Whether research procurement can be used more effectively as a tool for driving translation by the private sector, and particularly by SMEs.

At the level of individual Higher Education Institutions and NHS Trusts:

- Making translation happen in practice. How to link the direction of basic research to health priorities and needs more effectively;
- Strengthening Knowledge and Technology Transfer in Higher Education Institutions (HEIs); and
- Building more effective links between research, entrepreneurs and sources of finance.

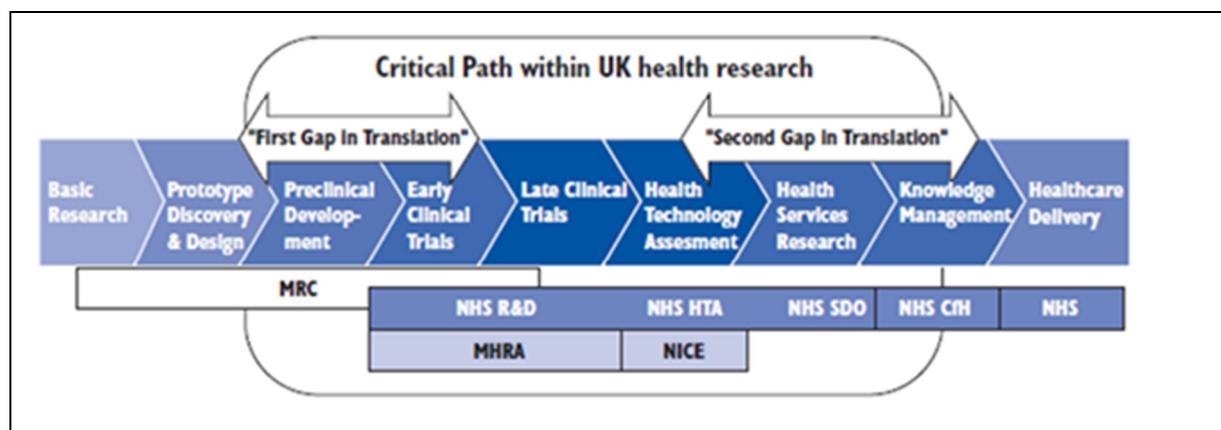
As a result the review suggests that there is a need to ensure that a clear and straightforward pipeline for translation of health research exists in the UK, that the funding and skills base needed are available, and that information and advice is easily obtainable.

The second gap in translating research into practice refers to the evaluation and identification of those new interventions that are effective and appropriate for everyday use in the NHS, and the process of their implementation into routine clinical practice. It states that in clinical trials, the eligibility of patients is rigorously predetermined and experimental conditions are carefully controlled. However, once shown to be effective in a clinical trial, evidence is also required to establish the benefit of using an intervention amongst the broader patient population in routine clinical practice. Given the finite resources available to the NHS and, indeed, all health systems, data are also required to evaluate the clinical- and cost-effectiveness of new and pre-existing interventions. Moreover, research into the organisational structures that deliver those interventions can highlight where improvements and efficiencies might be made. It is claimed that such processes, or, indeed, deficiencies in such processes, generate a gap in the translation of new medical interventions into everyday practice.

In this context, Knowledge Management, from research observation to routine clinical practice, can be broken down into four discrete activities: Knowledge Production, Knowledge Transfer, Knowledge Reception and Knowledge Use.

The first and second gaps in translation are illustrated in the following diagram:

Figure 3:1: Critical Pathth within UK Health Research



Blue boxes below parts of pathway correspond to specific responsibilities of public sector bodies supporting research. MRC: Medical Research Council. NHS R&D: National Health Service Research and Development. NHS HTA: NHS Health Technology Assessment programme. NHS SDO: Service and Delivery Organisation research programme. NHS CfH: Connecting for Health. Light blue boxes below parts of pathway correspond to the specific responsibilities of statutory regulatory agencies. MHRA: Medicines and Healthcare products Regulatory Agency. NICE: National Institute of Health and Clinical Excellence.

The review stated that certain cultural changes were necessary, supported by new and reformed incentives and other reforms, to ensure greater translation and uptake of research and innovation driven either from publicly-funded sources or from private and charity sectors. This included:

- Ensuring the health R&D ring-fence is effective;
- Creating a more positive overall culture in the NHS for research and innovation;
- The removal of barriers to closer working with partners across the public, private and charity sectors;
- Creating positive incentives for the NHS to undertake R&D;
- Creating incentives for the spread and uptake of best practice;
- Implementing new ideas in the NHS;
- More effective exploitation of Intellectual Property (IP) generated by the NHS; and
- Procurement and innovation.

While it is noted that these may not be immediately applicable to Northern Ireland and the other Devolved Administrations, it suggests consideration of alternative, more appropriate mechanisms to address the concerns raised.

The review also explicitly recognised the benefit of R&D funding in Northern Ireland, which 'has proven valuable in leveraging in significant amounts of external clinical research funding from partner organisations'.

The implementation of this review is cited as a driving factor for change in the DHSSPS R&D Strategy in Research for Health and Wellbeing 2007-2012²³.

²³ Research for Health and Wellbeing 2007-2012, R&D Office (2007).

3.3.3 A Shared Vision for UK Health Research (Office for Strategic Coordination of Health Research (OSCHR), March 2010)

This document describes the OSCHR vision for a UK health research and development strategy, summarising the aims of public funding and describes the UK health R&D landscape. It recognises that UK health R&D is operating in an increasingly challenging environment as it faces economic pressures to save money and increasing competition from other countries, as summarised in Sir David Cooksey's report. To meet these challenges it states public funders of research are working together to ensure UK health R&D becomes more innovative, productive and efficient, with the OSCHR engaging in planning and delivery activities to build health research for the 21st century. The OSCHR Board was established in 2007 with an independent chairman, Professor Sir John Bell, and a Board comprising MRC, the Department of Health (England), R&D organisations, the National Institute for Health Research (NIHR), and non-executive directors. It was agreed subsequently to invite participation of devolved administrations. In 2009 Northern Ireland, represented by the Director of HSC R&D, joined the Board. This report outlines the OSCHR's 8 main priorities, related vision statements and how these can be achieved.

The OSCHR vision for UK health research is summarised as follows:

'The public funders of health research are committed to working together to improve the competitiveness of UK health research, speed up the translation of basic science to patient benefit and create an environment attractive to the life sciences industry.'

The main priorities are:

- Building a strong academic base; To maintain and improve the UK's position as one of the global leaders in health research through sustained investment and the coordination of strategies across public funders;
- Moving from discovery to patient benefit; To create a clear and seamless funding landscape that facilitates and accelerates the translation of new discoveries for patient and economic benefit;
- World-class research and development infrastructure and capacity; To create and maintain a world-class infrastructure that underpins research in the university sector and harnesses the unique potential of the NHS;
- Building a highly-skilled workforce across the entire translational health R&D landscape; To maintain and improve the UK's strong international position by developing a strong skills base with the capacity to meet the health research challenges of the 21st century;
- The NHS – A unique competitive advantage for the UK; To enhance the conditions that make the NHS an internationally recognised centre of research and to unlock the research potential of large electronic patient record databases for the benefit of biomedical science, patient safety and public health;
- Contributing to national wealth; To create a strong culture of partnership encouraging cooperation between research funders in the public, charity and commercial sectors, and facilitating collaboration between academics, industry and the NHS;
- Public Health Research; To create a vibrant research community in public health where partners are properly engaged and where a new cohort of young investigators emerges to address major health problems at a population level; and

- Methodologies to take new medicines to the patient quickly and safely; To establish the UK as a focus for excellence in developing novel methodologies for clinical and translational research to speed up drug development and ultimately improve patient safety.

These priorities provide an overview of the UK health research vision and the ideological landscape in which HSC R&D is operating.

3.3.4 A Shared UK research funding stream

An early action by the OSCHR partners was to develop a funding mechanism to enable the participation of devolved countries in a small number of funding programmes of the NIHR, known as NIHR Evaluation, Trials and Studies (NETS). The 2010/11 NETS Annual Review²⁴ states that 'NETS programmes form an essential component of health research in the UK and the projects it supports continue to deliver high-quality results informing policy and practice'²⁵. That review goes on to state that

'While the delivery of NETS projects is exceptional – at least 99 per cent complete successfully – what they deliver is also crucial. The 'needs-led, science-added' approach pioneered from the NETS programme - focussing attention on the selection and prioritisation of topics, rigorous peer review, and active monitoring of project - has been instrumental in ensuring that projects deliver reliable and relevant evidence'.

Thus, the NETS programmes do not stand alone but are a key mechanism that enables academics and clinicians to work together to deliver the best evidence for quality, efficiency and cost-efficiency in health and healthcare. The NETS Annual Review states

'NETS projects therefore have the potential to make significant contributions to the NHS's efficiency drive. Beyond the NHS, high-quality research evidence can enable policy-makers to identify effective ways to tackle health inequalities and improve public health'.

The remits of the various NETS programmes are:

Health Technology Assessment (HTA): To produce independent research information about the effectiveness, costs and broader impact of healthcare treatment and tests for those who plan, provide or receive care in the NHS.

Health Services & Delivery Research (HS&DR): To produce rigorous and relevant evidence on the quality, access and organisation of health services, including costs and outcomes. The programme will enhance the strategic focus on research that matters to the NHS including research on implementation and a range of knowledge mobilisation initiatives. It will be keen to support ambitious evaluative research to improve health services.

Public Health Research (PHR): To evaluate public health interventions, providing new knowledge on the benefits, costs, acceptability and wider impacts of non-NHS interventions intended to improve the health of the public and reduce inequalities in health. The scope of the programme is multi-disciplinary and broad, covering a range of interventions that improve public health.

²⁴ Reference: 2010-2011 Annual Review NIHR Evaluation, Trials and Studies. www.netscc.ac.uk

²⁵ [www.netscc.ac.uk/about/annual review.asp](http://www.netscc.ac.uk/about/annual%20review.asp)

The total nominal budget for NETS in 2011/12 was £77.5 million. To enable participation in these programmes by researchers based outside of England, a proportion of the funding accruing to a country as a consequence of the Barnett formula must be allocated to the NETS funding. The required annual contribution from Northern Ireland is £2.6 million.

To-date Northern Ireland is the only Devolved Administration which has not provided any funds to NETS, as such Northern Ireland researchers cannot directly apply for funding. An alternative mode through which NI-based researchers could participate in NETS programmes would be for NI to bear the full cost of any proposals deemed fundable through NETS, including any costs incurred by collaborators elsewhere in the UK.

3.3.5 Investing in UK Health and Life Sciences²⁶ (Business Innovation and Skills, December 2011)

This strategy sets out the government's commitment to amalgamate life sciences in the UK. It sets out to:

- Open up universities to more collaboration;
- To invest in the best British ideas at an early stage;
- To tear down the regulatory barriers that hinder technology adoption and diffusion; and
- Open up the NHS to new innovations and new clinical trials.

The strategy recognises that the UK already possesses an unrivalled concentration of academic excellence. However, it emphasises the need for collaboration across disciplines and organisations, and the development, recruitment and retention of the best scientists, clinicians and entrepreneurs if the UK is to be at the forefront of the industry. To achieve this, it aims to put innovation at the heart of education through fellowships and professorships, while embedding commercial skills into the clinical and post-graduate curriculum and introducing a higher-level Apprenticeship for Life Sciences.

Moreover, it states the UK is building an integrated system to make it easier to translate discovery into development. This includes investment in translational research and unlocking patient data, and an acceleration of the setup of clinical trials. This is to be achieved in England by the commitment of a further £800million over five years to Biomedical Research Centres by the National Institute for Health Research. The establishment of two new Translational Research Partnerships includes one centre in Northern Ireland (Respiratory Research at Queen's University Belfast / Belfast Health and Social Care Trust), the costs of their participation being funded by HSC R&D.

The process from development of clinical trials to their initiation is also to be revised. In England, this encompasses a revision of pricing to take a broader account of value, the integration of infrastructure to drive adoption and diffusion (through the establishment of a number of Academic Health Science Networks (AHSNs) across the country), and the removal of obstacles to technology adoption and diffusion. Northern Ireland's process for initiation of clinical trials is similar albeit with a simpler, more streamlined approach as appropriate for a smaller region.

The importance of investing in innovation and health care is recognised, claiming that this is demonstrated by the protection of the £4.6billion science budget and increases to the Department of Health research budget. In addition, external innovation is cited as playing a significant role in the UK

²⁶ Investing in UK Health and Life Sciences, *Department for Business, Innovation and Skills, (December 2011)*.

and as a result the strategy aims to strengthen the tax system to make innovation pay, and address the financing and regulatory barriers that slow innovations reaching patients.

Overall this document and the strategies underpinning it represent the necessity of working with industry to make the UK a world leading centre for discovery, development, manufacture and adoption.

This is directly relevant to Northern Ireland, and specifically HSC R&D. Northern Ireland provides a microcosmic example of this approach as it shares the aims and aspirations outlined above, most notably in relation to the importance of clinical trials and translational research, as specified in the DHSSPS strategy 'Research for Health and Wellbeing 2007-2012'²⁷.

3.4 Structure of Health & Social Care R&D in Northern Ireland

The DHSSPS R&D office was established in 1998 to support the broad spectrum of R&D through direct research funding and through less direct mechanisms. This involved balancing longer term investment in infrastructure against the more responsive direct support for research grants.

Since 2009 HSC R&D has been co-ordinated by the Research and Development Division within the Public Health Agency (HSC R&D). It works to support research in Northern Ireland, including that in the Health and Social Care Trusts.

In addition to direct funding, HSC R&D promotes, coordinates and facilitates the conduct of R&D by HSC and non-HSC organisations in clinical, academic and voluntary sectors. It supports the development and maintenance of a tissue bank, specialist clinical research facilities such as the Northern Ireland Clinical Research Network (NICRN), Northern Ireland Cancer Trials Centre and Network (NICTC / NICTN) and other enabling infrastructure such as R&D offices within HSC trusts.

While the nucleus of HSC R&D is essentially local, it promotes good working relationships with its counterparts in the rest of the UK. This extends also to the Republic of Ireland and international organisations such as the US National Cancer Institute.

The HSC R&D strategy, Research for Health and Wellbeing 2007-2012, consists of five strategic priorities:

- Develop an infrastructure to support R&D;
- Build research capacity;
- Build research portfolio;
- Translate research findings into practice through innovation; and
- Build patient and public involvement in R&D.

Cumulatively, it was envisaged that this strategy would lead to a well-developed network for clinical research and associated support structures, and a well-trained HSC research workforce. It was also predicted to establish excellent local, national and international collaborations, additional external research income and an outlet for commercial exploitation of products.²⁸

²⁷ Research for Health and Wellbeing 2007-2012, *R&D Office (2007)*.

²⁸ Stout, Professor Robert, Research for Health and Wellbeing 2007-2012, *R&D Office (2007)*.

3.5 Northern Ireland strategy and policy documents

As R&D is a key factor in the development and delivery of all aspects of HSC services and DHSSPS policies, there are a wide range of policy and strategic documents that are relevant to this assignment. In the following paragraphs we have summarised some of the key, relevant strategies to provide an overview of the broader policy environment in which HSC R&D has operated over the review period.

3.5.1 Programme for Government 2008 – 2011

The Programme for Government sets out the priorities and budgets for the Executive. Each Department had targets and associated public service agreements under the Programme for Government, specifically targets relating to the three areas of cancer, diabetes and mental health, and key goals respectively.

As such whilst the PfG (2008 – 2011) did not specifically refer to HSC R&D, there are seven targets relating to Cancer, Diabetes and Mental Health, which could be considered as an indication of the importance of addressing these health and wellbeing concerns in the Northern Ireland population²⁹.

3.5.2 Programme for Government 2011 - 2015

The Programme for Government (PfG) 2011-2015 was published on 12th March 2012 and specifically sets targets for cancer, diabetes and mental health.³⁰

3.5.3 Service Framework for Cancer Prevention, Treatment and Care (DHSSPS, 2009)

The Service Framework for Cancer Prevention, Treatment and Care outlines the standards which patients, clients, carers and their wider families can expect. It sets standards in relation to the prevention, diagnosis, treatment, care, rehabilitation and palliative care of individuals and communities at a greater risk of developing cancer.

The Service Delivery Framework encompasses a wide range of standards which aim to improve the prevention, diagnosis, treatment and care for individuals. Research is a key part of their development and directly links the trajectory of focused research and patient care.³¹

3.5.4 Cardiovascular Health and Well-being Service Delivery Framework (DHSSPS, 2008)

The Service Delivery Framework for Cardiovascular Health and Well-being outlines the standards that patients, clients, carers and their wider families can expect. It sets standards in relation to the prevention, diagnosis, treatment, care, rehabilitation and palliative care of individuals and communities who currently have a greater risk of developing cardiovascular disease, including diabetes.

As such, the Service Delivery Framework for Cardiovascular Health and Well-being utilises substantial research to justify each of its overarching standards.³²

²⁹ Detailed targets in Appendix

³⁰ Detailed targets in Appendix

³¹ See Appendix 1

3.5.5 Service Framework for Mental Health and Well-being (DHSSPS, 2010)

The Service Framework for Mental Health and Well-being outlines the standards that patients, clients, carers and their wider families can expect. It sets standards in relation to the prevention, assessment, diagnosis, treatment, care, rehabilitation and palliative care of individuals and communities who currently have or are at a greater risk of developing mental illness.

As a result of extensive research the Service Framework for Mental Health and Well-being represents a comprehensive, accurate record of issues facing the mental health sector and as a result of this knowledge can propose realistic and effective standards for the future.³³

3.5.6 Service Delivery Framework Summary

The Service/Service Delivery Frameworks summarised above, each set out the standards of care to be provided in each area. Each of which has noted that that the established standards are based upon the outcomes of research in that area. This demonstrates the importance of R&D in the delivery of Health and Social Care to patients and those responsible for commissioning care

³² See Appendix1

³³ See Appendix1

4 STATISTICAL INDICATORS OF HEALTH AND WELL-BEING IN NORTHERN IRELAND

Summary

High-level population statistics relating to the three research interest areas demonstrate the on-going need for further work in these areas. The importance of research relating to Cancer prevention, treatment and care is clearly evident. A review of the high levels statistics has shown that the rate of diagnosis of many cancers has increased but that the survival rates have also improved. Clinical trials and other clinical research studies such as those that have led to changes in clinical care and improvements in surgery techniques have been integral to the latter being achieved.

There is also evidence to support the need for enhanced research in the field of diabetes. It is widely recognised that obesity continues to be a common problem in modern society and considering the relationship between being overweight and the increased risk of developing type 2 diabetes, the need for further research into prevention and treatment will only increase as obesity levels escalate. Moreover, it will play an important part if the aim set out in the Obesity Prevention Framework (2011 – 2021) of reducing the level of obesity in Northern Ireland to 2005/06 levels by 2021, is to be achieved and maintained.

Mental illness continues to be an issue in Northern Ireland, over the last five years, the total number of admissions to hospital under the mental health programme of care increased by 2.4%. The NI suicide rate also increased from 10.4 (deaths per 100,000) in 2000/02 to 15.9 (deaths per 100,000) in 2008/10. Furthermore, projections relating to dementia suggest a 41% increase in the number of diagnoses by 2021.

4.1.1 Introduction

In order to contextualise the need for HSC R&D, the following paragraphs provide an overview of the key macro level statics relating to Cancer, Diabetes and Mental Health over the period under review.

4.1.2 Cancer

Table 4.1: Rate / incidence of Cancer 1998-2009

Year of diagnosis / death	Rate/incidence			
	Number of cases	Crude diagnosis rate per 100,000 persons	Number of deaths	Crude death rate per 100,000 persons
1998	8,603	512.8	3,668	218.6
1999	8,605	512.5	3,555	211.7
2000	8,727	518.6	3,562	211.7
2001	8,737	517.2	3,673	217.4
2002	9,185	541.4	3,665	216.0

Year of diagnosis / death	Rate/incidence			
	Number of cases	Crude diagnosis rate per 100,000 persons	Number of deaths	Crude death rate per 100,000 persons
2003	9,479	556.7	3,744	219.9
2004	9,480	554.3	3,758	219.7
2005	9,663	560.4	3,740	216.9
2006	10,209	586.2	3,867	222.0
2007	10,725	609.7	3,837	218.1
2008	11,397	642.1	3,949	222.5
2009	11,770	657.9	3,805	212.7

Source: Northern Ireland Cancer Registry

As shown in the table above, the number of cases of cancer in Northern Ireland increased by 36.8% from 1998 to 2009. However the crude death rate from cancer per 100,000 persons has decreased by 2.7%. This would suggest an increase in the numbers of those who are being diagnosed as well as improvements in treatments.

The Northern Ireland Statistics and Research Agency (NISRA) Statistical Bulletin: Deaths in Northern Ireland (2010) states that in 2010 4,018 deaths were attributable to cancer. Moreover, it also highlighted that:

- Cancer, all circulatory diseases and all respiratory diseases accounted for nearly three-quarters (72%) of all deaths in 2010;
- Prior to 2005 the number of cancer deaths had remained relatively stable at around 3,700 each year;
- Whilst the total number of deaths due to cancer remains relatively stable, cancer now accounts for a greater proportion of all deaths in Northern Ireland. In 2010 cancer represented 28% of all deaths compared to 17% of all deaths in 1980; and
- In 2010 of the 4,018 cancer deaths, 909 were caused by lung cancer, 270 by colon cancer, 271 by breast cancer, and 245 by prostate cancer. People who die from cancer are usually younger than people who die from other natural causes. In 2010 the average age at death for those who died from cancer was 72 compared to 78 for other natural causes.³⁴

Cancer also accounts for a significant number of acute hospital beds and day cases in Northern Ireland.

³⁴ Deaths In Northern Ireland, Northern Ireland Statistics and Research Agency, (2010).

4.1.3 Diabetes

There are two main sources of data relating to the prevalence of diabetes in Northern Ireland, they are Diabetes UK and the Institute for Public Health in Ireland. Both of which publish statistics from 2006 onwards. The following tables and paragraphs provide an overview of the data available.

Table 4:2: Diabetes Diagnosis 2006-2011*

Year of diagnosis	NI Prevalence	Number of people with diabetes	GB Average Prevalence	Known diagnosed population in the UK (in millions)
2006	3.1%	55,000	3.5%	2.2
2007	3.1%	56,924	3.6%	2.3
2008	3.3%	60,822	3.8%	2.5
2009	3.5%	65,066	4.3%	2.6
2010	3.7%	68,980	4.5%	2.8
2011	3.8%	72,693	4.7%	2.9

Source: QOF and Diabetes UK

*Incorporates persons aged 17 years and over.

The figures above are based upon results from the Quality and Outcomes Framework (QOF). Established in 2004, the QOF is a system to remunerate general practices for providing good quality care to their patients, and to help fund work to further improve the quality of health care delivered. It is a fundamental part of the General Medical Services (GMS) Contract, introduced on 1st April 2004. The QOF establishes prevalence figures for particular diseases and conditions based upon specific registers of patients produced by general practices, thereby measuring the burden of a disease in a population at a particular point in time. This includes the area of diabetes, which is defined by the QOF as:

‘Since 2006, all patients aged 17 years and over with diabetes mellitus (specified as type 1 or type 2 diabetes)’.

As shown in the table above, the prevalence of diabetes in Northern Ireland increased by 0.7% from 2006 to 2011 and the number of people being diagnosed by 17,693 (32%) from 2006 to 2011. Concurrently the GB average prevalence increased by 1.2%, and the known diagnosed population increased by 32% (from 2.2 million in 2006 to 2.9 million in 2011). This suggests an increase in the number of people being diagnosed while highlighting that it is a growing problem across the UK that requires equal research funding.

4.1.4 Dementia

Dementia is also an important area for consideration in relation to mental health, as shown in the following table there are an estimated 17,700 people with Dementia in Northern Ireland.

Table 4:3: Estimated current and projected number of people with dementia and / or a diagnosis by Health and Social Care Trust

	Health & Social Care Trust					
	Belfast	Northern	South Eastern	Southern Health	Western	Total
Estimated No of people with dementia in 2010	3773	4674	3694	3102	2522	17,765
Estimated No of people with dementia in 2021	4315	6848	5335	4677	3805	24,980
% increase in number of people with dementia	14	47	44	51	51	41
No of people with a diagnosis 2010	2596	2410	2112	1880	1639	10,637
No of people without a diagnosis 2010	1177	2264	1582	1222	883	7,128
% of people with dementia with a diagnosis	69	52	57	61	65	61
No who will have a diagnosis in 2021	2969	3531	3051	2834	2473	14,858
No of people without a diagnosis in 2021	1346	3317	2285	1843	1332	10,123

Source: Alzheimer's Society³⁵

This table illustrates the predicted increase in people with dementia by 2021 across all Health and Social Care Trusts (HSCTs). The current and predicted figures demonstrate the scale of the growing problem and the need for further research into the cause, cure and care, as defined in Improving Dementia Services in Northern Ireland: A Regional Strategy consultation paper by the DHSSPS in May 2010. This outlined some key areas where research is needed that included but are not exclusive to:

- Factors that place individuals at risk or help protect against dementia;
- Whether treatment of raised blood pressure reduces the risk of dementia; and
- People's experiences of assessment and diagnosis, as well as conducting research with seldom heard groups in order to gain a fuller understanding of their perceptions and needs.

It also proposed the conditions necessary for future research:

- Strategic interactions among researchers and clinical colleagues to ensure that research is informed by clinical needs and research findings are translated into improved outcomes for patients;
- Collaboration with substantial dementia research groups based elsewhere in the UK and internationally;
- Continued support for NICRN-based clinical trials that involve people with dementia, with the full support of HSC Trusts being essential; and

³⁵ www.alzheimers.org.uk/

- Support for multi-disciplinary, multi-professional research with strong involvement of HSC Trusts, patients, carers and organisations that represent and support them.

The strategy stated that dementia's worldwide impact called for a co-ordinated approach to research, pooling talents and resources. It emphasised that NI researchers and clinicians need to collaborate with others to maximise the impact of research funding and expertise.

5 OVERVIEW OF FUNDING

Summary

HSC R&D has supported 184 cancer, diabetes or mental health research projects since 1998 and has provided over £40.7 million of funding to these projects at an average of £221,199 per project.

The total amount of funding available through the single regional HSC R&D Fund reached its peak of £13.5 million in 2008 and declined subsequently. Currently the level of research spend per capita is less than 50% of that in England (£6.57 compared to £15.12) and 53% of the funding per capita in Scotland.

5.1 Introduction

In the following section we have provided an overview of the total amount of HSC R&D funding 2008 – 2011, in the fields of Cancer, Diabetes and Mental Health, as well as an over of the total number of research projects which have been funded.

The table below provides an overview of the amount of funding awarded in each research areas and the total number of research projects funded.

Table 5:1: Research projects funded by HSC R&D

Research area	Number of funded research projects	Total number of Principal Investigators	Total funding
Diabetes	49	26	£10,386,137.00
Mental Health	35	25	£8,367,630.00
Cancer	100	57	£21,946,982.00
Total	184	108	£40,700,749.00

The following tables provide a breakdown of each health category and illustrate those projects active and complete.

Table 5:2: Number and status of Diabetes projects

Diabetes		
Active		6
Complete		43
Research type	PhD/Fellowship/Studentship	19
	Other research projects	30

Table 5:3: Number and status of Mental Health projects

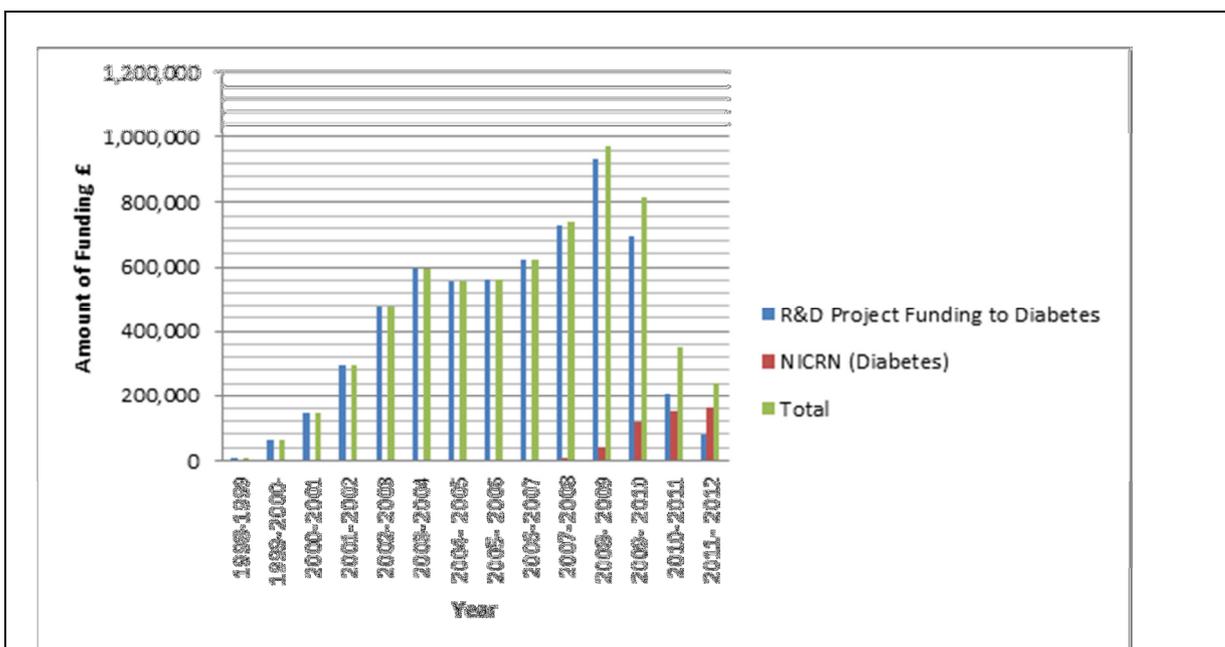
Mental Health		
Active		14
Complete		21
Research type	PhD/Fellowship/Studentship	12
	Other Research Projects	23

Table 5:4: Number and status of Cancer projects

Cancer		
Active		30
Complete		70
Research type	PhD/Fellowship/Studentship	42
	Other Research Projects	58

5.2 HSC R&D Funding for Diabetes 1998-2011

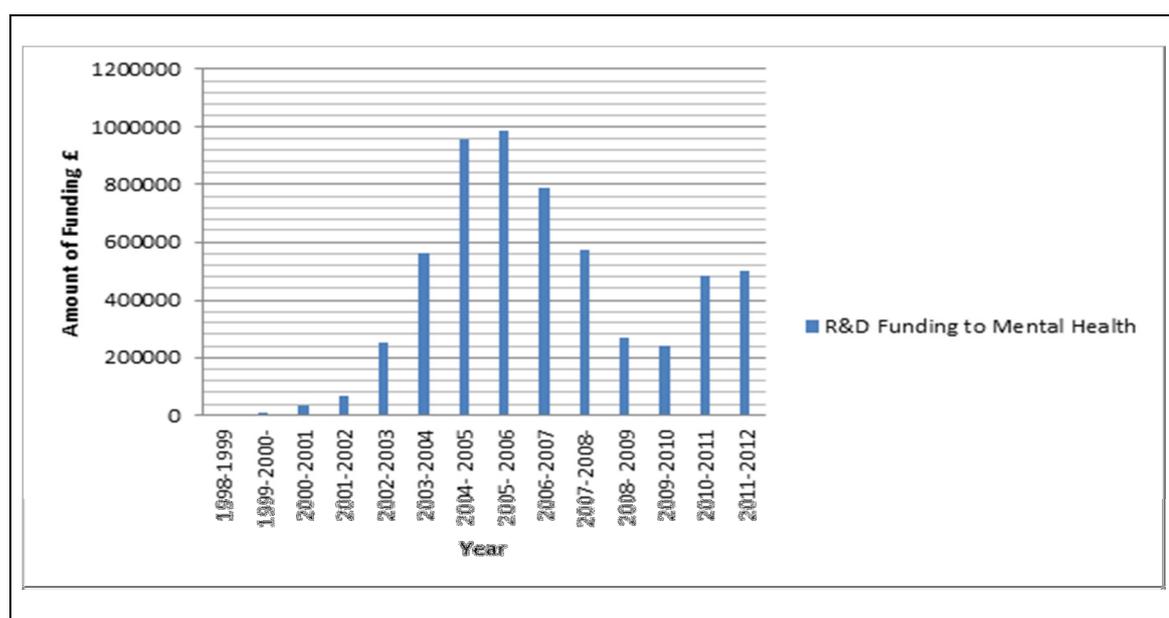
Figure 5:1: Funding and Expenditure in relation to Diabetes R&D



From 1998 to-date on average 5% of total R&D funding has been spent on Diabetes research and development. The financial years 1999/00 and 2000/01, saw the highest percentage spend on Diabetes with each representing 9% of total R&D spend. Over the past three years, the total percentage spend on diabetes has been decreasing from 5% in 2009/10 to 1% in 2011/12.

5.3 HSC R&D Funding for Mental Health 1998-2011

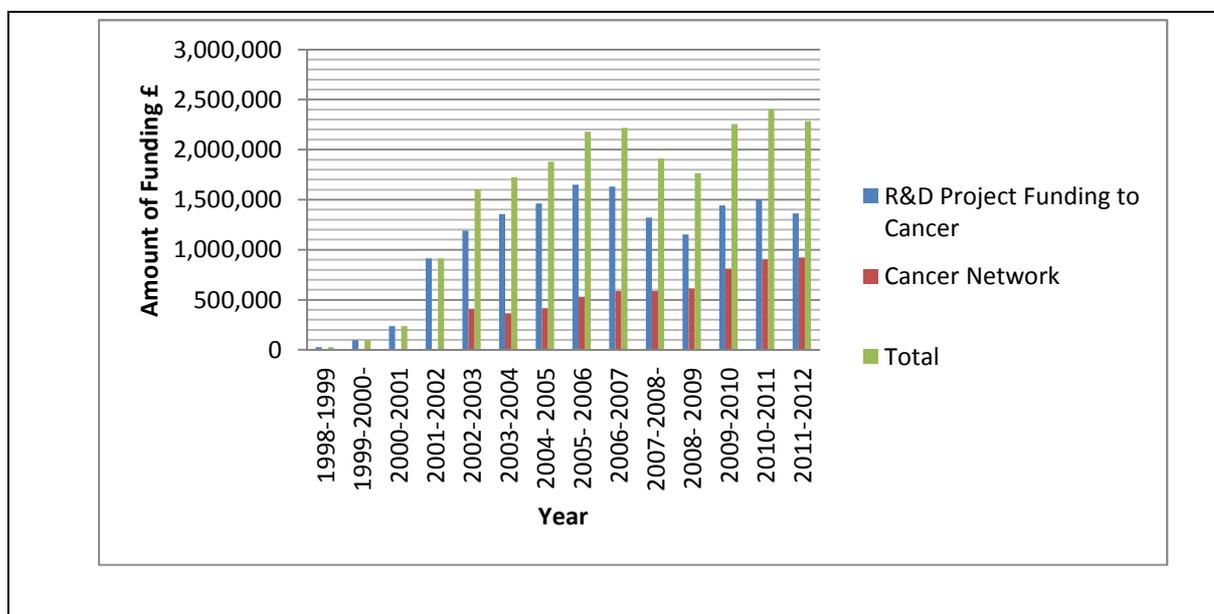
Figure 5:2: Funding and Expenditure on Mental Health R&D



From 1998 to-date on average 4% of total R&D funding has been spent on Mental Health research and development. 2004 – 2007 saw the highest percentage of R&D funding spent on Mental Health **representing** a total of 24% over the three years. Subsequent to this, funding in this area continued to decrease with only 1.8% of total R&D funding spent in this area in 2009/2010. Recently, in 2010/11 and 2011/12 funding has since increased to 4.1% and 4.8% respectively.

5.4 HSC R&D Funding for Cancer 1998-2011

Figure 5.3: Funding and Expenditure on Cancer R&D



From 1998 to-date on average 14% of total R&D funding has been spent on cancer R&D. The highest percentage of R&D spend was during the year 2001/02 where 22% was allocated to this research area. From 2003/04 – 2006-07 funding steadied out at 14% of total R&D spend, followed by a slight decrease to 9% in 2008-09. In recent years funding has increased to around 13% of total R&D spend.

5.4.1 R&D spend per capita by UK Health Departments

The total HSC R&D budget has increased from £192,016 in 1998 to £10,288,308 in 2011, having reached a peak of £13,537,522 in 2008.

The implementation of the Culyer Report enabled the establishment of a single R&D Fund for Health & Social Care in Northern Ireland. The transfer of R&D funds from across the sector was implemented over a period of some five years. The annual total fund reached in its peak in 2008-09. During the Comprehensive Spending Review period 2006 – 2010, the Fund in Northern Ireland was boosted by £1M from the Regional Innovation Strategy of the Department of Enterprise, Trade and Investment. However, between 2008 and 2010 the fund decreased by over £3M, leading to a significant downturn in expenditure locally.

This pattern contrasts significantly with the same period in each of the other UK regions where their Health departments effectively doubled the fund for health research.

Given the complexity of the funding environments and the range of organisations involved it is difficult to give an accurate overview of how the HSC R&D budget compares to other GB regions.

However, we do know that that the research budget for the National Institute for Health Research in England was £921 million in 2010/11

Table 5:5: Research funding per capita

Region	Research budget £m (2010-11)	Population (million)	Funding per capita (£)
NI HSC R&D	11.82	1.79	6.57
NISCHR (Wales)	43.62	3.04	14.35
CSO (Scotland)	64.60	5.28	12.23
NIHR (England)	921	60.62	15.12

Sources: ONS population estimates (2010); NIHR Annual Report; HSC R&D and correspondence with CSO and NISCHR

As shown above the total per capita health and social care research budget is significantly less - up to a factor of 2.3 times less - in Northern Ireland than elsewhere in the UK. Even at its peak in 2008 the total HSC R&D budget in Northern Ireland equated to around £7.63 per capita, less than 50% of what is available in England. For the 2011-12 financial year the NI budget was decreased to just under £10.3 million, £5.75 per capita. No significant decrease has been reported by any other country. As part of the Spending Review announcement in 2010 the commitment given for England was that 'The Department of Health, through the NIHR and the DH Policy Research Programme, will increase spending on health research in real-terms over the spending review period'.

6 SURVEY

Summary

Given the relatively long period of time which this evaluation covers (14 years), it is not realistic to expect a 100% response rate, as researchers have retired, moved on, died or, were otherwise non-contactable. Surveys were returned for 50% of projects which were deliverable, representing 52% of the total amount of funding issued to the three research areas.

The funding helped to support 57 post graduate qualifications (32 of which were PhDs) and 81 individuals to progress further in their careers. This is important as it contributes to the development of research capacity within Northern Ireland and workforce development.

The results relating the health and health sector impacts were less clear, as 10% of respondents noted that it was too early to say if their research had any impacts on the health of individuals or the health service.

Overall the results relating to the economic impact of the funded research were very positive in that 110 jobs were supported and an additional £53 million was leveraged. The amount of leverage generated by the projects equates to around £4.14 per £1 invested. 60% of respondents noted that the HSC R&D support had a considerable influence of the acquisition of further funding.

In this section we summarise the methods and findings of the survey that was issued to Principal Investigators (PIs).

6.1 Survey Method

The project team developed a survey based on the Buxton and Hanney Payback Framework Model (see Appendix 1). The aim of the survey was to gather more detailed data on what the funding was used for and the outcomes of the funding.

The PHA Research and Development Office provided details of all Cancer, Diabetes and Mental Health funded projects from 1998-2011. Of 184 funded research projects (49 for diabetes; 35 for mental health; and 100 for cancer), contact details were available for 108 lead researchers (termed Principal Investigators, PIs). The project team then issued an email with a link to an online version of the survey to all contacts provided. The email also provided the title and the amount of funding provided by HSC R&D of the research projects in question. PIs were asked to complete the survey within four weeks; a reminder email was issued during weeks three and four.

6.2 Response Rates

As a small number of PIs had moved on, retired or died it was not possible to contact all the PIs for 15 of the 184 projects³⁶. Therefore, 169 surveys were deliverable. Responses were received for 84 projects, a rate of 50%.

The following table provides an overview of the survey responses by research area.

³⁶ Of these 15, 8 were under the cancer category, 4 were diabetes and 3 were mental health.

Table 6:1: Overview of Survey Responses

Research Area	Total number of surveys issued	Total number of surveys completed	Total response rate
Cancer	92	51	55.4%
Diabetes	45	20	44.4%
Mental Health	32	13	40.6%
Total	169	84	49.7%

6.3 Knowledge

The key element of knowledge generation is the range of activities that were undertaken to disseminate research findings; this would include publications, presentations and other publicity activities. Each year PIs are required to provide HSC R&D Division with details of publications relating to their funded project, as such this evaluation did not particularly focus on this area of activity. Respondents were however, asked to indicate the range of activities they engaged in to disseminate research findings.

In total 44% (n=37) of respondents completed this question. The following table summarises the responses of PIs who said they undertook dissemination activities.

Table 6:2: Number of dissemination activities that utilised research undertaken

Activities	Cancer	Diabetes	Mental Health	Total
Presentations / Conferences	8	4	3	15
Publications / Reviews /Reports	12	4		16
Study Day	1			1
Workshops	1		1	2
Part of Large Consortium		1		1
Collaboration with others in the field			1	1
Press and Media			1	1
TOTAL	22	9	6	37

6.4 Benefits to Future Research

In this section we consider the extent to which the research capacity within the sector has been developed as a result of the funding. This includes qualifications gained and experience gained. In order to assess the extent to which experience and understanding of research staff has developed as a result of the project we asked PIs to provide details of career progression of the research team.

6.4.1 Jobs Supported

Another key element of the economic impact of the HSC R&D funding is the number of jobs supported via the funded research projects. The survey asked respondents to provide details of the number of posts supported and the job title of funded posts. The following table provides an overview of responses.

Table 6:3: Jobs Supported

Job Category	Cancer	Diabetes	Mental Health	Total
Research Fellow / Clinical Research Fellow	10	8	10	28
Research / Statistician Position	3	-	-	3
Research Nurse / Research Midwife	7	5	2	13
Research Fellow / Senior Clinical Research Fellow	10	8		
Clinical Specialist	2	-	-	2
Post-Doctoral Research Fellow / Research Assistant /Scientist	11	3	-	14
PhD Studentship / Fellowship	6	3	1	10
MD fellowship	2	2		5
Secretary/admin	2	-	-	2
Research Technician / Tissue Procurement Technician	3	2	-	5
Research Assistant / Associate	7	4	10	11
Lecturer	-	1	1	2
Medical Trainee	-	-	2	2
Other/not stated	12	1	3	12
Total	62	29	19	110

Other responses included:

- Laboratory Assistant;
- Principal Investigator;
- Student, Biomedical Scientist;
- Research radiographer;
- Tumour verification officer; and
- Postgraduate Scientific officer.

98% of respondents completed this element of the survey. As shown in the above table 110 jobs were supported at an average of 1.3 jobs per research project.

The range and variation of types of jobs supported demonstrates the vast impact of HSC R&D funding across the health and academic sector. While some are relatively senior posts and therefore have the

potential for their research for to be applied more directly within the health system, others provide a crucial but informed support role within this sector. It should also be noted that the level and description of the jobs noted in the above table are a direct reflection of responses to the survey and may not be an accurate reflection of what was actually funded, for example HSC R&D does not fund lecturer posts, however it will fund a proportion of a lecturer's salaries to allow them to undertake research.

6.4.2 Qualifications gained

The support of students to complete qualifications via research is an important aspect of increasing expertise and capacity within the research sector. In the following table we have set out the qualifications gained via the responding projects.

Table 6:4: Qualifications Gained

Qualifications	Cancer	Diabetes	Mental Health	Total
	No.	No.	No.	N
Studying for / Received PhD	21	8	10	39
Masters / MSc / MPH /M.Phil.	3	3	3	9
MD	8	8	2	18
Total	32	19	15	66

As shown in the above table, 66 individuals gained qualifications as a result of the HSC R&D funding. The support given to students to complete qualifications by research was regarded as very important to developing research capacity within Northern Ireland and to attracting further funding in the future; this is discussed further in upcoming sections of this report.

6.4.3 Career Progression

The UK Clinical Research Collaboration (UKCRC) noted that in any area of health the factors that can influence the amount of research activity include scientific opportunity, size and quality of the research workforce, the extent to which the specific issues are traceable (or researchable), the burden of disease and the level of charity fundraising. As such the qualifications gained and the career progression that has been supported through HSC R&D is an important element of the size and quality of the R&D workforce and the overall levels of research activity.

The following table summarises the responses relating to the career progression of individuals working in the research projects.

Table 6:5: Career Progression

Research Area	Number of responses stating a progression	% that stated a progression	Number of individual progressions
Cancer	31	61%	48
Diabetes	15	75%	23
Mental Health	6	46%	10
Total	52	62%	81

As shown above 62% of respondents noted that the careers of those working on the research projects advanced because of the HSC R&D funding. This related to 81 individuals. Examples of career progression provided by respondents included:

- Specialist registrar to clinical specialist;
- PHD Student to post-doctoral researcher;
- Research Fellow to Registrar; and
- Research Fellow to permanent NHS post.

6.5 Informing Policy

Respondents were asked to indicate if, in their view their research had impacted on policy development.

Table 6:6: Impact on Policy

Research Area	Yes	No	Don't Know	TOTAL
Cancer	8	34	9	51
Diabetes	3	15	2	20
Mental Health	5	6	2	13
Total Overall	16	55	13	84

Therefore, as shown above, 19% of respondents noted that the findings of their research had informed policy, 15% did not know.

6.6 Health and Health Sector Benefits

One of the primary reasons for undertaking research within the health sector is to investigate ways to achieve better health outcomes for individuals and/or to improve health service delivery. As such PIs were asked to indicate if their research impacted upon the health of individuals and/or health services.

Table 6:7: Health and Health Sector Benefits

Health Impacts	Cancer		Diabetes		Mental Health		Total	
	% of respondents							
	Yes	No	Yes	No	Yes	No	Yes	No
Increased length and / or quality of life	14	26	4	15	2	6	20	46
Improvements in Service Delivery	12	30	0	20	2	6	14	56
Cost Reduction in the delivery of existing services	10	29	1	18	2	7	13	54
Equity (e.g. better targeting and service accessibility)	12	31	1	18	4	6	17	55
Other	5	21	0	12	1	4	6	27

As shown in the above table, 20% of respondents noted that their research increased the length or quality of life and 17% of PIs noted that their research impacted upon equity of health services. 14% of respondents said that their research had a positive impact on improvement in service delivery. Whilst the majority of respondents noted that their research has not had an impact on the health of individuals or health services, 10% of respondents noted that it is too early to identify the health impacts of their research. The 2007 strategy ‘Research for Health and Wellbeing 2007-2012’ also noted that the ‘most challenging aspect is recognising the incremental nature of the research process and the time lags between discovery and application’³⁷.

Some examples of reported health and health sector benefits included:

“The work has shown fundamental molecular events involved in evolution of colorectal cancer. While we have gained a better understanding of the process, we do not as yet have a strong risk classifier.”

“We have identified new risk factors for kidney failure which are now being studied in follow-up projects. The immediate clinical benefits of [the] research include a much greater awareness of the importance of diabetic nephropathy as a public health problem.”

“There have been improvements in quality of patient surgical outcome and in surgeon confidence (but not formally measured).”

³⁷ Research for Health and Wellbeing 2007-2012, DHSSPS, 2007.

In addition, the annual and final reports on their projects provided by PIs to HSC R&D contain a wealth of specific indicators of beneficial impacts for the population, for patients and for care. These include:

“Through genetic analysis, clearer identification of the patients who can benefit from specific chemotherapy drugs. Such tests also indicate the patients who would be unlikely to benefit, thereby saving the costs of drugs and any possible side-effects of the unnecessary treatment.”

“The identification of genetic variants that are significantly associated with other biochemical indicators of cancer. These can decrease the inconsistencies in outcomes and treatment decisions associated with single indicators alone.”

“Improved ability to distinguish the cellular changes that are specific to cancer from those that accompany healthy ageing.”

“The ability to lower the risk of chronic diseases by identifying behaviours that might be modified, e.g. dietary changes or exercise.”

6.7 Economic Benefits

There are two main factors which can be used to indicate the economic impacts of the research, that is jobs supported and the amount of additional funding attracted. In the following tables we have presented the analysis of the survey findings in relation to economic benefits. This information has been supplemented further by any available information from local Health and Social Care Trusts relating to the economic impacts of participating in clinical trials.

6.7.1 Additional funding

32% of respondents provided data on the total project costs and the amount of additional project funding provided from other sources. In the following table we have summarised this data based on survey responses.

Table 6:8: Direct additional project funding

	Total HSC R&D Funding	Total Project Costs	Additional direct project funding	Percentage of project costs covered by HSC R&D	Number of Projects
Cancer	£6,930,776	£13,517,713	£6,586,937	51%	13
Diabetes	£3,872,944	£7,647,917	£3,774,973	51%	12
Mental Health	£71,504	£1,114,504	£1,043,000	6%	2
Total	£10,875,224	£22,280,134	£11,404,910	49%	27

As shown above an additional £11.4 million of funding was received for the 27 projects for which we have responses, this equates to around £422,000 additional funding per project and a leverage of £1.04 for every £1 invested.

6.7.2 Benefits to the Northern Ireland Economy

Furthermore, PIs were then asked if the research that had been funded by HSC R&D had led to further research and how this further research was funded. 52% of (44) respondents noted that the HSC R&D funded research led to further research funding. Of these projects, 36 provided details of amounts and details of other funders, these projects attracted further funding of over £41 million. In the following table we have noted if this additional funding has been sourced from Northern Ireland, the UK, Europe or, International funders.

Table 6:9: Sources of additional follow-up funding

Location of funder	Number of projects	Total additional funding
NI	7	£590,112
UK	21	£35,445,242
EU	3	£372,839
International	5	£5,548,800
TOTAL	36	£41,956,993

Therefore, as shown in table 6:9, 36 of the 84 HSC R&D funded projects which responded to the survey leveraged an average of £1,165,472 additional follow-on funding each. Of this additional funding over £40 million, was attracted from sources outside of Northern Ireland (three respondents noted the source of their funding but not the amount).

This compares favourably with other studies, such as the survey of the impact of the NHS Health Technology Assessment Programme³⁸, which found that whilst 46% of projects went on to receive further funding the amount of additional funding was just under £200,000 per project.

If this additional £41 million follow-on funding is added to the additional £11.4 million that was leveraged for the 27 projects, analysed in table 6.8 above, this equates to a total leverage of £53.3 million. According to respondents the total HSC investment R&D for both the initial and follow-on projects was £10.8 million, plus £2 million follow-on funding giving a total investment of £12.8 million. This equates to a leverage of £4.14 for every £1 invested, as set out in the following table.

³⁸ *An Assessment of the impact of the NHS Health Technology Assessment Programme. Hanney, S., Buxton, M., Green, C., Coulson, D. and Raftery, J. Health Technology Assessment, 2007; Vol. 11: No. 53*

Table 6:10: Leverage calculation

HSC R&D Project funding	£10,875,224
HSC R&D follow-on funding	£2,001,529
Total HSC R&D funding	£12,876,753
Additional Project Funding	£11,404,910
Follow-on funding	£41,956,993
Total additional funding generated	£53,361,903
Return on Investment = $53,361,9093 \div 12,876,753 = 4.14$	

Much more detailed analysis would be necessary to demonstrate what proportion of this follow-on money was fully leveraged by the original HSC funding.

In addition to the 52% of respondents who noted further project funding a further 17% (15) of responding projects noted that the initial HSC R&D funding led on to further capital investment. Whilst there are only a small number of these projects (15) the level of investment from both HSC R&D and other funders is significant, as shown in table 6:11.

Table 6:11: Additional Capital funding

Funding Organisation	Amount	Number of projects	Location of funder
HSC R&D	£392,453	2	NI
SPUR (Support Programme for University Research supported projects)	£75,000,000	5	NI
SRIF 3 (Science Research Investment Fund)	£660,000	1	UK
FSA (Food Standards Agency)	£969,268	1	UK
CRUK (Cancer Research UK)	£2,000,000	1	UK
INI (Invest NI)	£139,413	2	NI
NIKRF (Northern Ireland Kidney Research Fund)	£92,000	1	NI
MRC	£5,000,000	1	UK
National Disability Authority	£102,839	1	EU
TOTAL	£84,355,973	15	
Without HSC R&D	£83,963,520		

These follow-on capital funding grants leveraged on average over £5.5 million per project. If the follow-on HSC R&D, Invest NI and the DEL SPUR funding is excluded from the analysis, this equates to £8,824,107. Moreover, if NI funding is excluded from the analysis, this means an additional £8,732,107 was invested into Northern Ireland from external funders.

The SPUR grants noted in the above table were provided by the Department for Employment and Learning (DEL) to support the capital development of the Northern Ireland Cancer Research and Cell Biology (CCRB). Consultation with key staff indicated that whilst the initial funding provided by HSC R&D was relatively small within the larger funding pot, a cocktail of funding was required to establish the physical infrastructure. The HSC R&D funding helped to develop the research capacity that was a key element in attracting other funders.

Respondents were also asked to indicate how important the HSC R&D funding was in securing funding from other sources. 69% of PIs responded to this question as summarised in table 6:12.

Table 6:12: Importance of HSC R&D in securing additional funding

Importance of HSC R&D project to securing later funding			
Research Area	Small	Moderate	Considerable
Cancer	5	4	28
Diabetes	1	3	9
Mental Health	0	3	5
Total	6	10	42

As shown in the table above, 60% of those who responded to this question noted that the HSC R&D funding had a considerable influence on attracting additional funding from other sources. However, much more detailed analysis would be necessary to demonstrate what proportion of this follow-on money was fully leveraged by the original HSC funding.

6.7.3 Clinical Trials

The Northern Ireland Clinical Trials Network was established by HSC R&D to facilitate and co-ordinate the participation in clinical trials across the five HSCTs in Northern Ireland (as will be discussed in more detail in a later section). The Northern Ireland Cancer Trials Network (NICTN) which is also resourced by HSC R&D undertakes this role for clinical trials relating to cancer.

7 CONSULTATIONS

Summary

There was generally high regard for the HSC R&D funding and the staff within HSC R&D. All consultees noted the high levels of leverage that was gained from the HSC R&D funding and its importance in 'pump priming' HSC research. It was also recognised that the level of support that HSC R&D can provide to the sector is constrained due to its limited budget and that the sector itself is further constrained due to the inability of Northern Ireland to participate in highly-relevant funding streams that are available to the rest of the UK.

HSC R&D has fully or partially funded a relatively large number of high quality research posts within Northern Ireland. In addition to the economic benefits associated with these posts, the funding has allowed universities, HSC Trusts and research centres to maintain and attract a body of highly experienced and qualified staff, which is crucial to the continued development of the sector.

There have been a relatively large number of high quality posts that have been supported through the HSC R&D funding directly and indirectly. This has been through posts that have been fully funded or research projects which have been part funded and have been able to attract more funding. These posts are for experienced and highly qualified researchers.

It was recognised among a number of consultees that high quality research should be at the core of policy development and that research is needed to evaluate the effectiveness of policies.

Most consultees agreed that there appeared to be a 'bottle neck' from research to the translation of findings into policy or services.

It was generally recognised that not all health sector organisations have a strong research culture and that more needs to be done to ensure that research becomes embedded within organisations, while some consultees suggested that HSCTs should have targets relating to research. A few consultees noted that they were concerned that R&D generally has a low profile across the health and social services in Northern Ireland and there should be stronger links between R&D and those responsible for the development of policies within the Trusts and the DHSSPS.

In order to provide a more detailed understanding of the importance of R&D within the health sector generally and to gather more qualitative evidence of the impact of HSC R&D funding we undertook a consultation exercise with a wide range of key stakeholders who have a detailed understanding of the health sector R&D in Northern Ireland:

- the three areas of research (cancer, diabetes and mental health);
- Public Health; and
- Private Sector leverage and investment.

Appendix 5 provides a list of all those who were consulted (27 individuals in total).

Each consultee was contacted and asked to participate in the research and each consultation broadly followed the five categories of the payback framework. In addition, consultees were asked to comment on the extent to which the HSC R&D funding facilitates collaboration with other researchers and research bodies and barriers that exist in undertaking research and translating research findings.

7.1 Consultation themes

A number of themes have been emerging from the consultation process, they can be categorised under the following headings:

7.1.1 Economic

It was noted that whilst the HSC R&D funding is often a small element of the overall funding required, particularly for long-term or large infrastructure projects, it is often vital in leveraging funding from other sources. It was noted that the peer review, quality assurance role that is undertaken by the HSC R&D Office when making funding decisions is important to other funding bodies and the perception was that the HSC R&D Office support was regarded as highly as Medical Research Council funding among other funders.

It was the perception among those who were consulted with that the HSC R&D Office “punches above its weight” in that it leverages much more funding than it could ever provide.

There have been a relatively large number of high quality posts that have been supported through the HSC R&D funding directly and indirectly. This has been through posts that have been fully funded or research projects which have been part funded and have been able to attract more funding. These posts are for experienced and highly qualified researchers.

The support in the development of the research infrastructure was also seen as important in attracting the best people to these posts and maintaining high calibre researchers in Northern Ireland.

There was a perception among many of those interviewed that much of the research that is being undertaken, particularly in biomedical sciences has commercial potential which is not being fully exploited. A few barriers to commercial exploitation were noted by consultees, lack of time from key clinical and research staff to provide any further input following the initial research phase. The EU regulations on undertaking clinical trials are applied consistently across the UK and a range of Government initiatives are ensuring that they are compatible with attracting biotechnology and pharmaceutical companies to set up clinical trials. In a very small number of cases, trial sponsors wish to engage in contracts under English law; this requires time for the other UK countries to negotiate a solution. Consultees from the HSCTs noted that the timescales associated with research governance within the Trusts are currently being addressed through a Trust wide co-ordinated initiative. Interestingly, a 2010 publication that looked at R&D permissions across the UK and Ireland stated that ‘Local R&D approval was both quick and timely for the 150 NHS Trusts in England. Local R&D approval was similarly quick in Northern Ireland and the ROI, but not as timely. Scotland was slower, but timely relative to Scottish Research Ethics Committee (REC) review. Wales was neither quick nor timely. SwiFT commenced in 192 (64%) acute hospitals in 158 organisations. Participation varied across countries: 76% (Scotland), 72% (England), 44% (Northern Ireland), 38% (Wales) and 19% (ROI).

A number of consultees, particularly those who have been engaging with private sector companies noted that the research sector in Northern Ireland is generally regarded as world class and has attracted a large number of private sector companies and philanthropic organisations to invest in research in Northern Ireland. The presence of key individuals within the R&D sector was generally regarded as vital to attracting this income, as private sector companies often approach individuals

directly, if they are regarded as leaders in their field. The support from the HSC R&D funding is a key element of this as it has allowed individuals to lead investigations which have raised their own profile and that of Northern Ireland.

A number of consultees noted that the support provided by the HSC R&D which allows HSC Trusts to participate in trials allows the Trusts to generate savings as all treatment costs are covered during the trial. Whilst it was outside the scope of this study to calculate these savings a number of consultees believed that these could be substantial.

7.1.2 Knowledge production and research targeting and capacity building

The support provided to students to undertake fellowships was highly regarded. The research undertaken as part of a fellowship is often exploratory or early stage research which can lead to more in-depth research or better targeting of future research. The fellowships are regarded as prestigious and generally speaking only the highest calibre of graduates are provided with an HSC R&D fellowship therefore the standard of research undertaken as part of a fellowship is generally high. In addition the support given to students to complete fellowships has helped the career progression of many researchers.

Many of the larger funded research projects particularly in biomedical sciences do not tend to impact upon service delivery, health outcomes or health policy for a very long time. Therefore, whilst they provide greater knowledge, the users of that knowledge tend to be other researchers in the short to medium term.

Many consultees noted that dissemination/knowledge transfer could be carried out better. Dissemination of research findings was seen as very important among those consulted with, not only to increase knowledge across the research and health sector, but also to raise the profiles of Universities, research centres and researchers. However, it was noted that once researchers have completed their research and published the findings (most likely in an academic journal), they tend to move on. They are often under pressure to start the next project or applying for further research grants. A number of consultees noted that clinical investigators, are often extremely busy and are least likely to have the time or support to disseminate findings further than an academic journal or within their own organisation. Potentially more support could be provided to researchers to ensure that their findings are disseminated at an appropriate level to maximise their impact.

It was clear from the consultations that stakeholders in the various sectors required different outcomes from the research findings. For example, for academic researchers the priority format of dissemination is usually high impact or prestigious journals, not least due to the Research Excellence Framework (REF) ratings associated with prestigious publications. Many key stakeholders in policy making or service delivery roles viewed publications in peer reviewed journals as a secondary outcome.

7.1.3 Policy, Practice and Product Development

Those who were consulted with who were responsible for the development or implementation of policy within the health sector highlighted the need for high quality research evidence to shape and inform policy development and also research is needed to understand the impact of effectiveness of policy. Trust staff also noted that research findings should be used to inform not only how services are delivered but also to guide the audit and evaluation of current services. There was a perception

amongst some of those consulted with that R&D is too distant from policy development and that good quality research should be at the heart of informing policy direction.

Many of those consulted with noted that biomedical sciences research can take a long time to get to the stage of product development or to have a proven effect that will influence policy, therefore for these projects there are no direct policy or product development impacts for a number of years. However, a small number of projects which have received HSC R&D funding are at the stage of seeking patents and are receiving support from Invest NI in this respect.

HSC R&D has supported the development of the infrastructure which allows HSCTs to participate in clinical trials, in the form of support to the Northern Ireland Clinical Trials Network and the Northern Ireland Cancer Trials Network. Whilst Trusts can generate income from these trials, the findings and results from commercial studies will go to the research sponsor (the company paying for the trial) and may never be known to the Trusts. Furthermore, it can take many years for pharmaceuticals and other therapies that have been trialed to be accepted by the National Institute for Health and Clinical Excellence (NICE) and be available for clinicians to prescribe. Therefore whilst the HSCTs may participate in clinical trials the impact of the trials in terms of prescribing policies or service delivery may not be seen for a number of years.

7.1.4 Health and the Health Sector

A small number of the consultees interviewed were able to identify a direct or indirect impact on health and / or the health sector as a result of the HSC R&D funding. For example indirect impacts were noted in the delivery of cancer treatments due to the infrastructure support that is provided to the Northern Ireland Cancer Trials Network. Following clinical trials undertaken by the network, women with breast cancer are now treated over a period of three weeks instead of five. This has created significant savings to the health service and patients benefit from having shorter treatment timescales.

There was a general agreement among those who were consulted with that more could be done to ensure that research findings were translated into improvements in health and health service delivery, although there were no specific suggestions on how this could be achieved. One issue that was noted by several consultees was that clinicians do not have protected time to undertake research (unless they apply for and receive research funding). Often clinicians are also best placed to identify specific research questions relating to the health of patients and service delivery. It was suggested that by supporting clinicians to undertake research specific health service impacts could be achieved more directly. Support could be making it easier for clinicians to apply for funding or making them more aware of the range of funding options that are available to support research.

One consultee noted that as a direct result of their HSC R&D funded research they have influenced clinical practice; their research led to the development and dissemination of practical clinical guidelines for the management of chronic kidney disease, and this was supported by improved education for medical students, nurses and junior doctors on diabetic kidney disease.

All of the consultees who were involved in health service delivery noted that the time taken to transfer research findings into changes to therapies or health service delivery is too long. Whilst it was recognised that HSC R&D provides support for translational research, a number of consultees referred to a 'bottle neck' in implementing findings. A number of those who were consulted with believed that this is partly due to the lack of a research culture within all statutory health organisations and the

apparent disconnection between research and those who responsible for making policy and planning services. Examples of this included the reporting structures within the Trusts where research staff do not report directly to Chief Executives.

7.1.5 Collaboration

Collaboration is an important element of health research, it not only allows researchers to access different sources of funding but it also allows the implementation of large scale regional or national studies and is often necessary to answer specific research questions. During the consultations PIs were asked about the extent to which HSC R&D funding facilitated collaboration and how important that collaboration was to their research or research institution. All of those who were consulted with who were actively involved in delivering research noted the need to collaborate to deliver meaningful research (such as access to large numbers of patients).

A number of consultees noted that collaboration is becoming more important to a range of funders in order to demonstrate the additionality of the proposed research and that the relevant stakeholders in the sector are engaged.

All of those who had been involved in collaborations at various levels noted the importance of the support provided by HSC R&D to facilitate this. The support ranged from providing funding to allow researchers to collaborate in UK or national studies and networks, the development of partnerships with research centres in the Republic of Ireland (ROI) or, facilitating collaboration among researchers in Northern Ireland.

Collaboration was seen by many of those consulted with as an important element of raising the profile of the Northern Ireland R&D sector. Being part of a larger or multi- centre study can build the reputation of local researchers and help to develop their careers. Participating in collaborative studies can also provide access to international experts, which can strengthen the study and attract further research projects and associated funding.

A number of consultees also noted the support they received from HSC R&D in the development of international networks to facilitate collaboration.

7.1.6 Barriers and other issues

This inability of Northern Ireland-based researchers to apply to the NIHR programmes that are managed on a UK-wide basis (termed NETS programmes, described in Section 3) was seen by respondents as a major constraint to research activity in the province. All of those who mentioned this believed that if Northern Ireland could meet its required contribution they would be able to attract a greater sum. A small number of consultees also noted that they believed that lack of access to those programmes has deterred senior and experienced researchers from taking up posts in Northern Ireland as lack of access to the funding available through the NIHR would curtail their research activities in the future and therefore ultimately their career progression.

A number of those who were consulted with from both academic and HSCT backgrounds noted that research was not a priority within many organisations and that many key stakeholders in the health sector did not fully engage with research or see its benefits. This was notable within the HSCTs where R&D staff are often physically distant from other administrative staff, located in annexes or offices at the far edges of the Trust estate.

Also Directors of Research within the Trusts do not report directly to Trust Boards, (reporting on R&D within Trusts is via Medical Directors) and Trusts do not have R&D targets.

It was recognised among the HSCT staff who were consulted with that the structures, processes and procedures required to deliver meaningful and effective research within the Trusts are only starting to emerge following the Review of Public Administration (RPA) and the culture of engaging in research and with researchers is starting to become embedded within the Trusts. The support provided by the Northern Ireland Clinical Research Network (NICRN) was seen as key in this, by allowing the Trusts to participate in larger regional or national studies that would not have happened otherwise.

Therefore, the historical lack of research culture within some Trusts and other key organisations, the lack of targets for R&D activities and the physical location of research staff appear to have contributed towards a disconnect between policy and service planning and research and development.

A number of those who were consulted with recognised the importance of the support provided by HSC R&D to develop the research infrastructure in Northern Ireland and how this infrastructure has now allowed a number of large scale studies to be implemented that have attracted large amount of funding from other sources. However, there were generally high levels of agreement amongst consultees that now the infrastructure is in place, future funding plans should now prioritise research projects or programmes. However, what was not clear from the consultations is that the costs associated with developing the research infrastructure are almost exclusively staff costs. These staff have been put in place to facilitate the ongoing development of R&D within health and social services sector. As such these costs are recurrent and not 'one off' funding payments.

Whilst all consultees recognised that the budget that is available for R&D in Northern Ireland is relatively small which limits the scale and range research that can be undertaken, a number of consultees also believed that the HSC R&D policy was also very restrictive in what in what type of research it will fund. The HSC R&D strategy was set in 2007 and provided the framework for funding for the next five years. A small number of consultees noted the perception that because funding allocations were agreed in 2007 there was very little room for manoeuvre to fund projects that were not proposed at the time of the strategy development. However, consultations with HSC R&D staff noted that whilst the strategy was designed to be as flexible as possible, which would allow funding to be allocated to research as issues emerged the cuts in the budget made it increasingly difficult to be as flexible as they would like.

Staff from the HSCT Research and Development Offices noted that the discretionary funding provided by HSC R&D was vital in helping to undertake research to investigate emerging issues and that it should be extended to allow more flexibility.

A large majority of those who were consulted with noted the lack of protected time to allow consultants to undertake research. It was noted that clinicians are often best placed to identify areas which require further investigation. However, the vast majority of clinicians are employed to undertake clinical work 100% of the time, which allows no time to undertake research. A small number of those consulted with were consultants who were also undertaking research and they noted the difficulties in maintaining momentum for the research and finding time to disseminate the findings once the research is completed. All of the HSCT staff consulted with noted that consultants should have some protected time to undertake research (if required). It should be noted that consultants are entitled to apply for research funding (with approval from their Trust) which would allow the protected time to

undertake research. Feedback from consultees would indicate that there is a lack of awareness among clinical staff of this process.

An important issue for academic researchers is that HSC R&D funding counts as prestigious income and contributes towards REF ratings for the university. Local universities are competing against other UK universities who have access to the NIHR funding which also contributes toward RAE/REF ratings. As researchers in Northern Ireland cannot directly access NIHR funding this places even greater importance on the HSC R&D funding.

8 CASE STUDIES

8.1 Introduction

Whilst it is recognised that three case studies cannot be fully representative of all the HSC R&D funded projects, they provide good examples of the incremental nature of the impacts associated with research within the Health and Social Care field. The case studies also demonstrate the diversity of activities that are supported by HSC R&D. The case studies also demonstrate how the initial research, funded by HSC R&D helps to target future research, which, as noted in section seven is often funded by other funders who are external to Northern Ireland.

In order to provide a more detailed overview of the full range of impacts from HSC R&D funding three case studies were undertaken. Case studies are often a useful tool to demonstrate qualitative impacts of research and can provide a more robust overview of the impact of research than questionnaires alone.

Whilst it is recognised that three case studies cannot provide a representative sample of the 184 funded projects, it was agreed that the chosen case studies should provide examples of the range of outputs and impacts derived from the HSC funding. The case studies provide an example of the funded activities and impacts associated with:

- Research infrastructure;
- Health and Social Care Trust Research; and
- Clinical research.

Principal Investigators (PIs) were invited to undertake a detailed interview with members of the evaluation team. Each interview followed the structure of the Payback Framework using a standardised interview pro forma. In the following paragraphs we have summarised the findings of each case study.

8.2 Case study 1: Northern Ireland Clinical Research Network (NICRN)

8.2.1 Background

The NICRN was chosen as a case study as it is a good example of how the HSC R&D funding has been used to develop the research infrastructure across Northern Ireland. The Northern Ireland Clinical Research Network (NICRN) was established in 2006 to support the contribution of the clinical research community in NI to the work of the UK Clinical Research Collaboration (UKCRC) and the associated UK Clinical Research Networks (UKCRN) by facilitating the delivery of high quality clinical trials and other clinical research across the Trusts in Northern Ireland. The main activities of the NICRN are to:

- Maintain a portfolio of network studies;
- Assist with processes involved in setting up a study, in particular ethical, regulatory and local research governance approval for clinical trials;
- Facilitate Training & Education; and
- Ensure that research opportunities are maximised within available resources.

The NICRN comprises of ten special interest groups, each headed by a prominent, specialist clinician, they are:

- Critical Care;
- Child Health;
- Dementia;
- Diabetes;
- Heart Disease;
- Primary Care;
- Renal
- Respiratory medicine;
- Stroke; and
- Vision.

A Mental Health interest group is also currently being established and is expected to be formalised by late 2012. Each interest group has two main roles:

- To recruit and manage the care of patients enrolled on clinical studies; and
- To provide scientific direction by choosing and/or designing studies that will be run by that group.

As the Northern Ireland Cancer Trials Network existed before the NICRN, they are structured, funded and reported on separately.

8.2.2 Inputs

The NICRN received £5,501,043 in funding from HSC R&D from 2006/07 to 2011/12 (an average of £916,840 per annum). The NICRN has a total of 44.5 WTE staff (as of April 2012), including research nurses to support participation in clinical trials in all five NI HSCTs.

8.2.3 Outputs

The NICRN parallels and interacts with similar Clinical Research Networks UK-wide. This approach was a national strategic decision taken by the UK government and the associated Departments of Health to ensure a quality based approach to undertaking R&D within the broad NHS family. This also allows clinicians (and therefore patients) in Northern Ireland to have access to new and experimental treatments that may not have been available across the UK and Ireland.

The ability of Trusts in Northern Ireland to participate in clinical trials is important for a number of reasons. Firstly, it provides patients in Northern Ireland the opportunity to access the latest treatments that are available across the UK and Ireland and therefore they provide an important equality of access role. Also in compliance with Health Service Guidance 97, when clinical trials are being sponsored by a private sector company such as a pharmaceutical company, it is the responsibility of the HSC organisation to ensure full cost recovery. That is to say that any and all action defined as non-standard care must be accounted for and funded by the commercial partner i.e. the company pays for the treatments that are being trialed, for example the drugs. This means the Trust where the study is being undertaken is not required to provide the pharmaceuticals that would have been used if the patient was not on the trial, therefore the Trust is saving on the cost of treatment. In addition to this the Clinical Research Nurses that monitor the patient during the trials are directly resourced via

the NICRN and are paid for by HSC R&D and that the cost of nurse/AHP time, consumables etc. are reimbursed through the commercial funder. Due to the complex nature of prescriptions and other therapies it is outside the scope of this study to calculate the savings to local HSCTs by patients participating in clinical trials, but it is likely to be considerable.

In addition to the savings associated with clinical trials, where the trial is a commercial trial, private sector companies also pay per patient recruited onto the trial. Since the establishment of the NICRN there has been a standardisation of how this income is treated as Trusts are now beginning to establish the financial processes that allows them to ring fence this income which means the income can be re-invested to support further research within the Trust. In the following table we have provided an overview of income reported by the five individual Trusts in relation to Diabetes clinical trials.

Table 8:1 Diabetes Income (2008 – 2011)

Trust	No. of diabetes trials	Income (£)
Belfast	8	1,075,690
Northern	4	14291*
South Eastern	7	68,276
Southern	1	not known
Western	10	68,276
Total	30	1,212,242
* excludes £11,059 of HSC R&D discretionary funding		

As noted in the above table from 2007 to 2011, Northern Ireland health and Social Care Trusts reported over £1.2 million in income from participating in clinical trials in diabetes alone. To date the Southern Trust has not been able to provide information relating to income from clinical trials due to internal financial processes. There is a slight overlap in the data presented in tables 8.1 and 8.2 as some trials were undertaken across a number of Trusts (multi-centre).

In 2011 2,076 patients had been recruited on to 27 diabetes clinical trials, five of these trials were multi-site trials meaning that more than one Trust participated in the study. Fourteen of these trials were funded by organisations located outside Northern Ireland, 10 of which were private sector companies.

Table 8:2: Diabetes Clinical Trial 2008 - 2011

Trust	No. of studies	No. of patients recruited	NI Funded	UK Funded	Private Sector Funded
BHSCT	9	1677	3	3	3
SEHSCT	8	130	1	3	4
SHSCT	1	34		1	
WHSCT	5	201		1	5
NHSCT	4	34	2		2
Total	27	2076	6	8	14

Note: of the 20 studies carried out, 5 were multi-site studies accounting for the differences in total between number of studies carried out and the total number of studies the trusts were involved in.

Feedback from Directors responsible for research in each of the Trusts has indicated that without the support from the NICRN and the research nurses that are provided via the Network they would not be able to participate in clinical trials. Research Directors and other research staff in the Trusts noted that in addition to the research nurses, the support provided by NICRN in relation to research governance and research training was a key factor in them participating in regional studies and leading their own research projects.

Four of the five Trusts were able to provide information relating to the amount of income generated by participating in clinical trial studies.

The ethos of the CRN was to have a combined national approach to undertaking studies across all of UK. Research stakeholders in Northern Ireland have various roles and functions and via attendance at appropriate national platforms and meetings (funded via NICRN). This will result in better managed studies and more efficient delivery of accrual in shorter timeframes. The NICRN clinical leads are expected to attend the national topic and speciality group meetings and it is at this level that new and emerging studies can be discussed and expressions of interest highlighted. This information should come back to local Clinical management groups and for local PIs to be identified who can participate. Participation in National studies has financial implications for participating sites and potential health implications for clients and patients, as they will have greater access to new therapies. However, given the small population numbers in Northern Ireland, it should be recognised that the larger studies are usually led by large, well established English research centres, but by attending national meetings and having a voice all these issues of access at least can be recognised and funders then have a means of trying to address them.

8.2.4 Dissemination

The NICRN is not responsible for disseminating research outputs itself. The findings of commercial studies are usually not publicly disseminated and are only reviewed by the sponsoring company. Clinical leads in each of the interest groups that are facilitated via the network are responsible for the dissemination of research findings. At present the NICRN does not record the dissemination of

activities of each of the special interest groups, however this has been noted as an area under development.

8.3 Case Study 2: Western Health and Social Care Trust

8.3.1 Background

Members of the evaluation team met with staff from the WHSCT R&D unit to discuss the impacts of the research undertaken within the Trust and the importance of the support from HSC R&D. The Western Health and Social Care Trust was formed in 2009 following the Review of Public Administration (RPA). The RPA and the establishment of the NICRN made radical changes to the research processes and research governance across all the trusts in Northern Ireland. As expected with new processes and procedures these took a while to become embedded and the staff consulted with noted that the level of research activity within the Trust has been increasing over the past few years.

The Trust is currently involved in a number of research activities:

- Clinical trials;
- Academic research projects; and
- Clinical Research and Innovation.

8.3.2 Inputs

The Trust received support from NICRN in the form of research nurses and from HSC R&D with discretionary funding. (Discretionary funding is a pump-priming mechanism. It is allocated directly to Trust R&D Directors who use it to support high-quality, early stage research that has the capacity to develop into a larger study, fundable from other sources). In addition, the Trust has funded a further three (FTE) research nurses. Staff from the WHSCT noted that without the support of the NICRN they would not be able to participate in clinical trials.

The Trust is also a lead partner (alongside the University of Ulster and Derry City Council) in a consortium which developed the Clinical Translation and Research Innovation Centre (C-TRIC). C-TRIC was established in a purpose-built facility in 2009 to promote and facilitate translational and clinical research. The primary objective of C-TRIC is to reduce the time to market and the costs associated with research and development of innovative health technologies, medical devices and therapeutics. C-TRIC is structured to provide key support staff to facilitate clinical research and innovation, enabling the streamlining of developments from the laboratory to the market place through a focused 'bench to point of care' approach. It is intended that this focused activity will create commercial opportunities to develop and exploit partnerships between academic researcher, clinical practitioner and industry. The way C-TRIC is structured is unique in Northern Ireland.

C-TRIC was established with £2 million of funding from a range of organisations, including the EU funding programme Interreg IIIA (£1.3m), WHSCT (£300,000) and Derry City Council (£200,000). HSC R&D Division also provides funding to support two laboratory technicians in C-TRIC. The Director of R&D in the WHSCT is also the Chief Executive of C-TRIC.

8.3.3 Outputs

The Director of R&D in the Trust has been the co-lead investigator in research projects which have received HSC R&D funding. The most significant of which is known as the ESMON study, which reviewed the efficacy of self-monitoring of blood glucose in patients with newly diagnosed type 2 diabetes. The study received funding from HSC R&D and from other sources, including Diabetes UK. The study was conducted in collaboration with the academic staff from University of Ulster and the findings concluded that self-monitoring had no effect on blood sugar control among patients with newly diagnosed type 2 diabetes.

As a direct result of this study the lead PI was then invited to participate in an NHS working group on diabetes, to examine the practice of self-monitoring of blood sugar among people with type 2 diabetes. This working group then developed a set of guidelines on the use of self-monitoring equipment for use across the NHS. The report noted that savings can be achieved by the NHS by stopping self-monitoring among patients who do not benefit from it. Self-monitoring can be uncomfortable and distressing for the patient and costly for Health Service, therefore it should not be encouraged among patients who gain no clinical benefit from continuing to test. The working group report also noted that future research should be focused on identifying those who would benefit from self-monitoring.

C-TRIC also currently has 11 clients, most of whom are private sector life science companies. C-TRIC generates income from clients by renting office and laboratory space

C-TRIC is also currently working with Randox Laboratories and the University of Ulster in the development of tailored drug therapy for patients with Rheumatoid Arthritis. This project received funding from the UK Technology Strategy Board and the Medical Research Council (MRC) and matched funding from Randox. It is anticipated that personalised drug therapies will reduce the overall treatment costs to the NHS.

8.3.4 Dissemination

The WHSCT research staff have been involved in a wide range of dissemination activities. The Research Director has several publications in high quality peer reviewed journals. The ESMON study (as noted earlier) was published in the British Medical Journal³⁹. This in turn led to participation in a NHS working group and the publication of guidelines for self-monitoring in diabetes patients.⁴⁰

As noted above the work on self-monitoring of blood glucose also led to the development of a set of guidelines, which was published by the NHS.

C-TRIC is not directly responsible for the dissemination of research findings as it facilitates research projects rather than leads them. However, it does produce a wide range of publicity materials which provide information about the range of research and innovation projects that are taking place. It also hosts an annual international Translational Medicine conference which showcases the work of C-TRIC and successful projects.

³⁹ O'Kane, M.J. et al (2008). *Efficacy of self monitoring of blood glucose in patients with newly diagnosed type 2 diabetes (ESMON study): randomised controlled trial. British Medical Journal May, 2008.*

⁴⁰ *Self monitoring of blood glucose in non-insulin treated type 2 diabetes. A report prepared by an NHS Diabetes Working Group*

8.4 Case Study 3: Molecular Breast Cancer Research

8.4.1 Background

The Centre for Cancer Research and Cell Biology (CCRCB) within Queens University Belfast (QUB) has been undertaking research into specific sub types of breast cancer, which have not responded well to traditional forms of treatment and have poor survival rates. The CCRCB has been undertaking research into which particular sub types would benefit most from personalised medicines.

8.4.2 Inputs

The CCRCB was funded almost £840,000 in 2006 to undertake exploratory research to develop and validate a test for the diagnosis and prediction of response to therapy for a particular sub type of breast cancer (BRCA1 deficient/basal). Women with a deficient or mutated BRCA1 gene are known to have a higher risk of developing breast cancer. This sub type is known to be hereditary and in the past was shown to be resistant to traditional forms of treatment. The study was funded for a period of six years. This funding allowed the research team to demonstrate that BRCA1 mutated breast cancer had the potential to respond to targeted/personalised forms of treatment. The research established the fundamental biological basis for further investigation. The HSC R&D funding supported two Postdoctoral Research Fellows to undertake the study, as well as laboratory consumables.

8.4.3 Outputs

The original research funded by HSC R&D identified the need to investigate potential treatment options for women with BRCA1 mutated breast cancer. The research team published a landmark paper in the Lancet suggesting that the best preventative treatment for BRCA1 linked breast cancer is bilateral mastectomy. A bilateral mastectomy is now a recognised and common approach to treating this breast cancer sub type. In addition the research team published the first evidence that BRCA1 mutated breast cancer was likely to respond to platinum based chemotherapy. This work has led to a number of international clinical trials of platinum in BRCA1 linked breast cancer.

Following on from this research, the team then received further funding from Cancer Research UK (£1.1M), Breast Cancer Campaign (£200K) and the Medical Research Council (£200K), to undertake further research to examine how BRCA1 linked breast cancers respond to a range of different chemotherapy types such as Taxanes. Further research also discovered that the same gene has a role in ovarian cancer.

CCRCB is now working in collaboration with a US biotechnology company and a local biomedical company to develop a testing kit that will identify which patients would respond to the inhibitory drugs. The PI noted that the involvement of private sector companies at this stage is vital as it is very difficult to get funding for this type of translational or implementation research. The test is being trialled clinically in the US and the samples are being analysed by the local biomedical company. If successful the test could be commercialised. However, it is likely to take up to four years before it could be marketed.

The support from HSC R&D has impacted upon the research capacity with the CCRCB and Northern Ireland generally, as it has helped to increase the profile of the centre and as a consequence has attracted high quality students and post-doctoral fellows.

8.4.4 Dissemination

The research team have been actively involved in dissemination throughout the research, mostly in the form of peer reviewed academic journals, such as the Lancet, Clinical Cancer Research and The Oncologist. In addition a number of the research teams publications are also available on the website of other funders (e.g. www.cancerresearchuk.org). This work has also led to further studies from other research groups demonstrating improved response rates among BRCA1 linked breast cancer when treated with a new class of therapeutics (PARP inhibitors) that functions to selectively kill cells with a DNA damage repair defect (for example The New England Journal of Medicine).

The PI noted that the increasing difficulty in accessing funding is one of the biggest barriers to research. Support from the HSC R&D is particularly important as it ring fenced for Northern Irish researchers and allows sufficient fundamental research to be completed to demonstrate the need for further investigation to other funders. Researchers are often at a disadvantage when applying for UK wide funding as they are competing against large well established medical research centres in the UK and as such the proof of concept funding from HSC R&D helps provide an advantage. Northern Irish researchers would struggle to get funding for preliminary studies without the support from HSC R&D.

There are issues associated with translating research results and like other regions this is not always done effectively. One issue being that academic researchers are not incentivised to progress research findings any further than peer reviewed publications. Currently, academic performance is judged on the number and quality of peer reviewed publications and not on the impact of their research. In addition it is difficult to get funding for translational research. The collaboration with the private sector in this research has allowed further investigation to take place as to how the research findings regarding BRCA1 gene mutations can be translated into changes in diagnosis and therefore treatment. The support provided to clinicians to undertake fellowships was also seen as providing an important role in translating research finding into clinical practice as often clinical researchers can help to link findings to clinical practice and the dual role that clinical researchers provide is paramount.

9 BENCHMARKING

Based on the level of evidence available and the existence of other studies, the three countries chosen for benchmarking were:

England: It has the largest body of knowledge on the value of medical research, has relatively simple ways to track research inputs, and is a similar funding and research environment to Northern Ireland;

Sweden: It has worked on socio-economic impacts of health R&D, in particular in comparison to other countries approaches; and

Canada: It has a clear main government funder of health research, organised into subject specific institutes that need to report on impacts. Also has a pan-Canadian framework/indicators for return on investment in health research.

Comparing these countries with Northern Ireland and each other is complex, and in many cases data collected is not directly comparable. However, within each country there is some information on how research impacts are identified, and in particular how different payback categories are collected. In this section, we identify the high-level comparison of the three countries. The full comparison benchmark report can be found in Appendix 6.⁴¹

9.1 International context

Whilst in this benchmarking we have focused on three countries in particular, there is a noteworthy trend across the world in assessing the impacts from publicly funded health research. In Ireland, the Health Research Board (HRB) analysed the return on investment from their research funding using a payback approach, and has developed an ongoing monitoring system for HRB health research funding.⁴² In this study, the HRB identified significant economic benefits from selected research projects it had funded, including over £7m in sales from spin off companies and additional external research funding leveraged.

Other countries have their own approaches to evaluating health research impacts. Spain uses payback approaches⁴³ and long-term evaluations.⁴⁴ Finland uses a meta-evaluation approach to gather information on the impacts of R&D.⁴⁵ The Netherlands has developed numerous approaches at different levels (funder, university) including societal impact models.⁴⁶ The USA is moving forward with their STAR Metrics model to assess research funded by NIH.⁴⁷ There is clearly international appetite

⁴¹ In the appendix, for each benchmark country we assess the research inputs, health status around the three disease areas (cancer, diabetes and mental health) and explore any existing approaches to measuring impacts of research funding. We then classify the main impacts of research in the countries according to the impact categories identified in the Payback Assessment of Northern Ireland in chapter 6.

⁴² Nason et al. (2011). *Evaluating health research funding in Ireland: assessing the impacts of the Health Research Board of Ireland's funding activities*. *Research Evaluation*, **20**(3): 193–200.

⁴³ See: <http://www.gencat.cat/salut/depsan/units/aatrm/html/en/dir404/doc13384.html>

⁴⁴ Espinosa de los Monteros (1996). *Lessons from an evaluation of Spanish public-sector biomedical research*. *Research Evaluation*, **6**(1): 43-51.

⁴⁵ Hyvärinen (2011). *TEKES impact goals, logic model and evaluation of socio-economic effects*. *Research Evaluation*, **20**(4): 313-323.

⁴⁶ Mostert et al. (2010). *Societal output and use of research performed by health research groups*. *Health Research Policy and Systems*, **8**:30. doi:10.1186/1478-4505-8-30

⁴⁷ For details see: <https://www.starmetrics.nih.gov/>

for understanding the impacts of health research, and these experiences can only serve to improve assessment approaches.

9.2 England

In England there are very few funders of health research who only fund research in England (they also fund other parts of the UK).⁴⁸ The main exception to this rule is the English Department of Health (DH) R&D funding, which in 2006 formed between 5-15% of the UK Clinical Research Collaboration (UKCRC) identified health research funding.⁴⁹ With English DH funding for research now distributed through the National Institute for Health Research (NIHR), there are significant levels of information on funding, activities and some evidence on impacts (although NIHR is a relatively new entity since 2006). NIHR in 2010/11 provided over £900m to health research in England.⁵⁰

NIHR and other major funding bodies (such as the MRC and Wellcome Trust) focus on understanding and monitoring the outputs and outcomes of research. The return on investment study funded jointly by the MRC, Wellcome Trust and the Academy of Medical Sciences (that identified Return On Investment for research in the UK on cardiovascular disease and mental health)⁵¹ identified rates of return of 39% and 37% for cardiovascular and mental health research respectively; there is no reason to suspect that these rates of return would differ greatly if only England were considered as the unit of analysis.

In the three disease areas identified in the main study (cancer, diabetes and mental health), England does not have strong data on economic impacts, but there is information on knowledge products developed across health research generally (citation data showing the MRC and Wellcome trust are above the world average in research output quality).^{52,53} All three major funders also have general health impact data on policy and products, and on capacity building (people and infrastructure). However, health and health sector impacts are considered too difficult to collect and attribute so the funders do not identify these regularly.

Economic benefits have been best identified in the "Medical Research: What's it Worth?" study conducted in 2008.⁵⁴ In this study, a historical analysis of research funding for cardiovascular disease and mental health research was linked to current health care, health status and economic GDP changes to identify a rate of return for health research investment. In this review, they identified a rate of return of 9p for health benefits, and 30p for GDP benefits on cardiovascular research. They also identified rates of 7p for health benefits and 30p for GDP benefits on mental health research. These rates were calculated by using health gains in Quality Adjusted Life Years (QALYs), and GDP gains

⁴⁸ If we make an assumption that all research funders that work across the UK have a split that reflects that of health research funding by the independent departments of health R&D budgets, then we can assume that England's share of any UK funding total (and potentially impact total) would be around 89%. This is based on the funding levels of each DH identified in the 2006 Cooksey Report: Cooksey (2006). *A Review of UK Health Research Funding*. London, UK: HM Treasury. p22-24.

⁴⁹ UK Clinical Research Collaboration (2006). *UK Health Research Analysis*. London, UK: UKCRC.

⁵⁰ Research & Development Directorate (2011). *National Institute for Health Research Annual Report 2010/11*. London, UK: English Department of Health.

⁵¹ Buxton et al. (2008). *Medical research - what's it worth? Estimating the economic benefits from medical research in the UK*. London, UK: Health Economics Research Group, Office of Health Economics and RAND Europe.

⁵² Medical Research Council (2011). *Economic Impacts Report 2010/11*. London, UK: Medical Research Council.

⁵³ Wellcome Trust (2009). *How we are making a difference: Assessment framework report 2008/09*. London, UK: Wellcome Trust.

⁵⁴ Buxton et al. (2008).

including spillovers to other sectors of the economy. Research was linked to these gains through a combination of research citation in clinical guidelines, uptake of recommended new practices, and investment in private sector medical research linked to publicly funded health research. The researchers also identified a time lag of around 17 years between research funding and realised economic benefit. In addition to this study, the MRC also identified £2.4bn in leveraged research funding for MRC researchers (follow-on funding) from 2006 forward, as well as IP worth £66m in 2010-11.⁵⁵ This is based on a research spend by the MRC between 2006-2010 of £1.89bn – representing a return on leveraged funding alone of 1.27:1. At the Wellcome Trust, it is possible to identify £129m in venture capital funds brought in by Wellcome researchers in 2008/09,⁵⁶ based on a spend in that year of £720m.

9.3 Sweden

Health research funding in Sweden comes from a variety of sources, including two main central government agencies: the Swedish Research Council (Vetenskapsrådet) and the Swedish Governmental Agency for Innovation Systems (Vinnova). In addition to these two main funders, there are also health research funds provided by the Ministry of Education, Research and Culture, and by local County Councils, as well as research foundations and charities that provide funding.⁵⁷ In 2004, a total of 4.2m SEK was invested from public funds into basic research in the medical field (mainly through the Swedish Research Council - SRC), and a further 222m SEK into healthcare and public health research. There is also considerable funding from regional level funders, which put together totaled around 1.45bn SEK in 2005.⁵⁸

Research evaluation is a major part of Swedish health research funding, although this is performed through evaluations of specific programmes of funding, rather than through the systematic use of a research evaluation framework for the country's health research. However, this approach may be changing as Sweden hosted an international summit in 2008 on research evaluation.⁵⁹ For the three disease areas we are investigating, there is no data on research impacts by disease area. However, Sweden does collect data on knowledge products (citation values that are above the world average but have been declining in relation to other countries in recent years),⁶⁰ but capacity building, policy and product development, and health and health sector benefits are not routinely collected (just through programme evaluations). One Swedish study did identify economic return on health research funding, at an 8% return on clinical research investment.⁶¹ This study used the same approach approximately as the UK "Medical Research: What's it Worth?" study so the rate of return is directly comparable.

⁵⁵ Medical Research Council (2011).

⁵⁶ Wellcome Trust (2009).

⁵⁷ Tiessen (2008). *Health and Medical Research in Sweden: Observatory on Health Research Systems*. Cambridge, UK: RAND Europe.

⁵⁸ *Ibid.*

⁵⁹ Cox et al. (2008). *Evaluation of Impacts of Medical Research*. Stockholm, Sweden: Swedish Research Council

⁶⁰ Academy of Finland and Swedish Research Council (2009). *Clinical Research in Finland and Sweden: Evaluation Report*. Helsinki, Finland: Academy of Finland.

⁶¹ Roback, Dalal and Carlsson (2011). *Evaluation of Health Research: Measuring Costs and Socioeconomic Effects*. *International Journal of Preventive Medicine*. 2(4): 203–215

9.4 Canada

In 2009, Canada spent \$6.4bn on health research funding, with the vast majority of that funding coming from the public sector (federal government, provincial government and higher education).⁶² The government of Canada's S&T strategy in 2007 set out a need to build excellent research, to translate that research into practical applications, and to strengthen the pool of skilled individuals. This shows an emphasis on impacts (knowledge, practice and capacity) that is mirrored in government health funding plans such as the Canadian Institutes for Health Research (CIHR) Roadmap.⁶³ The three disease areas identified in this study are mainly supported through CIHR,⁶⁴ with responsibility for the research falling under subject specific institutes (in Cancer,^{65,66} Nutrition, Metabolism and Diabetes; and Neuroscience and Mental Health), with additional funding support from disease specific charities and provincial research funders.^{67,68} In cancer, different funders have collected knowledge impact data (citations),⁶⁹ but generally only CIHR collects data across all parts of the payback framework. For diabetes, only CIHR collects payback impact data. In mental health, while some funding is assessed through auditing of government funds and program specific evaluations,⁷⁰ only CIHR performs payback style impact assessments.

The recent publication of a pan-Canadian impact framework and indicators may help assess total health impacts,⁷¹ but currently, understanding of impacts is restricted to CIHR funding. Cancer research in Canada ranks second among G7 countries in terms of citation analysis;⁷² while diabetes research funded by CIHR is number one in the G7 for relative citation values.⁷³ For mental health research, Canada also performs better than the world average for relative citation values, with Canada ranking third in the world behind only the USA and the UK.⁷⁴ Economic benefits are identified qualitatively in Canada currently, with information on commercialization and net health benefits outlined by CIHR Institutes. The Institute for Nutrition, Metabolism and Diabetes identified 2:1

⁶² Statistics Canada (2010). *Science Statistics: Estimates of Total Spending on Research and Development in the Health Field in Canada 1998 to 2009*. Ottawa, Canada: Statistics Canada.

⁶³ CIHR (2009). *Science Statistics: Estimates of Total Spending on Research and Development in the Health Field in Canada 1998 to 2009*. Ottawa, Canada: CIHR.

⁶⁴ Canadian Cancer Research Alliance (2011). *Cancer Research Investment in Canada, 2008: The Canadian Cancer Research Alliance's Survey of Government and Voluntary Sector Investment in Cancer Research in 2008*. Toronto: CCRA.

⁶⁵ CIHR Institute of Cancer Research (2008). *Bar Chart: CIHR Cancer Research Funding over the last 8 fiscal years*. Available at: <http://www.cihr-irsc.gc.ca/e/35623.html>

⁶⁶ Institute for Nutrition, Metabolism and Diabetes (2011). *Internal Assessment for 2011 International review*. Ottawa, ON: CIHR.

⁶⁷ Canadian Cancer Research Alliance (2011).

⁶⁸ Canadian Diabetes Association (2011). *Annual Report: Financial Statements*. Ottawa, Canada: Canadian Diabetes Association

⁶⁹ Campbell et al (2008). *Science Statistics: Estimates of Total Spending on Research and Development in the Health Field in Canada 1998 to 2009*. Montreal, Canada: Science-Metrix; Campbell et al (2009). *Bibliometric Analysis of Research Supported by the National Cancer Institute of Canada—Phase II*. Montreal, Canada: Science-Metrix; Campbell et al (2010). *Bibliometrics as a Performance Measurement Tool for Research Evaluation: The Case of Research Funded by the National Cancer Institute of Canada*. *American Journal of Evaluation*. **31**:66

⁷⁰ Archambault, Côté and Gringras (2003). *Bibliometric Analysis of Research on Mental Health in the Workplace in Canada, 1991-2002*. Montreal, Canada: Science-Metrix.

⁷¹ Panel on Return on Investment in Health Research (2009). *Making an Impact: A Preferred Framework and Indicators to Measure Returns on Investment in Health Research*. Ottawa, ON: Canadian Academy of Health Sciences.

⁷² Campbell et al. (2008).

⁷³ CIHR Institute of Nutrition, Metabolism and Diabetes (2010). *Bibliometric Study of Obesity Research in Canada, 1998-2007*. Ottawa, ON: CIHR. Available at: <http://www.cihr-irsc.gc.ca/e/41601.html#2.2>

⁷⁴ Lariviere et al. (2010). *Bibliometric Analysis of INMHA-related Research, 1997-2008*. Montreal, Canada: Observatoire des sciences et des technologies.

leveraged funding for a specific suite of gastroenterology grants, but doesn't identify total leveraged funding in diabetes.⁷⁵

9.5 Conclusions

To summarise, there is not a consistent approach to assessing research impacts, within a country, or across them. There are also complications across disease types, where data may be routinely collected on funding (although by no means everywhere) but impact data is not assessed by disease area. Even where economic data exists, based on payback-style studies, the findings may not be comparable if the methods of identifying what an economic impact is are different.

For English funders it is difficult to break out the impacts for England alone, since the MRC and Wellcome Trust (the two more established funding bodies) provide funding across the UK and do not break down impacts by region. While NIHR does allow England only funding comparisons, their impact assessment infrastructure is still immature and will take time to become established enough to provide solid data. In Sweden, there are many different funders, each of which takes multiple approaches to measuring research impact through program and project evaluations. There is interest in standardised approaches to measuring impact, but this has not yet led to a standard framework for monitoring and evaluation. In Canada, the main funder (CIHR) has a standardised approach to measuring and monitoring impacts, although despite having a framework in place since 2005, the CIHR has not consistently collected impact data using the framework. However, individual assessments of disease areas or institutes provide some comparable data. As with England and Sweden, being able to access data specifically on disease areas for the main health research funder is currently not possible in Canada.

The table below compares the three countries with the five impact categories from the Payback Framework in terms of their approaches to impact assessment and any identifiable comparable impacts. We have not attempted to compare across disease categories since impact data on specific diseases is lacking outside of Canada, and even in Canada it is largely qualitative and anecdotal at this time.

Table 9.1: Overview of benchmark countries for impact analysis

	England	Sweden	Canada
Assessment framework	3 different frameworks for the 3 main funders – similar impact categories to Payback Framework	No frameworks, but evaluations for programs	Main funder has one framework that is reflected in recent new frameworks – based on Payback Framework
Input data	Good quality, linked to UK Clinical Research Collaboration (UKCRC)	Data on research inputs is good quality, but complex due to number of funders	Poor quality, not yet classified consistently – even at funder levels
Knowledge products	Consistent data on bibliometric outputs and citations. Citation data show both the MRC and	Regular bibliometric analyses of knowledge products. Citation data shows Swedish health research	Good data on publications and citations. Citation data places Canada in the top 3 G7 countries for cancer and diabetes

⁷⁵ Institute for Nutrition, Metabolism and Diabetes (2011).

	England	Sweden	Canada
	Wellcome Trust research performing above the world average.	is above the world average, but is getting caught by other countries (relative strength is declining).	research.
Capacity building	All collect some information on who is being trained, some collect information on what happens to trainees	Funders aspire to build capacity, but data is lacking on how this is achieved	CIHR institutes collecting data on capacity building approaches and why they succeeded
Policy and Product Development	Data collected by all three funders with roughly comparable indicators	Data is in individual program evaluations so is detailed but difficult to compare	Product development data is now routinely collected and policy data is in progress
Health and health sector	Complex data to collect and analyse, although funders are developing indicators	Health and health sector benefits are generally not addressed by funders	CIHR has aspirations of health / health sector indicators, but does not have them presently
Broader social and economic benefits	Individual studies are more advanced than monitoring approaches. One study identified returns of 1.37:1 for mental health research in the UK, and 1.39:1 for cancer research. Leveraged funds from MRC funding have been identified as around 1.27:1.	There is interest in economic analyses, but so far only one study on overall clinical return on investment One study identified returns of 1.08:1 for clinical research in Sweden.	CIHR institutes identify economic impacts, but data is not routine or consistent. One study identified returns of 2:1 on leveraged funding for diabetes research – but this was an individual funding program only.

9.6 Comparing Northern Ireland economic benefits

In the current study, we have identified a return of 4.14:1 on research funding provided by HSC R&D in Northern Ireland. While the structure of economic evaluations in other countries does not allow a direct comparison of this ratio with existing findings, we can see that the leveraged funding return is higher than the return on clinical research identified using a net health benefits and GDP approach (that did not include leveraged research funds) in both England (1.37/1.39:1) and Sweden (1.08:1). It is also larger than the leveraged funding data available in England (where the MRC leveraged funding at 1.27:1) and Canada (where a specific program by the INMD leveraged private sector funding at 2:1). These numbers are based on different methods and should be taken only as an indication that in Northern Ireland, health research funding is successful in generating additional research income for the country, at least in a comparable way to the economic success of research funding in England, Sweden and Canada.

10 CONCLUSIONS AND RECOMMENDATIONS

In the following paragraphs we have summarised the key findings from the previous sections and provided recommendations for the future of HSC R&D based on these findings. It should be noted that whilst this review focused on the areas of Cancer, Diabetes and Mental Health, an assumption is being made that the findings from these three areas can be extrapolated to apply across the whole health and social care R&D sector.

10.1 Conclusions

The review of the relevant literature demonstrated the need for continuing to build up health sector R&D, its overall importance to the economy and the key role that R&D plays in the planning and delivery of health and social services. Specifically key policy documents relating to the three areas of research, such as 'A Fitter Future For All: Consultation Report: Obesity Prevention Framework for Northern Ireland 2011-2021' (DHSSPS, 2011) and 'Protect Life: A Shared Vision: The Northern Ireland Suicide Prevention Strategy and Action Plan 2006-2011', emphasise the importance of valid, published research in their development and that continued research is fundamental to their future progress.

High-level population statistics relating to the three research interest areas demonstrate the on-going need for further work in these areas. The importance of research relating to cancer prevention, treatment and care is clearly evident. A review of the high levels statistics has shown that the rate of diagnosis of many cancers has increased but that the survival rates have also improved. Clinical trials and other clinical research studies have been integral to the latter being achieved.

There is also evidence to support the need for enhanced research in the field of diabetes. It is widely recognised that obesity continues to be a common problem in modern society and considering the relationship between being overweight and the increased risk of developing type 2 diabetes, the need for further research into prevention and treatment will only increase as obesity levels escalate. Moreover, it will play an integral role in relation to the aim set out in the Obesity Prevention Framework (2011 – 2021) if reducing the level of obesity in Northern Ireland to 2005/06 levels by 2021, is to be achieved and maintained.

Mental illness continues to be an issue in Northern Ireland, over the last five years, the total number of admissions to hospital under the mental health programme of care increased by 2.4%. The NI suicide rate also increased from 10.4 (deaths per 100,000) in 2000/02 to 15.9 (deaths per 100,000) in 2008/10. Furthermore, projections relating to dementia suggest a 41% increase in the number of diagnoses by 2021.

Between 1998 and 2011, just over £40 million HSC R&D funding was issued to 108 Principal Investigators to undertake research in the fields of cancer, diabetes and mental health.

The total health and social care R&D budget is significantly less in Northern Ireland per capita than the rest of the UK. Even at its peak in 2008 the total HSC R&D budget in Northern Ireland equated to around £7.63 per capita, less than 50% of what is available in England (an estimated £15.12). In Scotland and Wales the level of R&D funding per capita is estimated to be in the region of £12.23 and

£14.38 respectively⁷⁶. Caution should be noted when comparing the level of HSC funding with other countries and regions. Directly comparable benchmarking is difficult not least because, unlike other UK regions and European countries, in Northern Ireland we have a combined Health and Social Care system and therefore HSC R&D is broader than purely health research.

Whilst the standard of support and quality assurance provided by the HSC R&D Division staff was generally well regarded, the low level of funding available was a significant issue amongst those consulted. Many PIs noted that their research activities were restricted due the lack of access to very large funds such as those available in England via the NIHR or through the arrangements for UK-wide sharing of programmes to which NI does not currently contribute. In addition, from the peak total of £13.5 million in 2008, the HSC R&D budget has since contracted to £10.2 million. Therefore, not only are PIs in Northern Ireland unable to access larger pots of funding available elsewhere in the UK, the local R&D budget has also been in decline since 2009. Given that the R&D programmes provided by each of the UK Health Departments focus on the provision of evidence for health and healthcare within the context of devolved services, the ultimate deficit in Northern Ireland is in the services provided to patients and the population.

There was a general perception among those who were consulted within the HSC Trusts that the Trust working culture could be more conducive to the performance of high quality research. This was evidenced by a number of factors, including the absence of a requirement for local HSC Trusts to report (to HSC Board or DHSSPS) on their R&D activities. This is also related to the finding that a number of consultees felt that R&D within the health and social care sector in Northern Ireland needed an increase in profile.

10.1.1 Survey and Consultation Findings

As a small number of PIs had moved on, retired or died it was not possible to contact the PIs for 15 of the 184 projects. Therefore, 169 surveys were deliverable. Responses were received for 84 projects, a rate of 50%.

The responses to the survey were analysed under the five payback categories of:

- Knowledge;
- Benefits to future research and research use;
- Informing policy and product development;
- Health and Health sector benefits; and
- Broader economic benefits.

10.1.2 Knowledge

Responses to the survey and consultations with key stakeholders indicated that R&D funding has contributed significantly to the generation of knowledge in the three research areas. Although not all

⁷⁶ Source NIHR Annual Report 2010/11; London. Department of Health

projects were yet complete, 44% of survey respondents noted that they have been actively engaged in dissemination activities such as publishing in peer reviewed journals, presentations and conferences.

10.1.3 Benefits to Future Research

Developing the research capacity and research workforce is important for future research. Results showed that 57 individuals achieved postgraduate qualifications and 81 individuals gained a career progression as a result of the HSC R&D funding. Furthermore, 110 jobs were supported by the 84 projects for which survey information was returned, equating to around 1.3 jobs per project. We also know from the information provided on career progression that these tended to be high quality posts.

10.1.4 Economic Benefits

PIs were asked about additional and follow-on funding resulting from the HSC R&D funding. In total 36 projects recorded follow-on funding of over £41 million, at an average of £1,165,472 additional follow-on funding each. In total the respondents provided information on additional and follow-on funding totalling just over £53 million. Based on this figure we estimated that a further £4.14 was generated for every £1 of HSC R&D funding.

It was clear from the consultations that the HSC R&D funding is a catalyst for accessing further (often larger) funding: - 60% of those who responded in the survey noted that their HSC R&D funding had a considerable impact on accessing funding from other sources.

In addition to the financial information gained through the survey of PIs, consultation with key stakeholders noted that local HSC Trusts also benefited financially from participating in clinical trials. Obtaining exact data relating to income generated in Trusts directly by cancer, diabetes or mental health trials proved to be difficult for a number of reasons. In general, the Trust finance systems do not easily allow further analysis of the sources of income. And even for those Trusts able to provide a more detailed breakdown of sources of income, it can be difficult to ascertain if the trial was directly related to one of the specific disease areas. However, data were received from four of the five Trusts⁷⁷ in relation to income from diabetes clinical trials. This showed that from 2008 to 2011 four HSC Trusts generated over £1.2 million in direct funding from participating in clinical research / trials in relation to diabetes alone.

Furthermore, when a patient is enrolled on a clinical trial, the trial sponsor (usually a private sector company), covers the cost of the treatment for that patient, meaning that the Trust saves on treatment costs that they would have been subject to otherwise. Given the complexity of treatments and associated costs, calculation of these savings to the Trusts was beyond the scope of the current study.

10.1.5 Health

As is noted in other studies⁷⁸ the impacts of the funding to HSC R&D on health outcomes and health sector impacts can be difficult to quantify. 20% of respondents to the survey noted that one of the health impacts of the research was an increased length or quality of life for patients. In addition, 17% of respondents noted that their research indicated better targeting and accessibility of services. The difficulty in directly attributing health impacts to health research was also noted among those countries

⁷⁷ Southern Health and Social Care were unable to provide this information.

⁷⁸ For example; Frank, C. and Nason, E. 2009. *CMAJ*, March, 3, 180 (5)

reviewed in the benchmarking study, for example the 'Medical Research: What's it worth' report⁷⁹. However, two consultees noted that as a direct result of their HSC R&D funded research they were part of groups who developed clinical guidelines, one on the self-monitoring of glucose levels and the other relating to the management of chronic kidney disease.

10.2 Recommendations

In the following paragraphs we have provided recommendations for the future delivery of HSC R&D funding.

10.2.1 Strategy development

- Strategy development: we recommend that consultations for a new strategy for HSC R&D should include policy makers and those responsible for planning and delivering services. The new strategy could then indicate research requirements for Northern Ireland so that funding might be considered for each. Important considerations would include the need for research and the potential to deliver outputs and outcomes against the payback framework. Subsequently, when project funding is provided, the payback framework elements should be referenced in the letter of offer of grant support.
- Given the level of additional and follow-on funding attracted by researchers (as identified through survey responses) the DHSSPS should urgently consider (in close consultation with the research community) contributing to NIHR. This would enable NI researchers to participate in the NETS programmes of the NIHR. **As part of this a cost/benefit analysis should consider the impact of the funding over a five to ten year period with interim reviews to ensure its continued benefit to Northern Ireland.**
- The evident success in leveraging of the annual HSC R&D budget should be built upon. Strategies might include direct bi-lateral partnerships with other research funders; continuing to work within funding consortia to enable projects of a larger scale than would be possible locally; ensuring the timely development of local funding opportunities so that research findings, capabilities etc. would enhance the competitiveness of NI based researchers in UK, EU or other significant funding opportunities.
- Funding Allocation: The need for enhanced flexibility in the allocation of HSC R&D funding was mentioned by some consultees. Consultations with the Trusts noted that the annual budget provided to Trust R&D Directors by HSC R&D did alleviate this to some degree. It was felt that more of the funding might be discretionary or set aside to deal with emerging research needs. However it is recognised that this would need to be balanced with maintaining the supportive research infrastructure across the province that was put in place during the current 5 year strategy period with the intention that it would assist researchers to attract funding from elsewhere.
- Our consultations highlighted the opportunity to enhance the profile of research within Trusts and among policy-makers and service planners in the DHSSPS and across HSC organisations. For example, the reporting structures between those responsible for managing R&D and senior management within each organisation might be reviewed.

⁷⁹ Medical research what's it worth. Health Economics Research Group, Office of Health Economics, RAND Europe. Medical Research: What's it worth? Estimating the economic benefits from medical research in the UK. London: UK Evaluation Forum; 2008.

- It was the perception among many of those consulted with from Trusts that research was not sufficiently high up the agenda of the executive committees. Consideration should be given to the most appropriate way of ensuring that research is embedded and becomes more central to decision-making processes within HSC organisations. In addition to benefits for each organisation, this would enhance further the effectiveness of the HSC R&D Strategic Advisory Committee on which all of the organisations are represented and provides very valuable input to major HSC R&D activities.
- It was also evident through our consultation exercise that research generally and HSC R&D had a low profile within the HSC sector. This creates even greater difficulty in raising awareness of the benefits that research can provide for health or social care policy or service delivery. We recommend that this lack of visibility be addressed and steps taken to rectify it. **Any action in that direction would help to ensure that HSC R&D can have the greatest possible impact on the development of health and social care.**

10.2.2 Monitoring R&D Impacts

- It is always difficult to collect evaluation data retrospectively as PIs move on to the next stage of their research or are no longer available to provide detailed information. Research funders elsewhere in the UK are now developing tools for ongoing measurement and monitoring of the impact of health research. All of the three major funders of health research (MRC, NIHR and Wellcome Trust) have developed such systems. The NIHR identifies England-specific impacts and the MRC has developed eVal, an online tool enabling an annual survey of funded researchers to identify the outputs and outcomes of their work. Launched in 2009, it has replaced manual end-of-grant reporting by researchers. The eVal had an 83% response rate in the first year of use, and 91% in the second year.⁸⁰ The eVal system addresses numerous potential impacts under the concept of inputs, outputs and outcomes. Inputs are MRC inputs (funding, human capital inputs, and collaboration), outputs are directly created by the research (knowledge generation, human capital stock, and knowledge transfer and exchange), and outcomes are the result of outputs (human capital flow, public policy and public engagement).⁸¹ We feel that such ongoing monitoring is essential as it can provide reassurance that the projects are on schedule, especially given the length of time it can take impacts to emerge. **For these reasons we would recommend that HSC R&D adopts a similar online approach for monitoring its funded projects. The survey should allow easy quantitative analysis consistent with the domains of the payback framework used in the current study.**
- All HSC Trusts should have access to evidence on the impact of the R&D that they support, including appropriate financial information on the income generated through clinical research (including clinical trials). **It is recommended that each Trust ensures that any surplus it generates is reinvested to support further research.**

10.2.3 Knowledge

- Health professionals who have been awarded Doctoral Fellowships usually return to full-time clinical roles. The learning and experience they have gained through the Fellowship is well known to enhance their practice, their future career prospects and overall contribution to their

⁸⁰ See: <http://www.mrc.ac.uk/Achievementsimpact/Outputsoutcomes/e-Val/About/index.htm>

⁸¹ Medical Research Council (2011). *The Medical Research Council Economic Impact Report 2010/11*. London, UK: MRC.

organisation. But in addition we recommend that a structured approach is taken to ensuring that, as far as possible, they are supported to continue to undertake high quality research. This would, for example, allow them to investigate specific and 'live' health and health service delivery issues that they have identified through their clinical work and ensure that robust findings are rapidly implemented in practice.

10.2.4 Health and health Sector benefits

- There was high level of agreement amongst consultees and survey respondents that it often took a long time for research findings to be translated into changes to treatments or service delivery. It was also noted that sometimes clinicians are not aware that changes to a particular health service or practice are a direct result of a clinical trial. However 20% of survey respondents noted that their research had impacted positively upon the quality and/or length of life of patients.
- Many of those consulted with noted that access to clinical trials was a key element in supporting health outcomes and health service improvements. The development of the NICRN was regarded as vital to increasing access to clinical trials across Northern Ireland. Research conducted on the impacts of UK medical research found that it can take 17 years for the health benefits of publicly funded health research to spill over into the economy. Thus many benefits of studies supported through the NICRN should be expected to emerge in coming years.

10.2.5 Informing Policy and Product Development

- Whilst it is recognised that the UK Health Departments' R&D funds, including HSC R&D, provide support for translational research, there was a widely recognised bottle neck for the implementation of research findings. Whilst this is not unique to Northern Ireland⁸², consideration should be given to the most appropriate mechanisms to increase translational and implementation activities. These could include extending the timescales and budgets of research projects to allow direct dissemination to relevant health service delivery organisations or ensuring that funded projects include, and achieve, appropriate dissemination targets. A more radical example of how this is achieved elsewhere includes the Department of Health's (England), Policy Research Programme (PRP). Through this programme high quality research is commissioned to provide evidence necessary for the Department's policy remit. The PRP works alongside other NIHR research programmes and allocates a multi-million pound budget annually. In Northern Ireland it would be highly appropriate to consider additional funding to enable such policy-relevant research. In addition, given that the majority of policy / strategy documents originating with DHSSPS now highlight what research is necessary; applications for HSC R&D funding should include an indication of their local policy relevance.

10.2.6 Economy

- The Northern Ireland Programme for Government and current Economic Strategy all emphasise the central role of R&D. Research in health and social care is an extremely valuable element of the total R&D capacity of a region. While the primary focus of HSC R&D is to provide high quality research evidence to support policy and practice, it is recommended that further engagement with

⁸² A recent study (*Tracking the impact of research on policy and Practice: investigating the feasibility of using citations in clinical guidelines for research evaluation*. Kryl, D. et al *BMJ Open* 2012, 2. Noted that the research community as a whole could be better at translating the findings of medical research into tangible health and healthcare benefits.

Invest Northern Ireland be pursued, e.g. joint funding initiatives enabling direct academic, clinical and business collaboration in pursuit of shared goals of value to all three sectors.

- Results from the survey and additional data received from individual HSC Trusts showed that R&D can generate substantial income in the form of research grants and income from clinical trials, in addition to meeting the full cost of undertaking the research. As well as capturing this financial information by Trusts, it is recommended that reports are compiled to indicate the impact of each study with regard to the domains of the payback framework (i.e. IP income, jobs created etc). This information would be of value in demonstrating the essential nature of R&D and also to underpin any future study on the spill over impacts into the wider local economy.

APPENDIX 1: NORTHERN IRELAND STRATEGY AND POLICY DOCUMENTS

11 NORTHERN IRELAND POLICY AND STRATEGY DOCUMENTS

11.1 Programme for Government 2008 - 2011

The Programme for Government 2008-2011 set out the priorities and budgets for the Executive. Each Department had targets and associated public service agreements under the Programme for Government, specifically targets relating to the three areas of cancer, diabetes and mental health, and key goals respectively, they were:

Cancer:

- From September 2008; to ensure a comprehensive Human Papillomavirus Virus (HPV) immunisation programme was in place with a view to achieving a long term reduction of 70% in the incidence of cervical cancer;
- From December 2009; to ensure a screening programme for those aged 60-69 was in place, with a view to achieving a 15% reduction in mortality from Bowel Cancer by 2011;
- By 2009 to extend the regional breast cancer screening programme to cover those aged 65-70; and
- By 2009 98% of cancer patients should have commenced treatment within 31 days of decision to treat and 95% of patients referred with suspected cancer should have begun treatment within 62 days.

Diabetes:

- By 2011 it aimed to halt the rise in obesity. (Evidence suggests obesity increases the risk of becoming diabetic; an obese women is ten times more likely to become diabetic than one who is not overweight).

Mental Health:

- By 2013 anyone with a mental health problem or learning disability should have been promptly and suitably treated in the community and no-one should have remained unnecessarily in hospital; and
- By 2011 the suicide rate should have been reduced by 15% (suicide can be seen as a manifestation of poor mental health and well-being).

As such whilst the PfG (2008 – 2011) did not specifically refer to HSC R&D, there are seven targets relating Cancer, Diabetes and Mental Health, which could be considered as an indication of the importance of addressing these health and wellbeing concerns in the Northern Ireland population.

11.2 Programme for Government 2011 - 2015

The Programme for Government (PfG) 2011-2015 was published on 12th March 2012 and specifically sets targets for cancer, diabetes and mental health, they are:

Cancer:

- From 1st April 2014, the extension of bowel cancer screening to everyone aged 60-74; and

- By 2012/13 Improve patient and client outcomes and access to new treatments and services, and specifically enhance access to life-enhancing drugs.

Diabetes:

- Invest £7.2 million in programmes to tackle obesity through support of the Obesity Prevention Framework (£2 million in 2012/13; £2.4million in 2013/14; £2.8 million in 2014/15).

Mental Health:

- Although the PfG (2011-2015) does not contain any specific targets that are exclusively related to mental health, this topic is included in the first priority. This states that in order to achieve long term economic growth the labour market must be rebuilt and the economy rebalanced to improve the wealth and living standards of everyone. To do this involves acting to improve the mental health and wellbeing of all people. Hence one of the key commitments within priority one is to allocate an increasing percentage of the overall health budget to public health. One of the key outputs for this is to strengthen the cross sectoral / cross departmental drive on improving health and mental well-being and reduce health inequalities by setting new policy direction and associated outcomes based on the most recent bodies of evidence available; and
- Reference to Mental Health is also made in the third priority. This focuses on making real improvements to people's health and wellbeing, both physically and mentally, enhancing community safety, achieving improved safeguarding outcomes for children and adults most at risk of harm, and protecting and improving the environment in which we live. To do this involves improving health (mortality and morbidity) and wellbeing (including social inclusion and safeguarding) of everyone.

11.3 Service Framework for Cancer Prevention, Treatment and Care (DHSSPS, 2009)

The Service Framework for Cancer Prevention, Treatment and Care outlines the standards which patients, clients, carers and their wider families can expect. It sets standards in relation to the prevention, diagnosis, treatment, care, rehabilitation and palliative care of individuals and communities at a greater risk of developing cancer.

The framework seeks to promote care which is based upon research evidence. It emphasises the importance of valid and relevant clinical studies, including clinical trials and qualitative research, in the effectiveness and acceptability of services. It is this research which provides the rationale for its 52 overarching standards that aim to transform the quality of service provision in relation to cancer, thereby demonstrating how research is used to inform DHSSPS strategy.

It notes that research suggests possible risk factors that may contribute to breast cancer, establishing possible links between regularly drinking large amounts of alcohol and a slight increase in risk. This provides important contextual evidence for the framework and what it is setting out to achieve⁸³.

Research, in its various forms, is cited as enhancing the quality of cancer patient care and outcomes. This is as result of participation in clinical trials and other clinical research studies, where 'the high

⁸³ Service Framework for Cancer Prevention, Treatment and Care, *Department of Health, Social Services and Public Safety, (October 2009), pg 129.*

quality, protocol-driven care delivered by trained research staff standardises care and improves patient outcomes⁸⁴.

Based on evidence from an NHS strategic review (Cancer Working Group, 1999), it is also suggested that low levels of research activity and recruitment into clinical trials contributes to poorer outcomes for cancer patients in the UK and to the variability of outcomes across the country. This directly influences one of the overarching standards within the framework, whereby all patients who are eligible for an existing clinical trial should be offered the chance to be treated in a clinical trial by the multidisciplinary team.

Other notable overarching standards include:

- All men and women who are eligible to participate in the Bowel Cancer Screening Programme should be invited for screening every two years and be provided with the appropriate information and support to allow them to make an informed decision to take part;
- All year 9 girls should be routinely given the HPV immunisation to protect against future risk of cervical cancer;
- The public should be made aware of the early signs and symptoms of cancer so they know when they need to go to their doctor for advice; and
- The Service Delivery Framework for Cancer and Prevention encompasses a wide range of standards which aim to improve the prevention, diagnosis, treatment and care for individuals. Research is a key part of their development and directly links the trajectory of focused research and patient care.

11.4 Cardiovascular Health and Well-being Service Delivery Framework (DHSSPS, 2008)

The Service Framework for Cardiovascular Health and Well-being outlines the standards that patients, clients, carers and their wider families can expect. It sets standards in relation to the prevention, diagnosis, treatment, care, rehabilitation and palliative care of individuals and communities who currently have a greater risk of developing cardiovascular disease, including diabetes.

It cites key statistics and research relating to type 1 and type 2 diabetes in the adult population of Northern Ireland. This data shows the significant number of adults with the disease, and provides important evidence supporting the need for further research into prevention and treatment.

It states there is an established link between cardiovascular disease and the total amount of dietary fat. It notes the use of obesity research which stated that the occurrences of cardiovascular disease could be reduced by a review of how the problem of obesity and bad diet is looked at. Poor diet and obesity are also an important factor in type 2 diabetes.

The Framework states the establishment of best practice in relation to effective self-management of diabetes care, and how best to provide information, education, emotional support and psychological care, was based on research findings. It includes advice on the implementation of supportive and

⁸⁴ Bertelsen, 1991; Lennox et al, 1979; Boros et al, 1985, Brown et al, 1999 as quoted in Service Framework For Cancer Prevention, Treatment and Care, Department of Health, Social Services and Public Safety, (October 2009).

palliative care when disease is not responsive to curative treatment, (a standard which is applied to a number of service frameworks).

The standards it has established can be summarised as follows:

- All people with diabetes should have an accurate diagnosis made (80% by 2008/09; 90% by 2009/10 and 95% by 2010/11);
- All patients with diabetes should have access to structured education programmes and emotional and psychological support;
 - Newly diagnosed diabetic patients who should be provided with a structured patient education programme (40% in 2008/09; 50% in 2009/10 and 60% in 2010/11).
 - Percentage of diabetes teams who have access to specialist psychology support (50% in 2009/10; 60% in 2010/11 and 70% in 2011/12).
- All patients with diabetes should have access to, at a minimum, an annual review to a defined standard by an appropriately trained multidisciplinary team (40% in 2008/09; 60% in 2009/10 and 80% in 2010/11).

As such, the Service Delivery Framework for Cardiovascular Health and Well-being utilises substantial research to justify each of its overarching standards.

11.5 Service Framework for Mental Health and Well-being (DHSSPS, 2010)

The Service Delivery Framework for Mental Health and Well-being outlines the standards that patients, clients, carers and their wider families can expect. It sets standards in relation to the prevention, assessment, diagnosis, treatment, care, rehabilitation and palliative care of individuals and communities who currently have or are at a greater risk of developing mental illness.

Research is integral to the development of the standards, which are based upon valid, relevant published research. This includes documents and reports from bodies such as:

- National Institute for Health and Clinical Excellence (NICE) (e.g. Depression in Children and Young People: Identification and management in primary, community and secondary care, 2005);
- The Northern Ireland Association for Mental Health, (e.g. Mental Health Promotion: Building an Economic Case, 2007);
- The Royal College of Psychiatrists (e.g. Carers and confidentiality in mental health - Issues involved in information sharing, 2004); and
- The British Medical Association e.g. (Child and Adolescent Mental Health, 2006).

The framework indicates that research helps to identify early causes of mental illness and consequently what should be done to prevent this continuing into adult life. This is evident in reference to children with conduct disorder, whom research identifies as more likely to have on-going problems if they and their families do not receive early and comprehensive care/treatment⁸⁵.

⁸⁵ Service Framework For Mental Health And Wellbeing, Department of Health, Social Services and Public Safety, (December 2010), pg120.

The framework utilises research to inform the contextual information it provides. This is evident when it discusses children and young people, stating that 20% of which have a mental health problem in any given year⁸⁶.

Within the framework research is highlighted as a primary driver for moving policy forward, for example in referring to Gender Dysphoria, it is noted that 'much more research in the area is required'⁸⁷ in order for the cause and the subsequent treatment to be identified.

Therefore, the Framework notes that research has supported the identification of factors related to mental health and wellbeing, both in terms of causes and preventative measures. Due to the use of established research the framework is able to present factors contributing to mental illness and those which have been associated with good mental health and well-being.

Some of the standards in the framework include, but are not exclusive to:

- A person experiencing early signs of psychosis should have an assessment of their psychological, physical, clinical and social needs including a risk assessment undertaken by a mental health specialist(s) using an appropriate outcome measurement tool to aid diagnosis and age appropriate onward referral;
- A person using mental health services should have an integrated care pathway for their assessment, treatment, care and on-going management where health and social care (including primary care) work in partnership with users and their carers to develop the most appropriate and accessible services; and
- A person and their carers and members of the public, where appropriate, using or accessing mental health services should be provided with evidence-based, targeted mental health and wellbeing information including information in relation to their detention under the Mental Health Order 1986 if applicable.

As a result of extensive research the Service Framework for Mental Health and Well-being represents a comprehensive, accurate record of issues facing the mental health sector and as a result of this knowledge can propose realistic and effective standards for the future.

⁸⁶ Service Framework For Mental Health And Wellbeing, Department of Health, Social Services and Public Safety, (December 2010), pg224.

⁸⁷ Service Framework For Mental Health And Wellbeing, Department of Health, Social Services and Public Safety, (December 2010), pg199.

APPENDIX 2: STATISTICAL INDICATORS OF HEALTH AND WELLBEING IN NORTHERN IRELAND

12 STATISTICAL INDICATORS OF HEALTH AND WELL BEING IN NORTHERN IRELAND

12.1 Cancer

The table below details hospital statistics across Northern Ireland for the years 2006-2011. These figures represent a combination of Clinical and Medical Oncology data and detail hospital bed availability and occupancy levels as well as inpatient and day case admissions.

Table 12.1: Hospital statistics relating to Cancer

Year	Total Available Beds*	Total Occupied Beds	Inpatient Admissions	Day Case Admissions
2006-2007	30941	24997	3533	17815
2007-2008	31322	27419	3817	18901
2008-2009	29220	25383	3565	17686
2009-2010	28980	25852	3626	17425
2010-2011	31310	23972	3213	20265

Source: DHSSPS⁸⁸

* The hospitals referred to are: Belfast City, Cancer Centre, RBHSC (from 2010-2011), Antrim, Ulster, Craigavon Area, Altnagelvin Area, and Tyrone County (from 2010-2011).

This table shows that the total available beds has increased by 369 (from 30941 in 2006-2007 to 31310 in 2010-2011), while the number occupied has decreased by 1025 (from 24997 in 2006-2007 to 23972 in 2010-2011), the lowest level recorded. Likewise inpatient admissions have decreased by 320 (from 3533 in 2006-2007 to 3213 in 2010-2011). However day case admissions increased by 2450 (from 17815 in 2006-2007 to 20265 in 2010-2011).

12.2 Diabetes

The following table provides an overview of the prevalence of diabetes by Health and Social Trust (HSCT) in Northern Ireland, incorporating both type 1 and type 2 diabetes and is also based on QOF figures.

Table 12.2: Diagnosis by trust area 2009/2011*

Area	Adults diagnosed 2011	2009 figures	% increase	Population by Trust Area 2010	% of 2010 population with diabetes.
Belfast HSCT	16,549	15,073	9.7%	335,774	4.9%

⁸⁸ http://www.dhsspsni.gov.uk/index/stats_research/hospital-stats/inpatients.htm

Area	Adults diagnosed 2011	2009 figures	% increase	Population by Trust Area 2010	% of 2010 population with diabetes.
Northern HSCT	18,034	15,954	13%	458,746	3.9%
Southern HSCT	13,043	11,574	13%	358,647	3.6%
South Eastern HSCT	12,886	11,665	9%	346,794	3.7%
Western HSCT	12,181	10,800	13%	299,431	4.1%

Source: QOF, Diabetes UK and NINIS

*Incorporates persons aged 17 years and over.

As shown in the table above, the number of adults diagnosed with diabetes increased between 2009 and 2011 across all five Social Care Trust areas. The most significant rise was in the Northern Health and Social Care Trust, which increased by 2,080 cases between 2009 and 2011. The Belfast Trust experienced the highest number of adults diagnosed and percentage of diabetes per head of population at 4.9%.

The Institute of Public Health (IPH) has also published statistics relating to diabetes. However it should be noted the estimated prevalence rate is higher than estimates from the QOF. This is due to differences in methodology, while the QOF data is based upon persons aged 17 years and over, IPH figures only incorporates persons aged 20 years and over.

Table 12:3: Demographic variation in population prevalence rates in 2007 in Northern Ireland

	Males	Female	Persons	20-29 years	30-59 years	60+ years
Diabetes (Type 1 and Type 2 combined)	4.5%	6.0%	5.3%	0.5%	3.1%	13.4%

Source: Institute of Public Health; 'Making Chronic Conditions Count'

The table shows that the prevalence of diabetes is more common amongst females and increases dramatically with age. The higher prevalence rate amongst older adults along with an ageing population means that the percentage of all adults with diabetes who belong to the older age group will increase. IPH predicts that by 2010 the number of cases of diabetes will have risen by 26,957 to 94,219 (from 67, 262 in 2007), and the prevalence will have increased by 1.3% to 6.6% (from 5.3% in 2007)⁸⁹.

Over the past decade, there has been a marked increase in diabetes mortality with 89 deaths in 2000 and 203 deaths in 2010 (94 men and 109 women)⁹⁰.

In 2010 59% of adults (age 16 or over) were either overweight (36%) or obese (23%) and 27% of children (2-15 years) were overweight or obese in Northern Ireland⁹¹. This is significant when considering the link between weight and the risk of developing diabetes.

⁸⁹ Making Chronic Conditions Count: A systematic approach to estimating and forecasting population prevalence on the island of Ireland, *The Institute of Public Health, (February 2010)*.

⁹⁰ Deaths In Northern Ireland, *Northern Ireland Statistics and Research Agency, (2011)*.

'Obesity and Type 2 diabetes in Northern Ireland' published by the Northern Ireland Audit Office in 2009 provides figures regarding the occurrence of Type 1 and Type 2 diabetes, specifically:

- Type 1 diabetes accounts for 10-15 per cent of all cases in European countries, meaning type 2 accounts for 85-90 per cent⁹².

12.3 Mental Health

Mental Health is a generic and wide ranging term that covers a number of conditions and disorders. The World Health Organisation (WHO) defines mental health as a state of well-being in which an individual realises his or her own abilities, can cope with the normal stresses of life, can work productively and is able to make a contribution to his or her community. When a person becomes mentally unwell this can manifest itself in a number of different forms. For the purposes of this report we have presented information on suicide, self-harm and dementia to provide an overview of the range and prevalence of mental health related issues in Northern Ireland.

It is estimated that one in five adults in Northern Ireland have a mental health condition at any one time and that the annual cost to Northern Ireland of mental illness exceeds £3.5 billion each year⁹³.

The DHSSPS published statistics on activity within the Mental Health and Learning Disability programmes of care (POC) in hospitals within Northern Ireland for the year ending 31 March 2011. The key points which emerged from these statistics included:

- Over the last five years, the total number of admissions to hospital under the mental health programme of care increased by 2.4% (194), from 8,041 in 2006/07 to 8,235 in 2010/11;
- Since 2006/07, the total number of inpatients admitted under the mental health programme of care decreased by 23.4% (1,607), from 6,875 to 5,268 in 2010/11, whilst the number admitted as day cases almost trebled, from 1,166 in 2006/07 to 2,967 in 2010/11;
- Between 2006/07 and 2010/11, the average number of available beds under the mental health programme of care decreased by 23.9% (257) from 1,079 to 821;
- This decrease can also be seen when comparing the average number of occupied beds over the same five-year period. During 2010/11 there was an average of 734 occupied beds, a decrease of 163 (-17.5%) on the 897 occupied beds during the previous year, and a decrease of 238 beds (-24.5%) since 2006/07; and
- Across HSC Trusts, the highest average number of available beds within the mental health programme of care was reported in the Belfast HSC Trust (270.9) whilst the Southern HSC Trust reported the lowest (101.6).

The Northern Ireland Hospital Statistics: Mental Health and Learning Disability (DHSSPS, 2009/10) presents information on activity in mental health and learning disability hospitals in Northern Ireland

⁹¹ Your Health Matters, *Health, Social Services and Public Safety*, (2011).

⁹² Obesity and Type 2 diabetes in Northern Ireland, *Northern Ireland Audit Office*, (2009).

⁹³ Your Health Matters, *Health, Social Services and Public Safety*, (2011)

during the year ending 31 March 2010. It details information on inpatient, day case and outpatient activity, and compulsory admissions under the Mental Health (NI) Order 1986. Specifically it states⁹⁴:

- Between 2005/06 and 2009/10, the average number of available beds at mental health hospitals in Northern Ireland decreased by 10.3% (114.7), from 1,110.2 to 995.5;
- Between 2005/06 and 2009/10, the average length of stay in mental health hospitals increased by almost 7 days, from 47.7 days to 54.4 days; and
- DHSSPS have provided statistics relating to compulsory admission to mental health hospitals for the 2009/10. During which time, there were 1,043 compulsory admissions to mental health hospitals under the Mental Health (NI) Order 1986, of which, 571 were male and 472 were female.

Table 12.4: Rates (crude) (per 100,000 population) of registered suicides in Northern Ireland 3 year rolling average 1997-2009

Registration Year	Rates (crude) (per 100,000 population) of registered suicides in Northern Ireland, 3 year rolling average 1998-2009
2008 - 2010	15.9
2007-2009	14.7
2006-2008	15.4
2005-2007	14.3
2004-2006	12.6
2003-2005	9.8
2002-2004	9.3
2001-2003	9.5
2000-2002	10.4
1999-2001	9.8

Source: PHA Health Intelligence Briefing: Suicide and self-harm in Northern Ireland - February 2011

⁹⁴ Northern Ireland Hospital Statistics: Mental Health and Learning Disability 2009/10, DHSSPS, (19 August 2010).

APPENDIX 3: OVERVIEW OF OTHER RELEVANT NI POLICIES

13 OVERVIEW OF POLICY DOCUMENTS RELATING TO HSC R&D

Table 13:1: Overview of policy documents relating to HSC R&D

Strategy / Policy Document	Summary of Policy / Document
Developing Better Services (DHSSPS, 2002)	<p>The overarching aim of Developing Better Services is to develop a model of 'patient-centred' health care that provides high quality, safe and accessible services. The central vision is described as 'high quality, safe services which are accessible for all and provided by well trained, motivated staff in modern settings'⁹⁵.</p> <p>Under the patient centred model of care, the health service in Northern Ireland is driven by two distinct forces:</p> <ul style="list-style-type: none"> • Greater provision of generalist services within communities, including primary care services, chronic disease management, maintenance and enhancement of the independence of social services, and much of the surgery currently provided on an inpatient basis; and • Greater specialism, especially within acute hospital services. The role of the hospital is to support community-based care services in promoting health and wellbeing. As part of an integrated health system, hospitals need to be used efficiently and innovatively, through work with Managed Clinical Networks, whereby good practice and resources can be shared to the benefit of the patient. <p>The latter point has specific relevance as the Northern Ireland Clinical Trials Network (NICTN) is partially funded by DHSSPS R&D. It promotes high quality cancer care in Northern Ireland by inclusion of patients on a geographically more equitable basis into cancer clinical trials, translational research and other well-organised cancer research studies. Moreover, the Northern Ireland Clinical Research Network (NICRN) is also funded by DHSSPS R&D and supports high quality clinical trials across all DHSSPS Trusts. Thus DHSSPS R&D is of fundamental importance to fulfilling the aims and objectives as set out in the Developing Better Services policy.</p>
Regional Strategy for Health and Wellbeing in Northern Ireland 2005-2025	<p>In 2004 the DHSSPS published 'A Healthier Future: A 20 year vision for Health and Wellbeing in Northern Ireland 2005-2025'. The strategy is a vision for health and wellbeing in Northern Ireland over a twenty year period and it is intended to give the direction of travel for health and social services.</p> <p>This provides an important working strategy and highlights the significance and relevance of R&D to the future of Northern Ireland.</p> <p>The strategy notes that health and social care can provide an important focus for inward investment. By working with the Department for Enterprise, Trade and Investment (DETI) and Invest NI (INI) it is capable of promoting Northern Ireland as a centre of excellence in health</p>

⁹⁵ http://www.dhsspsni.gov.uk/index/hss/developing_better_services.htm

Strategy / Policy Document	Summary of Policy / Document
(DHSSPS, 2004)	<p>and social care research and development. Through partnerships with businesses and universities, treatment and care programmes could be implemented based on cutting edge technologies and techniques, with a view to their commercialisation.</p> <p>It also contains a 'Vision of Information and Communications Technology' (ICT) stating citizens should be able to:</p> <ul style="list-style-type: none"> access reliable information on health and social care issues; access information on the health effects of different lifestyle choices; and access information on their condition and any proposed care and treatment when receiving health and social care. <p>These principles reflect the need for accurate, up to date research in order for them to be fully implemented.</p> <p>The ability for Northern Ireland to continuously renew and modernise its services is directly linked to disseminating its own research and development. It emphasises that Northern Ireland has world class organisations and centres of excellence such as the Cancer Centre at Belfast City Hospital, with research in some cases 'leading to the development of locally tailored solutions, for example in relation to community-based approaches to tackling deprivation'⁹⁶.</p> <p>Research is cited as integral to the future success of the Northern Ireland economy. By promoting innovation in the DHSSPS, it will promote innovation throughout Northern Ireland and attract high technology, high value added inward investment, as well as attracting and retaining leading health and social care professionals.</p> <p>Think/Create/Innovate, the Regional Innovation Strategy for Northern Ireland is also incorporated into this policy⁹⁷. It was published in June 2003 and reviewed in July 2006 to provide a coordinated and consensual framework for the creation of a globally competitive, innovation-driven regional economy in Northern Ireland. It sought to create prosperity within Northern Ireland by using its knowledge, skills and capacity to innovate. It specifically identifies the need for DHSSPS R&D funding to enhance its research links with universities and to consider the application of Knowledge Transfer Partnerships to the health sector.</p>
Reshaping the System: Implications for Northern Ireland's Health and Social Care Services of the	<p>Following the publication of the McKinsey report in 2009 which instructed the government on how to achieve greater productivity within the NHS, the DHSSPS published this report. It set out:</p> <ul style="list-style-type: none"> • The Department's assessment of the funding required to maintain Health and Social Care in Northern Ireland (HSCNI) in its present form over the coming years; • High-level estimates of the cost saving potential of a far-reaching and integrated programme to improve productivity and quality;

⁹⁶ Regional Strategy for Health and Wellbeing in Northern Ireland 2005-2025, *DHSSPS, (2004)*.

⁹⁷ Think, create, innovate: The Regional Innovation Strategy for Northern Ireland, *Department of Enterprise Trade and Investment, (June 2003)*.

Strategy / Policy Document	Summary of Policy / Document
2010 spending review (DHSSPS, 2010)	<ul style="list-style-type: none"> • A vision for a reformed health and social care service for Northern Ireland arising from – and necessary for – these improvements; and • What it will take to successfully make the transition to this future system. Broadly, it stipulated that by 2014 there should be: <ul style="list-style-type: none"> • Enhanced and more effective services in home and community settings; • Better quality of acute care; and • A different service provision landscape; (e.g. primary care centres acting as hubs for integrated community health and social care; fewer acute hospitals, supported by ‘local hospitals’ providing local access to urgent care services). To enable change to happen the report states that a number of enablers must be put in place: <ul style="list-style-type: none"> • Political, professional and managerial leadership across the system; • Capability and capacity to implement the changes; • The right supporting infrastructure and systems; and • Compelling communication of the case for change and vision for the future. To implement the changes set out in this report requires significant research as part of the supporting infrastructure and is dependent upon a qualified research workforce. Clearly there is a role for R&D to identify how efficiency savings could be made without impacting on patient care standards and / or outcomes and how services can be re-structured to be more effective and efficient.
Transforming Your Care; A Review of Health and Social Care in Northern Ireland (December 2011)	This Review aimed to provide a strategic assessment across all aspects of health and social care services, examining the quality and accessibility of services, and the extent to which the needs of patients, clients, carers and communities were being met. It was to bring forward recommendations for the future shape of services and provide an implementation plan. It found that there was an unassailable case for change, which is summarised by these key reasons: <ul style="list-style-type: none"> • To be better at preventing ill health; • To provide patient-centred care; • To manage increasing demand across all programmes of care; • To tackle health inequalities; • To deliver a high-quality, evidence-based service; and

Strategy / Policy Document	Summary of Policy / Document
	<ul style="list-style-type: none"> • To support our workforce in delivering the necessary change. • As a result, 12 key principles for change were identified: • Placing the individual at the centre of any model by promoting a better outcome for the service user, carer and their family; • Using outcomes and quality evidence to shape services; • Providing the right care in the right place at the right time; • Population-based planning of services; • A focus on prevention and tackling inequalities; • Integrated care – working together; • Promoting independence and personalisation of care; • Safeguarding the most vulnerable; • Ensuring sustainability of service provision; • Realising value for money; • Maximising the use of technology; and • Incentivising innovation at a local level. <p>In relations to these principles, it states that all services should be able to demonstrate that they are able to meet well understood measures of quality. This was to include taking account of existing and emerging research on what produces the best outcome.</p> <p>The future model for integrated Health and Social Care devised by this report stipulated that:</p> <ul style="list-style-type: none"> • Every individual will have the opportunity to make decisions that help maintain good health and wellbeing. Health and social care will provide the tools and support people need to do this; • Most services will be provided locally, for example diagnostics, outpatients and urgent care, and local services will be better joined up with specialist hospital services; • Services will regard home as the hub and be enabled to ensure people can be cared for at home, including at the end of life; • The professionals providing health and social care services will be required to work together in a much more integrated way to plan and deliver consistently high quality care for patients; • Where specialist hospital care is required it will be available, discharging patients into the care of local services as soon as their health

Strategy / Policy Document	Summary of Policy / Document
	<p>and care needs permit; and</p> <ul style="list-style-type: none"> • Some very specialist services needed by a small number of people will be provided on a planned basis in the ROI and other parts of the UK. • The impact of this on ten major areas was examined, these were: • Population Health and Wellbeing; • Older People; • People with Long-Term Conditions; • People with a Physical Disability; • Maternity and Child Health; • Family and Child Care; • People using Mental Health Services; • People with a Learning Disability; • Acute Care; and • Palliative and End of Life Care <p>The application of this model to these service areas produced a list of 99 recommendations. A summary of the key themes of were:</p> <ul style="list-style-type: none"> • Quality and outcomes to be the determining factors in shaping services; • Prevention and enabling individual responsibility for health and wellbeing; • Care to be provided as close to home as practical; • Personalisation of care and more direct control, including financial control, over care for patients and carers; • Greater choice of service provision, particularly non-institutional services, using the independent sector, with consequent major changes in the residential sector; • New approach to pricing and regulation in the nursing home sector. • Development of a coherent 'Headstart' programme for 0-5 year old children, to include early years support for children with a disability; • A major review of inpatient paediatrics;

Strategy / Policy Document	Summary of Policy / Document
	<ul style="list-style-type: none"> • In GB a population of 1.8million might commonly have 4 acute hospitals. In NI there are 10. Following the Review, and over time, there are likely to be 5-7 major hospital networks; • Establishment of a clinical forum to ensure professionals are fully engaged in the implementation of the new model; • A changing role for general practice working in 17 Integrated Care Partnerships across Northern Ireland; • Recognising the valuable role the workforce will play in delivering the outcomes; • Confirming the closure of long-stay institutions in learning disability and mental health with more impetus into developing community services for these groups; • Population planning and local commissioning to be the central approach for organising services and delivering change; • Shifting resource from hospitals to enable investment in community health and social care services; and • Modernising technological infrastructure and support for the system. <p>There were some specific proposals relevant to R&D which included:</p> <ul style="list-style-type: none"> • Maintenance of existing and implementation of new screening and immunisation programmes where supported by clinical evidence; and • Incentivisation of Integrated Care Partnerships to support evidence-based health promotion, for example, clinician-led education programmes in the community. • The inclusion of such recommendations highlights the how clinical evidence and research is increasingly used to support the government programmes and that it has a significant role in future health promotion. • Research is used in this report to inform and support the argument that changes within HSC services are a necessity. This is done with reference to the areas of, amongst others, cancer and mental health. It states that further work needs to be done in order to increase cancer survival rates, citing a study by Cancer Research UK and the Department of Health which found that survival rates were 'persistently lower' in Northern Ireland, Denmark, England and Wales than in Australia, Canada and Norway⁹⁸. • Research applicable to mental health in is also referenced. It is stated that investment in mental health services in Northern Ireland is up to 30% less than in other parts of the UK because the model over consumes resource in hospital provision. Research by the Alzheimer's society is also referenced and is reported to have found that people with dementia stay longer in hospital than other

⁹⁸ The study was published in the peer-reviewed medical journal *The Lancet*, as quoted in *Transforming Your Care; A Review of Health and Social Care in Northern Ireland, DHSSPS, (December 2011)*.

Strategy / Policy Document	Summary of Policy / Document
	<p>people undergoing similar procedures. Such research further supports the overall conclusion of the report that planned and organised change is necessary to improve care and that preventative approaches can deliver better outcomes.</p>
<p>Quality 2020: A 10-Year Strategy to Protect and Improve Quality in Health and Social Care in Northern Ireland (DHSSPS, November 2011)</p>	<p>This strategy outlines a 10-year vision for HSC in Northern Ireland. It states what is to be achieved and specific goals and objectives to make the vision a reality. By 2020 it is envisaged that Northern Ireland will be recognised as ‘an international leader for excellence in health and social care’.</p> <p>It identifies a number of design principles that should inform planners and practitioners over the next 10 years, stating that a high quality service should:</p> <ul style="list-style-type: none"> • Be holistic in nature; • Focus on the needs of individuals, families and communities; • Be accessible, responsive, integrated, flexible and innovative; • Surmount real and perceived boundaries; • Promote wellbeing and disease prevention and safeguard the vulnerable; • Operate to high standards of safety, professionalism and accountability; • Be informed by the active involvement of individuals, families and communities, HSC staff and voluntary and community sectors; and • Deliver value for money ensuring that all services are affordable, efficient and cost-effective. <p>In delivering high quality health and social care this strategy also identifies the need to promote the following values:</p> <ul style="list-style-type: none"> • Empowerment - supporting people to take greater responsibility for their own health and social wellbeing, and putting people at the centre of service provision; • Involvement - ensuring that service users, their carers, service providers and the wider public are meaningfully involved, and if necessary supported, at all stages in the design, delivery and review of services at an operational and a strategic level so that, as far as possible, services are personalised; • Respect – showing respect for the dignity of all people who use the service, their carers and families and for all staff and practitioners involved in service delivery; • Partnership - engaging collaboratively across all disciplines, sectors and specialisms in health and social care, including the voluntary and independent sectors, to ensure an integrated team-based approach, and working with people in their local communities;. • Learning – promoting excellence in service delivery and founded on evidence-based best practice to achieve improvement and

Strategy / Policy Document	Summary of Policy / Document
	<p>redress;</p> <ul style="list-style-type: none"> • Community - anchoring health and social care in a community context; • Continuity - ensuring a co-ordinated and integrated approach to health and social care in all health and social care sectors, and ensuring continuity of care across the system; and • Equity and Equality - fairness and consistency in service development and delivery. <p>To make the vision a reality, the strategy identifies 5 strategic goals:</p> <ul style="list-style-type: none"> • Transforming the Culture; creating a new and dynamic culture that is even more willing to embrace change, innovation and new thinking that can contribute to a safer and more effective service; • Strengthening the Workforce; essential every effort is made to equip those who work in health and social care with the skills and the knowledge they require; • Measuring the Improvement; need more reliable and accurate means to measure, value and report on quality improvement and outcomes; • Raising the Standards; the service requires a coherent framework of robust and meaningful standards against which performance can be assessed, which means involving service users, carers and families in the development, monitoring and reviewing of standards; and • Integrating the Care; there is a need to ensure integrated care should cross all sectoral and professional boundaries to benefit patients, clients and families. <p>To achieve these it lists 10 key objectives. Most relevant to R&D is objective 6 which states 'We will promote the use of accredited improvement techniques and ensure that there is sufficient capacity and capability within the HSC to use them effectively'. To do this it proposes that capacity and capability is built up within the HSC to achieve the desired results, and there is development of the audit techniques used to measure how standards are being met. Moreover, research and innovation is be encouraged, and Benchmarking with other health and social care organisations outside Northern Ireland is be conducted to ensure that there is up-to-date information available on best practice.</p>
<p>Connected Health and Prosperity: Memorandum of</p>	<p>This document defines a Memorandum Of Understanding (MOU) to develop Health, Social Care and Economic opportunities in Connected Health for Northern Ireland, through better coordination of public assets and funding. This document is representative of the fact that the Minister for Health, Social Services and Public Safety, and the Minister for Enterprise, Trade and Investment agreed on greater co-operation between the DHSSPS and Invest NI in taking forward Connected Health solutions. It is hoped this will contribute to</p>

Strategy / Policy Document	Summary of Policy / Document
<p>Understanding Between The Department of Health, Social Services and Public Safety, and Invest Northern Ireland (Sponsored by the Department of Enterprise, Trade and Investment) (DHSSPS, December 2011)</p>	<p>improved health and well-being, patient care and support the wider economic development strategy.</p> <p>It provides a definition of Connected Health as a new model for healthcare delivery that uses technology to provide healthcare remotely. It aims to maximise healthcare resources and provide increased, flexible opportunities for patients (and often families/caregivers) to engage with clinicians and better self-manage their care. Connected Health encompasses telehealth, remote care (such as home care), disease, and lifestyle management, and can contribute to the management of chronic diseases such as Congestive Heart Failure (CHF); Coronary Heart Disease (CHD); Chronic Obstructive Pulmonary Disease (COPD); and diabetes.</p> <p>The Memorandum Of Understanding identifies where the organisations can work collaboratively on the Connected Health agenda. It states that the DHSSPS has a key role to play in contributing to the delivery of the Programme for Government and Economic Strategy, and is playing an increasingly supportive role in assisting Invest NI to deliver its objectives.</p> <p>It is suggested that the DHSSPS can strengthen its role in relation to Connected Health by:</p> <ul style="list-style-type: none"> • Supporting clinical research on Connected Health in Northern Ireland; • Supporting clinical collaborations including clinical trials relevant to Connected Health; • Supporting the development of a Connected Health ecosystem to stimulate innovation, application of connected health solutions and private sector investment; • Encouraging the private sector to invest in the delivery of Connected Health solutions for health and social care; • Participating in international collaboration with equivalent organisations, the private sector and academic research groups; and • Using innovative procurement processes to encourage new Connected Health solutions to meet clinical and business needs. <p>This will support Invest NI to promote Northern Ireland as a pro-business region in the Health and Life Sciences sector in the following project areas:</p> <ul style="list-style-type: none"> • Shared services; • ICT / Software; • Clinical services; • Connected Health; and • Service innovation. <p>It is claimed that Invest NI can support the role of the DHSSPS by targeting mobile Connected Health R&D and innovation projects, which address the priorities of DHSSPS, and other health authorities in the UK (and beyond). This would include particularly the management</p>

Strategy / Policy Document	Summary of Policy / Document
	<p>and prevention of chronic disease, such as:</p> <ul style="list-style-type: none"> • Congestive Heart Failure (CHF); • Coronary Heart Disease (CHD); • Chronic Obstructive Pulmonary Disease (COPD); • Diabetes; and • Stroke. <p>The document states that these conditions are linked to the proportion of the ageing population in Northern Ireland, which is expected to double in size by the year 2025. Moreover, it claims health service providers in the UK and the western world recognise that such conditions account for approximately 70% of present health service budgets and that current service models are unsustainable, which necessitates a different approach through Connected Health. This however requires investment in R&D and service innovation, met by the private and public sectors alike.</p> <p>It is proposed that Invest NI can play a role in targeting world-class Connected Health R&D and innovation investment to enable the DHSSPS to provide world-class solutions, which will deliver a modern high-quality and efficient public service.</p> <p>This is to be done through wider collaboration, detailed in a strategic action plan. In the first four years this will take account of four key areas:</p> <ul style="list-style-type: none"> • Targeted Connected Health R&D and innovation funding, including optimising assets across the various organisations; • The development of the NI Connected Health Eco System, along with international linkages; • Collaboration with international regions, particularly within Europe and North America, for mutual gain; and • Promoting the Connected Health agenda internationally, particularly within Europe and North America. <p>This strategic plan is to be produced and agreed within 6 months of the signing of the Memorandum Of Understanding (by June 2012)</p>

Source: RSM McClure Watters (2012)

These strategies note the importance of investment in HSC R&D to enable the health sector to contribute to the wider economy.

13.1 Overview of strategy documents relating to cancer

In the following table we have provided an overview the main strategic and policy documents relating cancer.

Table 13.2: Overview of strategy documents relating to cancer

Strategy / Policy Document	Summary of Policy / Document
Skin Cancer Prevention: Strategy and Action Plan 2011-2021 (DHSSPS, 2011)	<p>This outlines the rate of skin cancer within Northern Ireland, stating that in the period 2005-2009 an average of 3,128 new cases were diagnosed annually, and around 261 of which were malignant melanomas, the most serious type of skin cancer. In addition it claims the incidence of all forms of skin cancer has increased over recent decades, with malignant melanoma alone causing an average of 52 deaths per year during 2007-2009. In order to improve the survival rates it is suggested that increased public awareness around the importance of early detection is needed.</p> <p>It details the strategies used to combat this rise to date, such as the Northern Ireland Melanoma Strategy Implementation Group, however it states that due to the emergence of new scientific evidence and research, a new strategy and action plan is needed.</p> <p>The overall long-term aim of this strategy is to reduce the incidence of skin cancer and deaths from it among people in Northern Ireland. It sets out its objectives as:</p> <ul style="list-style-type: none"> • To increase public awareness regarding the dangers of overexposure to UV radiation from sunlight and from artificial tanning devices; • To reduce overall use of artificial tanning devices; • To increase individual and organisation-wide practice of sun safety behaviours; • To increase awareness about the early signs of skin cancer and the need for prompt attention; • To encourage earlier detection and treatment of malignant melanomas; and • To promote further research into knowledge, attitudes and behaviour and the epidemiology of skin cancer. <p>By 2016 the targets it sets out to achieve are:</p> <ul style="list-style-type: none"> • By 2016 to increase by 10% the proportion of men who take protective measures while in the sun to 90% (80% in 2008); • By 2016 to increase by 5% the proportion of the population who check their skin for signs of cancer, once a month or more, to 31% (26% in 2008); and • By 2016 to reduce by 30% the proportion of 16-25 year olds currently using sunbeds (from a baseline of 5% of all 16-25 year olds).

13.2 Overview of strategy documents relating to diabetes

The following table summarises the key policy and strategy documents relating to diabetes in Northern Ireland.

Table 13.3: Overview of strategy documents relating to diabetes

Strategy / Policy Document	Summary of Policy / Document
<p>A Fitter Future For All: Consultation Report: Obesity Prevention Framework for Northern Ireland 2011-2021 (DHSSPS, 2011)</p>	<p>Developed by the DHSSPS in 2011, this Framework begins to address the issues that have led to rising obesity levels and proposes a coordinated approach across government, sectors and society to deal with them. It makes a direct linkage between obesity and type 2 diabetes, stating that epidemiological research has indicated that obesity increases the risk of type 2 diabetes as well as other serious conditions. Moreover, it is suggested that obesity could be a contributing factor in death and prevalence rates associated with diabetes. The financial cost is also highlighted, referring to the Northern Ireland Audit Office Report 'Obesity and Type 2 diabetes in Northern Ireland'⁹⁹ which suggests that those suffering from diabetes is costing the health service across the UK around one million pounds every hour. The main aim from this framework is not just to halt the rise of obesity, but to reduce its level in Northern Ireland to 2005/06 levels by 2021.</p>
<p>'Obesity and Type 2 diabetes in Northern Ireland' (Northern Ireland Audit Office, 2009)</p>	<p>This report examines the effectiveness of health promotion strategies by the DHSSPS in influencing the risk factors of unhealthy eating and physical inactivity which can lead to the occurrence of type 2 diabetes. It details the impact of risk factors on the development of type 2 diabetes, highlighting that a failure to adequately address the rise of this chronic condition will affect individuals and their families, and the wider community, in terms of higher health care costs and reduced productivity. It emphasises that prevention plays a fundamental part in the control of type 2 diabetes and outlines how the government has attempted to implement effective measures. These included initiatives such as the Workplace Health Strategy, the Promoting Mental Health Strategy and Action Plan and the Northern Ireland Walking Action Plan. However it claims that as yet these have failed to halt the rise in obesity which underpins a similar rise in type 2 diabetes. In addition, it details the policy framework 'Investing for Health and Fit Futures' which provides a coherent structure and common branding for a wide range of health promotion programmes. Research is presented as integral to this framework and forms one of the policy advisory groups, which it states contributes to the integrated approach to addressing obesity and associated conditions. Moreover, as part of its recommendations it states that for the process to move forward the DHSSPS needs to include and deliver programmes demonstrated by research to be effective.</p>
<p>'Putting Feet First' (Diabetes UK, 2012)</p>	<p>Diabetes launched a GB wide campaign, which hopes to reduce amputations by 50% in five years¹⁰⁰. There were approximately 199 lower limb diabetes related amputations in Northern Ireland between March 2010 and April 2011, and of this figure Diabetes UK Northern Ireland has said 80% were preventable¹⁰¹.</p> <p>Recent figures show that people with diabetes are not receiving essential health</p>

⁹⁹ Obesity and Type 2 diabetes in Northern Ireland, *Northern Ireland Audit Office*, (2009).

¹⁰⁰ Diabetes amputation rates show huge regional variation, BBC News, <http://www.bbc.co.uk/news/health-17270379>, 7 March 2012.

¹⁰¹ Call to end diabetes amputations, *Diabetes UK*, <http://www.bbc.co.uk/news/uk-northern-ireland-17340485>, 13 March 2012.

Strategy / Policy Document	Summary of Policy / Document
	checks and as a result amputation is just one complication that diabetes patients are at risk of. According to figures from GP practices, around 5000 people have not received a vital check of their kidneys which puts them at higher risk of kidney failure, and 4220 people have not received retinal screening testing for eye disease, a leading cause of blindness in the country's working-age population. It is claimed that 90 per cent of sight loss could have been avoided if patients had been identified early enough and treated appropriately. ¹⁰²

Therefore the Obesity Prevention Framework shows that research in the field of diabetes is effectively used to inform wider policy issues, while it emphasises that there needs to be 'a special emphasis on research' if the desired outcomes are to be achieved. This is further emphasised in the Audit Office report, which highlights research as one of the determining factors in the progression of a diabetes strategy.

13.3 Overview of strategy documents relating to mental health

The following table provides an overview of the key policy and strategy documents relating to mental health in Northern Ireland.

Table 3.3: Overview of strategy documents relating to mental health

Strategy / Policy Document	Summary of Policy / Document
Counting the Cost: The Economic and Social Costs of Mental Illness in Northern Ireland (June 2004)	Published by The Northern Ireland Association for Mental Health in collaboration with the Sainsbury Centre for Mental Health, this paper presented an estimate of the economic and social costs of mental illness in Northern Ireland during the period 2002/03. Some of conclusions found by this study included: <ul style="list-style-type: none"> • Mental illness is costly in economic and social terms. This is demonstrated by the estimated figure of £2852 million for the total costs of mental illness; • The benefits of reducing the prevalence and severity of mental health problems are very substantial when highlighted in financial terms; • Mental illness is one of the largest single health problems in our society; • Northern Ireland has a higher overall prevalence of mental health problems of a magnitude estimated at 25% higher than England; and • Comparative studies have indicated that there is a lower spend on mental health services in Northern Ireland than in England. To be on parity with England the amount spent would need to be increased by some £60.2 million, an increase of 26.3 per cent.
Protect Life: A Shared	Suicide and self-harm is an important aspect of mental health and is a major public

¹⁰² 6000 people with diabetes in Northern Ireland at risk of amputation, *Diabetes UK*, http://www.diabetes.org.uk/About_us/News_Landing_Page/Nearly-6000-people-with-diabetes-in-NI-at-risk-of-amputation/, 8 September 2011.

Strategy / Policy Document	Summary of Policy / Document
<p>Vision: The Northern Ireland Suicide Prevention Strategy and Action Plan 2006-2011.</p>	<p>health concern. As a result of increasing concern about the rising number of suicides, especially amongst young people, in October 2006 the DHSSPS published the Protect Life strategy. The overall aim of this policy was a 10% reduction in the overall suicide rate by 2008 and a further 5% reduction by 2011. One of the overarching actions to be taken to achieve this was to initiate further in-depth research into the underlying causes of suicide and self-harm in Northern Ireland. The 'Review of the Evidence Base for Protect Life – A Shared Vision: The Northern Ireland Suicide Prevention Strategy Final Report' was published in January 2010. It recommended that actions for which substantial and consistent research evidence was available be implemented at national level as a matter of priority in the next phase of Protect Life. Thus demonstrating the role research has and is envisaged to play in future policy.</p>
<p>Bamford Review of Mental Health and Learning Disability (2007)</p>	<p>The Bamford Review was an independent review of the effectiveness of current policy and service provision relating to mental health and learning disability, and of the Mental Health (Northern Ireland) order 1986. It called for:</p> <ul style="list-style-type: none"> • the mental health of the whole community to be promoted and protected through preventative action; • people with a mental health need or a learning disability to be valued and given rights to full citizenship, equality of opportunity and self-determination; and • reform and modernisation of services that will make a real and meaningful difference to the lives of people with a mental health need or a learning disability, to their carers and families. <p>The review produced a series of 10 reports between June 2005 and August 2007, which together represent a far-reaching vision for radical reform and modernisation of mental health and learning disability law, policy and services. The review indicated a considerable number of areas of research need. These recommendations for research were further developed in the Bamford Action Plan launched by the Minister for HSSPS in 2009.</p>

The above table provides an overview of the role research plays in the development of policy and how it underpins past, current and future strategy. Moreover, it is demonstrated that despite significant work there remains a number of unanswered questions that require further research if HSC policy and the knowledge base on which it depends is to progress.

13.4 Summary of relevant NI policies

This review of the key strategic and policy documents relating to DHSSPS R&D highlights the following key issues:

- A number of key policy and strategy documents in the UK have demonstrated the need for health sector R&D, its overall importance to the economy and the key role it plays in the planning and delivery of health and social services;
- In a Northern Ireland context, each of the three areas being considered in this study (Cancer, Diabetes and mental health), have associated Service Delivery Frameworks. Within these Framework documents R&D has been noted as important in setting standards for the delivery of health services as set out in the Programme for Government;

- A wide range of other policies and strategies such as Developing Better Services (DHSSPS, 2002) and the Regional Strategy for Health and Wellbeing in Northern Ireland 2005-2025 (DHSSPS, 2004) have noted the importance of investment in HSC R&D and its subsequent contribution to the wider economy; and
- Documents relating specifically to the three areas of research, such as 'A Fitter Future For All: Consultation Report: Obesity Prevention Framework for Northern Ireland 2011-2021' (DHSSPS, 2011) and 'Protect Life: A Shared Vision: The Northern Ireland Suicide Prevention Strategy and Action Plan 2006-2011', emphasise the importance of valid, published research in their construction and that continued research is fundamental to their future development.

As such R&D is an important factor in the development and delivery of health and social services in Northern Ireland. In addition to this, the UK Government have developed a strong policy and economic argument in support further development with the field of health research.

APPENDIX 4: FUNDING FROM HSC R&D

14 FUNDING FROM HSC R&D

14.1 Diabetes R&D Funding

Table 14.1: Diabetes R&D Funding 1998 – 2011 (Projects and fellowships only, i.e. non-network expenditure)

Year	R&D Funding to Diabetes	Total R&D Spend	Percentage of total R&D spend on Diabetes
1998-1999	6,603	192,016	3%
1999-2000-	65,307	761,380	9%
2000-2001	144,561	1,603,438	9%
2001-2002	295,811	4,162,296	7%
2002-2003	479,587	7,508,448	6%
2003-2004	596,099	9,870,738	6%
2004- 2005	554,102	10,571,266	5%
2005- 2006	563,759	11,744,079	5%
2006-2007	621,438	11,514,263	5%
2007-2008	729,998	11,542,741	6%
2008- 2009	930,352	13,537,522	7%
2009- 2010	695,093	13,343,461	5%
2010-2011	204,269	11,820,157	2%
2011- 2012	78,345	10,288,308	1%

Source: HSC R&D

From 1998 to-date on average 5% of total R&D funding has been spent on Diabetes research and development. The financial years 1999/00 and 2000/01, saw the highest percentage spend on Diabetes with each representing 9% of total R&D spend. Over the past three years, the total percentage spend on diabetes has been decreasing from 5% in 2009/10 to 1% in 2011/12.

14.2 Mental Health R&D Funding

Table 14.2: Mental Health R&D Funding 1998 - 2011

	R&D Funding to Mental Health	Total R&D Spend	Percentage of total R&D spend on Mental Health
1998-1999	0	192,016	0
1999-2000-	6,646	761,380	0.9

	R&D Funding to Mental Health	Total R&D Spend	Percentage of total R&D spend on Mental Health
2000-2001	35,912	1,603,438	2.2
2001-2002	71,147	4,162,296	1.7
2002-2003	253,136	7,508,448	3.4
2003-2004	559,414	9,870,738	5.7
2004- 2005	957,301	10,571,266	9.1
2005- 2006	986,350	11,744,079	8.4
2006-2007	787,600	11,514,263	6.8
2007-2008-	573,364	11,542,741	5
2008- 2009	268,910	13,537,522	2
2009-2010	239,665	13,343,461	1.8
2010-2011	482,373	11,820,157	4.1
2011-2012	498,648	10,288,308	4.8

Source: PHA R&D Office

From 1998 to-date on average 4% of total R&D funding has been spent on Mental Health research and development. 2004 – 2007 seen the highest percentage of R&D funding spent on Mental Health representing a total of 24% over the three years. Subsequent to this, funding in this area continued to decrease with only 1.8% of total R&D funding spent in this area in 2009/2010. Recently, in 2010/11 and 2011/12 funding has since increased to 4.1% and 4.8% respectively.

14.3 Cancer R&D Funding

Table 5.7: Cancer R&D Funding 1998 – 2011 ((Projects and fellowships only, i.e. non-network expenditure)

	R&D Funding to Cancer	Total R&D Spend	Percentage of total R&D spend on Cancer
1998-1999	27,171	192,016	14%
1999-2000-	97,281	761,380	13%
2000-2001	236,067	1,603,438	15%
2001-2002	913,262	4,162,296	22%
2002-2003	1,192,005	7,508,448	16%
2003-2004	1,357,656	9,870,738	14%
2004- 2005	1,463,023	10,571,266	14%
2005- 2006	1,649,387	11,744,079	14%
2006-2007	1,631,447	11,514,263	14%
2007-2008-	1,322,448	11,542,741	11%
2008- 2009	1,152,849	13,537,522	9%
2009-2010	1,442,092	13,343,461	11%
2010-2011	1,499,763	11,820,157	13%
2011-2012	1,362,148	10,288,308	13%

Source: HSC R&D

From 1998 to-date on average 14% of total R&D funding has been spent on cancer R&D. The highest percentage of R&D spend was during the year 2001/02 where 22% was allocated to this research area. From 2003/04 – 2006-07 funding steadied out at 14% of total R&D spend, followed by a slight decrease to 9% in 2008-09. In recent years funding has increased to around 13% of total R&D spend.

14.4 Network Expenditure for Cancer and Diabetes

Table 5.8: R&D Funding 1998 – 2011 Network Expenditure for Cancer and Diabetes

	Cancer Network	NICRN (Diabetes)	Total NICRN Network Expenditure	Total Network Expenditure	Percentage Total NICRN Spend Diabetes	Percentage Total Network Spend Diabetes
2002-2003	409,771			409,771		
2003-2004	365,637			365,637		
2004-2005	415,286			415,286		
2005-2006	529,821			529,821		
2006-2007	586,908		26,125	613,033		
2007-2008-	587,466	7,849	109,872	705,187	7.1	1.1
2008-2009	612,173	40,132	831,582	1,483,887	4.8	2.7
2009-2010	812,904	119,840	1,188,285	2,121,029	10.1	5.7
2010-2011	905,365	148,829	1,618,683	2,672,877	9.2	5.6
2011-2012	922,700	161,081	1,726,496	2,810,277	9.3	5.7

Source: HSC R&D

APPENDIX 5: CONSULTEES

Name	Organisation
Carolyn Harper	PHA R&D Staff (Director of Public Health)
Dr Michael Neely	PHA R&D Staff (Assistant Director of Public Health)
Richard Wilson	Research Group Leader, Cancer Research Group
Peter Maxwell	Research Group Leader, Diabetes Research Group
Brendan Bunting	Research Group Leader, Neuroscience and Mental Health
Professor Ian Young	HSC Director of R&D Belfast HSCT Centre of Excellence for Public Health (Director)
Dr Maurice O'Kane	HSC Director of R&D Western HSCT
Dr Des Rooney	HSC Director of R&D Northern HSCT
Dr Peter Sharpe	HSC Director of R&D Southern HSCT
Dr David Hill/Paul Carlin	HSCT Director of R&D South Eastern HSCT
Mr John Compton	Health and Social Care Board (Chief Executive)
Frank Kee	Centre of Excellence for Public Health QUB
Professor James C. McElnay	Queens University Belfast (Pro-Vice-Chancellor for Research)
Prof Hugh McKenna	University of Ulster (Pro-Vice-Chancellor, Research and Innovation)
Sam Kinghan Gary Campbell	Invest NI (Knowledge Transfer Team, Innovation, Research and Technology Division)
Glenn Houston/ David Stewart	RQIA
Ken Logue	Atlantic Philanthropies (Senior Vice President for Programmes)
Jane Cope	National Cancer research
Eddie Rooney	Chief Executive PHA
Dr Paul Biagioni	Northern Ireland Clinical Research Network (Senior Manager)
McCance, Professor David	Consultant Physician/Endocrinologist
Gavin, Dr Anna	Director NI Cancer Registry
Prof Paul Harkin	Centre for cancer research and cell Biology, QUB
Professor Patrick Johnston	Dean, School of Medicine, Dentistry and Biomedical Sciences (JA)
Professor Roy McConkey	Professor of Developmental Disabilities

APPENDIX 6: INTERNATIONAL BENCHMARKING

15 INTERNATIONAL BENCHMARKING

15.1 Introduction

Based on the level of evidence available and the existence of other studies, the three countries chosen for benchmarking were:

- **England:** It has the largest body of knowledge on the value of medical research, has relatively simple ways to track research inputs, and is a similar funding and research environment to Northern Ireland;
- **Sweden:** It has worked on socio-economic impacts of health R&D, in particular in comparison to other countries approaches;
- **Canada:** It has a clear main government funder of health research, organised into subject specific institutes that need to report on impacts. Also has a pan-Canadian framework/indicators for return on investment in health research.

Within each benchmark country we assess the research inputs, health status around the three disease areas (cancer, diabetes and mental health) and explore any existing approaches to measuring impacts of research funding. We then classify the main impacts of research in the countries according to the impact categories identified in the Payback Assessment of Northern Ireland in chapter 6.

15.2 England

In England there are very few funders of health research who only fund research in England (they also fund other parts of the UK).¹⁰³ The main exception to this rule is the English Department of Health (DH) R&D funding, which in 2006 formed between 5-15% of the UK Clinical Research Collaboration (UKCRC) identified health research funding in the UK.¹⁰⁴ With English DH funding for research now distributed through the National Institute for Health Research (NIHR), there are significant levels of information on funding, activities and some evidence on impacts (although NIHR is a relatively new entity since 2006). NIHR in 2010/11 funded £210.5m in research grants, £604m in infrastructure funding, £81.4m in funding for people (through the NIHR Faculty funding) and £24.4m on research management systems.¹⁰⁵ Funding at NIHR is more aligned with the application on basic research performed through other funders (predominantly the Medical Research Council [MRC] and Wellcome Trust) (Figure).

¹⁰³ If we make an assumption that all research funders that work across the UK have a split that reflects that of health research funding by the independent departments of health R&D budgets, then we can assume that England's share of any UK funding total (and potentially impact total) would be around 89%. This is based on the funding levels of each DH identified in the 2006 Cooksey Report: Cooksey (2006). *A Review of UK Health Research Funding*. London, UK: HM Treasury. p22-24.

¹⁰⁴ UK Clinical Research Collaboration (2006). *UK Health Research Analysis*. London, UK: UKCRC.

¹⁰⁵ Research & Development Directorate (2011). *National Institute for Health Research Annual Report 2010/11*. London, UK: English Department of Health.

Figure 1: Research funding provided by the English Department of Health.



As part of the NIHR approach, and that of other major funding bodies such as the MRC and Wellcome Trust, there is a focus in England (and the UK more broadly) on understanding and monitoring the outputs and outcomes of research. This varies from anecdotal evidence of research successes, all the way to the return on investment study funded jointly by the MRC, Wellcome Trust and the Academy of Medical Sciences (that identified Return On Investment for research in the UK on cardiovascular disease and mental health).¹⁰⁶ That study identified rates of return of 39% and 37% for cardiovascular and mental health research respectively – there is no reason to suspect that these rates of return would differ greatly if only England were considered as the unit of analysis.

15.2.1 Cancer

Cancer research in England is predominantly funded by the NIHR, MRC, Wellcome Trust and Cancer Research UK (CRUK). CRUK funded £332m worth of cancer research in 2011, although this includes funding to all of the UK.¹⁰⁷ Using our assumption of 89% of research funding in the UK can be allocated to England (see footnote 48), this translates as an estimated £295m funding for English cancer research through CRUK. For NIHR, Wellcome Trust and MRC it is difficult to identify the amount or proportion of funding that was allocated to cancer alone. In studies that have estimated the proportion of funding to a single disease area, individual grant data over large time periods has been used to estimate total funding to the disease area.¹⁰⁸ In the current study, such an analysis is not feasible (nor entirely necessary). In 2002 the estimated total spend on cancer research in the UK was £250m; in 2006 it was estimated at £393m. Again, with our assumption of 89% of that being spent in England, the total cancer spend in 2002 would have been estimated at £223m, and at £350m in 2006.¹⁰⁹ This level of research spending is high, but is roughly linked to the burden of disease for cancer (Figure). In fact, between 2004 and 2006, cancer prevalence in England rose by over 5% (for 1, 5 and 10 year prevalence rates).¹¹⁰

¹⁰⁶ Buxton et al. (2008). *Medical research - what's it worth? Estimating the economic benefits from medical research in the UK*. London, UK: Health Economics Research Group, Office of Health Economics and RAND Europe.

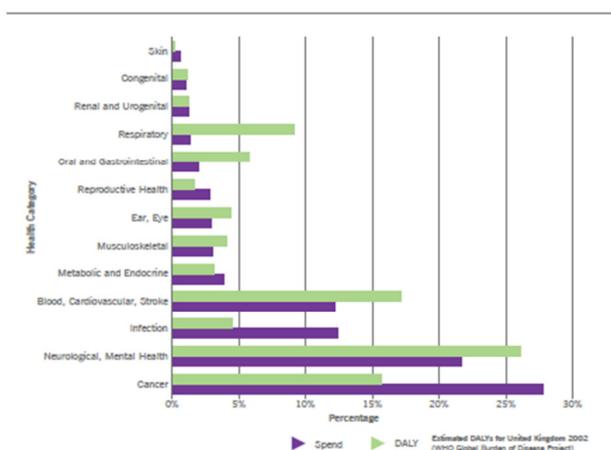
¹⁰⁷ Cancer Research UK (2011). *Annual Report and Accounts 2010/11*. London, UK: CRUK.

¹⁰⁸ Buxton et al. (2008). P17.

¹⁰⁹ National Cancer Research Institute (2009). *Analysis of the National Cancer Research Portfolio 2002-2006*. London, UK: NCRI

¹¹⁰ Maddams and Moller (2010). *One, Five and Ten Year Cancer Prevalence by Cancer Network, UK, 2006*. London, UK: National Cancer Intelligence Network.

Figure 2. Proportion of spend on research versus proportion of burden of disease (using DALYs). Taken from UKCRC (2007)



With numerous players in the cancer research area, there is no single approach to measuring impacts from cancer research in England. The MRC, Wellcome Trust and NIHR all have approaches to measuring impacts, but none specifically investigates cancer research (and only NIHR looks specifically at England). The different approaches to measuring research impact are covered in section 15.2.4, but it is notable that the only major cancer specific funder in England, CRUK, do not seem to have a standardised approach to measuring and monitoring research impacts, rather they maintain a rich catalogue of success stories that have arisen from CRUK funding.¹¹¹

15.2.2 Diabetes

As with cancer, the main public sector funders of health research in the UK do not maintain specific records on the funding for diabetes research. The main charity funder of diabetes research is Diabetes UK, who in the period 2005-2010 provided just under £30m to research in the UK. Using our approximation of 89% of UK research funding going to England (see footnote 48) then this is an input of nearly £27m to English diabetes research. In 2009, it was estimated that the MRC and NIHR provided a combined £51m to diabetes research, although it is difficult to identify what proportion of that went to English diabetes research.¹¹²

Diabetes in the UK has been on the rise, with an increase in people diagnosed of over 1.2m since 1996. This is projected to continue to rise, with estimates of 4m people with diabetes by 2025. In England in 2009, over 5% of the population was diagnosed as diabetic (over 2.2m people). This leads to great costs to the system, with the cost to the NHS in England at around £9bn per year.¹¹³

As with cancer research, the main public sector funders in England for diabetes are the MRC and NIHR. While both of these funding groups do keep information on the condition under study,¹¹⁴ this

¹¹¹ <http://info.cancerresearchuk.org/cancerandresearch/progress/> and <http://info.cancerresearchuk.org/cancerandresearch/ourcurrentresearch/>

¹¹² Juvenile Diabetes Research Foundation (2010). *Parliamentary Briefing*. London, UK: JDRF.

¹¹³ Diabetes UK (2010). *Diabetes in the UK 2010: Key statistics on diabetes*. London, UK: Diabetes UK.

¹¹⁴ The measurement approaches of MRC, NIHR and Wellcome Trust are outlined in section 15.2.4.

information is difficult to gather, since it relates to individual grants and does not classify grants as “diabetes”. This means that despite structures in place to analyse the impacts of research funded by MRC and NIHR, there is no clear data on the impacts for diabetes funding. Diabetes UK has no clear framework for evaluating research impacts, but in its latest research strategy, it does identify the need to evaluate research to show: international competitiveness, improvements for people with diabetes, changes to clinical guidance or health policy, development of new treatments and further funding of research.

15.2.3 Mental Health

Mental health research inputs are difficult to track in England, not only because funders are UK-wide, but also because definitions of mental health research vary across funders (and even within funders over time). Recent estimates of mental health research spending in the NHS put the 2002 figure at £129m,¹¹⁵ figures from 2006 identified that mental health research received 6% of the total R&D spend from the public sector on health research (around £57m),¹¹⁶ and in 2010 the Science and Technology Select Committee of parliament identified that DH R&D are the largest single funder of mental health research in England.¹¹⁷ In short, it is difficult to accurately identify current English research spending on mental health research.

Mental health as a health condition is one of the most prevalent in England, with a survey in 2000 identifying that 1 in 6 people had experienced some form of common mental health symptom in the week prior to being surveyed.¹¹⁸ In the 2007 survey, this number was very similar (just under 1 in 7).¹¹⁹ The cost of mental health issues is also high in the UK, with an estimated cost of over £105bn in 2010.¹²⁰

In terms of monitoring impacts from mental health research, since NIHR (the funding arm of DH R&D) is the main public funder of mental health research, most impact information is likely to be collected by them. However, NIHR’s research reporting is still in its early stages and as such doesn’t yet have information available on mental health research impact (there is also a complication over identifying what research is mental health within the NIHR funding envelope). However, in 2008, a study by the Health Economics Research Group, the Office of Health Economics and RAND Europe did look at long-term impacts from mental health research in the UK (not just England). The findings from this study will be identified in the next section.

¹¹⁵ Clarke and Chilvers (2005). *Mental health research system in England: yesterday, today and tomorrow*. *Psychiatric Bulletin*, 29:441-445.

¹¹⁶ UKCRC (2006).

¹¹⁷ See: <http://www.publications.parliament.uk/pa/cm200910/cmselect/cmsctech/335/335we02.htm>

¹¹⁸ London Health Observatory (no date). *Mental Health Prevalence*. Available at:

http://www.lho.org.uk/LHO_Topics/Health_Topics/Diseases/MentalHealthPrevalence.aspx

¹¹⁹ Bebbington et al. (2007). *Adult psychiatric morbidity in England, 2007: Results of a household survey*. London, UK: NHS Information Centre for health and social care.

¹²⁰ Centre for Mental Health (2010). *The economic and social costs of mental health problems in 2009/10*. London, UK: Centre for Mental Health.

15.2.4 Impacts of health research funding

NIHR are the only England specific funding body of the big three health research funders, and they have developed a “dashcard” approach to monitoring their funding impacts.¹²¹ The dashcard approach combines a logic model and balanced scorecard. Research funders in England and the UK have been fairly progressive in developing approaches to measuring and monitoring the impact of health research. All of the three major funders of health research (MRC, NIHR and Wellcome Trust) have developed systems to assess research impact in an on-going way. Obviously identifying impacts for only England is problematic for UK-level funders, but NIHR identifies England specific impacts.

The MRC have developed their e-Val tool, an online survey tool of funded researchers to identify the outputs and outcomes of their research. Launched in 2009, it has replaced end of grant reporting as an approach to identifying research impacts and has had success in getting information from researchers (83% response rate in the first year of use, and 91% in the second year).¹²² The e-Val tool addresses numerous potential impacts under the concept of inputs, outputs and outcomes. Inputs are MRC inputs (funding, human capital inputs, and collaboration), outputs are directly created by the research (knowledge generation, human capital stock, and knowledge transfer and exchange), and outcomes are the result of outputs (human capital flow, public policy and public engagement).¹²³

The Wellcome Trust approach to monitoring impacts has been in place since 2004, when it proposed a move to a more “outcome-based” approach to funding research.¹²⁴ The Trust has six domains in which they maintain and monitor information on research impacts: discoveries, applications of research, engagement, research leaders, research environment, and influence. The end of grant reporting for Wellcome funding identifies information on co-funding, research dissemination, intellectual property developed, public engagement and collaborations. Funded researchers are also asked to identify Wellcome funding in any future publications as this allows tracking of research products associated with Wellcome even after an end of grant report.¹²⁵ framework to help align performance measures or indicators with the strategic aims of NIHR (Figure). As yet, the findings from assessing indicators in the NIHR dashcard are not available. However, they promise to provide valuable insight into the way NIHR funded health research in England moves to impacts.

¹²¹ El Turabi et al. (2011). A novel performance monitoring framework for health research systems: experiences of the National Institute for Health Research in England. *Health Research Policy and Systems*. 9:13. <http://www.health-policy-systems.com/content/9/1/13>

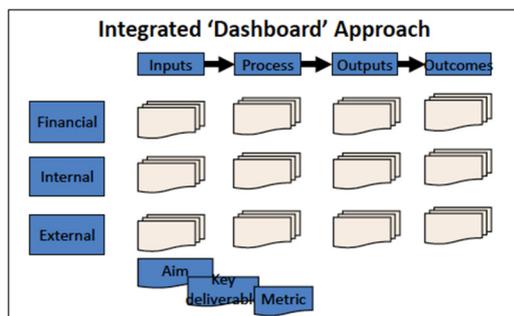
¹²² See: <http://www.mrc.ac.uk/Achievements/impact/Outputsoutcomes/e-Val/About/index.htm>

¹²³ Medical Research Council (2011). *The Medical Research Council Economic Impact Report 2010/11*. London, UK: MRC.

¹²⁴ Fazackerley (2004). Wellcome revises funding brief to focus on outcomes. *Times Higher Education*, 9th July 2004. Available at: <http://www.timeshighereducation.co.uk/story.asp?storyCode=189919§ioncode=26>

¹²⁵ See: <http://www.wellcome.ac.uk/Managing-a-grant/End-of-a-grant/index.htm>

Figure 3: NIHR dashcard framework*



* Source: El Turabi et al., 2011)

15.2.5 Knowledge products

Both the Wellcome Trust and MRC perform regular analyses of their knowledge impacts using bibliometric analysis. NIHR also perform some bibliometric analyses, but as yet data for these is not reliable due to the short time-scale in which NIHR has been active (since it only started funding research recently). MRC publications have been shown to be over twice the world average citation rate (relative citation rate 2.17), and higher citation rates than the rest of the UK for health publications.¹²⁶ Wellcome Trust publications also perform better than the world and UK averages (relative citation rate 1.83).¹²⁷ Both Wellcome and the MRC also collect data on the proportion of highly cited papers (HCPs) (top 5% citations in the world) that arise from their funded research, and compare them to the expected value for HCPs. For NIHR, there is no clear data on publication impacts available yet (although since NIHR is still a young funding body, this is not surprising). NIHR will collect bibliometric data on peer-reviewed outputs including number of papers and citations.¹²⁸

15.2.6 Policy and Product Development

All three major funders collect data on policy influence and product development as part of their impact frameworks. The MRC uses data collected from funded researchers on citations in policy documents and clinical guidelines, as well as key influences on policy setting by researchers (self-reported). MRC product impacts are collected around new research products in clinical development, and also through intellectual property data (also an economic benefit).¹²⁹ Wellcome Trust collects data from researchers on new research products being moved to the market, as well as on whether researchers have had interactions with policy.¹³⁰ NIHR do not have standard metrics developed on products, but they do have industry related metrics (looking at number of trials etc.) that can link to product development. NIHR also plan to collect information on "attention" – how research at NIHR is viewed in parliament (questions asked in parliament) and in the media.¹³¹

¹²⁶ Medical Research Council (2011). *Economic Impacts Report 2010/11*. London, UK: Medical Research Council.

¹²⁷ Wellcome Trust (2009). *How we are making a difference: Assessment framework report 2008/09*. London, UK: Wellcome Trust.

¹²⁸ El Turabi et al. (2011).

¹²⁹ Medical Research Council (2011).

¹³⁰ Wellcome Trust (2009).

¹³¹ El Turabi et al. (2011).

15.2.7 Capacity Building

Both the MRC and Wellcome Trust monitor the numbers of researchers and associated staff that they fund, and also their progress as researchers (particularly for the research students funded). The MRC monitors human capital in terms of inputs (the number of people funded), stock (current researchers funded) and flow (the movement of funded students after MRC funding finishes). The MRC also collect information on collaborations between researchers, researcher awards, and research materials developed (technically an infrastructure capacity for future research).¹³² The Wellcome Trust also collects information on inputs to capacity development (for people and research infrastructure), as well as identifying evidence of prizes won by individual researchers.¹³³ The Wellcome Trust also collects information on building receptor-capacity in the general public, by tracking how they have informed debate on biomedical sciences (visitor numbers, media coverage etc.). NIHR have identified that they will collect data on people in their framework, although this will be limited to the number of people funded and completion rates for students (input and process measures, rather than impacts).¹³⁴ They will also collect data on networks in NIHR.

15.2.8 Health and Health Sector

Collecting good information on health benefits of research is complicated, and in England, the three main funders have chosen to either not try to attribute health and health sector impacts to their research (the MRC) or they have identified research with the potential to impact health (Wellcome Trust and NIHR). Wellcome identify specific projects whose outcomes show the possibility of major health impacts if results are taken on board by the health sector.¹³⁵ It is understandable that the funders choose not to identify health impacts, since attribution and time lags can make linking research to health and health sector outcomes very complex.

15.2.9 Broader Social and Economic Benefits

The best evidence of the broader social and economic benefits of health research in the UK is the "Medical Research: What's it Worth?" study conducted in 2008.¹³⁶ In this study, a historical analysis of research funding for cardiovascular disease and mental health research was linked to current health care, health status and economic GDP changes to identify a rate of return for health research investment. In this review, they identified a rate of return of 9p for health benefits, and 30p for GDP benefits on cardiovascular research. They also identified rates of 7p for health benefits and 30p for GDP benefits on mental health research. These rates were calculated by using health gains in Quality Adjusted Life Years (QALYs), and GDP gains including spillovers to other sectors of the economy. Research was linked to these gains through a combination of research citation in clinical guidelines, uptake of recommended new practices, and investment in private sector medical research linked to publicly funded health research. The researchers also identified a time lag of around 17 years between research funding and realised economic benefit.

¹³² *Medical Research Council (2011).*

¹³³ *Wellcome Trust (2009).*

¹³⁴ *El Turabi et al. (2011).*

¹³⁵ *Wellcome Trust (2009).*

¹³⁶ *Buxton et al. (2008).*

Outside of this study, there is anecdotal evidence from research funders of the types of broader impacts that they are having, with each funder using their annual reports to identify a selection of broader impacts from specific projects. The MRC also produces an Economic Impacts Report,¹³⁷ which identifies the economic impact of spin out companies created from MRC funding, patents licensed and intellectual property (IP) value (in 2010/11 this was identified as £66.19m). In addition to these economic benefits, the report also identifies the value of non-MRC funding leveraged in association with MRC funds (over £900m in leveraged funds). Other anecdotal economic benefits identified include funding from private sector collaborations with universities and potential economic benefits of on-going MRC research. The MRC also identified £2.4bn in leveraged research funding for MRC researchers (follow-on funding) from 2006 forward, as well as IP worth £66m in 2010-11.¹³⁸ This is based on a research spend by the MRC between 2006-2010 of £1.89bn – representing a return on leveraged funding alone of 1.27:1.

In the Wellcome Trust's report on impacts,¹³⁹ the Trust identify that Wellcome funded researchers pulled in £192m in venture capital in 2008/09, based on a spend in that year of £720m. Unlike the MRC, there is no attempt to identify a full economic impact from Wellcome funded research. NIHR does not yet have data available on any economic impacts, but this data is being collected under the new "dashcard" reporting system.

15.3 Sweden

Health research funding in Sweden comes from a variety of sources, including two main central government agencies: the Swedish Research Council (Vetenskapsrådet) and the Swedish Governmental Agency for Innovation Systems (Vinnova). In addition to these two main funders, there are also health research funds provided by the Ministry of Education, Research and Culture, and by local County Councils, as well as research foundations and charities that provide funding.¹⁴⁰ In 2004, a total of 4.2m SEK was invested from public funds into basic research in the medical field, and a further 222m SEK into healthcare and public health research. There is also considerable funding from regional level funders, which put together totaled around 1.45bn SEK in 2005.¹⁴¹

While the majority of funding to health research in Sweden comes from industry, the largest public funder is the Swedish Research Council (SRC), which allocates around 4 billion Swedish kronor (SEK) annually,¹⁴² of which just over 1bn SEK went to medicine and health research in 2009 through the Scientific Council for Medicine and Health.¹⁴³ Biotechnology and life-sciences also get some funding through Vinnova. Since the SRC fund a far larger volume of health research, we will mainly address their role and impacts here.

Research evaluation is a major part of Swedish health research funding, although this is performed through evaluations of specific programs of funding, rather than through the systematic use of a research evaluation framework for the country's health research. However, this approach may be

¹³⁷ Medical Research Council (2011).

¹³⁸ Medical Research Council (2011).

¹³⁹ Wellcome Trust (2009).

¹⁴⁰ Tiessen (2008). *Health and Medical Research in Sweden: Observatory on Health Research Systems*. Cambridge, UK: RAND Europe.

¹⁴¹ *Ibid.*

¹⁴² See: <http://www.vr.se/inenglish/aboutus/activities/researchfunding.4.69f66a93108e85f68d48000239.html>

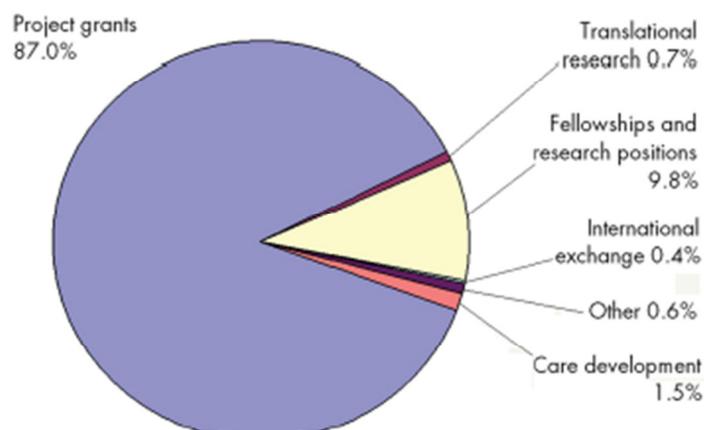
¹⁴³ Swedish Research Council (2010). *VR Facts 2010*. Stockholm, Sweden: Vetenskapsrådet

changing as Sweden hosted an international summit in 2008 on research evaluation at which numerous approaches to systematic research evaluation were discussed.¹⁴⁴ As of yet however, there is no standardized approach in place at SRC or elsewhere in Sweden.

15.3.1 Cancer

In Sweden, cancer research is the domain of two main research funders: the government funded SRC; and the independent charity, the Swedish Cancer Society. The SRC provided around 4.5% of its funding to cancer research in 2006 (roughly 26m SEK).¹⁴⁵ The Swedish Cancer Society distributed 389m SEK in 2011 for research in its field.¹⁴⁶ The breakdown of Cancer Society funding in 2006 is shown in Figure . In addition to the above, the Swedish Children's Cancer Foundation (Barncancerfonden) allocated 85m SEK in 2005.¹⁴⁷

Figure 4: Breakdown of research spending by the Swedish Cancer Society (Teissen, 2008)



Cancer prevalence in Sweden has been slowly increasing, with incidence rising by around 2% a year in Sweden. In 2010, it was estimated that in Sweden there is approximately a 30% chance of developing cancer before turning 75.¹⁴⁸ In particular, breast cancer and prostate cancer are the most common for women and men respectively.

The SRC does not have a standard approach to measuring the impacts of its cancer research, and neither does the Swedish Cancer Society. Both, however, do perform evaluations of programs of research.

¹⁴⁴ Cox et al. (2008). *Evaluation of Impacts of Medical Research*. Stockholm, Sweden: Swedish Research Council

¹⁴⁵ Tiessen (2008).

¹⁴⁶ See: <http://www.sweden.gov.se/sb/d/6949/a/88149>

¹⁴⁷ Tiessen (2008).

¹⁴⁸ Statistics – Health and Medical Care (2011). *Cancer Incidence in Sweden 2010*. Stockholm, Sweden: Socialstyrelsen

15.3.2 Diabetes

The Swedish Diabetes Association's Research Foundation (Stiftelsen Svenska Diabetesförbundets Forskningsfond) supports research on diabetes and provided around 12m SEK in 2009.¹⁴⁹ The SRC also fund diabetes research, providing 4.7% of their research budget (circa 27m SEK) to diabetes research in 2006.¹⁵⁰

Diabetes is a public health issue in Sweden, especially among young people where incidence has been increasing. In 2006, an estimated 300,000 people in Sweden had diabetes, roughly 3% of the population.¹⁵¹ Interestingly however, any recent increases in prevalence in Sweden seem to be down to decreased mortality rather than increased incidence of diabetes. However, increasing obesity in Sweden will likely lead to higher incidence of type-2 diabetes in the aging population, an event that would place heavy burdens on the public health system.¹⁵²

As identified for cancer, the SRC has no standard approach to measuring the research impacts of its research into diabetes. In fact, the Diabetes Association also does not have a standard approach to measuring research impact, but they do perform evaluations of projects and programs (predominantly to identify success stories for their research).

15.3.3 Mental Health

Since the SRC has a focus on basic biomedical research, its role in delivering mental health research is small, with only 4% of its budget (23m SEK) allocated to mental health research in 2006.¹⁵³ With such a fragmented research system in Sweden (with multiple funders providing research funds based on the level of research undertaken (applied, basic, industry etc.) it is difficult to isolate where mental health research funds come from, or indeed how much is allocated.

Psychiatric disorders are common in Sweden, particularly amongst women where 1 in 4 report some sort of psychological distress. The suicide rate in Sweden is also slightly above the EU average.¹⁵⁴ A recent study suggests that up to 30-40% of people in Sweden experience anxiety or depression.¹⁵⁵

Since the SRC does not have a standard approach to measuring research impacts, and other mental health research funders are hard to isolate, it is not possible to identify a specific approach to measuring mental health research impacts in Sweden.

15.3.4 Impacts of health research funding

As identified above and in numerous documents on the Swedish research system, there are many different potential funders of health research in the country. While the SRC clearly provides the majority of funding for basic biomedical research, clinical and more applied research funding can come from a wide variety of sources including local and regional funding bodies. This means it is

¹⁴⁹ See: http://www.diabetes.se/Templates/Extension_218.aspx

¹⁵⁰ Tiessen (2008).

¹⁵¹ Eliasson and Bostrom (2006) Chapter 5.2: Major public health problems – diabetes. *Scandinavian Journal of Public Health*. **34**(Suppl 67): 59–68.

¹⁵² *Ibid*

¹⁵³ Tiessen (2008).

¹⁵⁴ See: <http://tinyurl.com/7yx7ckb>

¹⁵⁵ Molarius et al. (2009). *Mental health symptoms in relation to socio-economic conditions and lifestyle factors – a population-based study in Sweden*. *BMC Public Health*, **9**:302 doi:10.1186/1471-2458-9-302

increasingly difficult to set a standard approach to measuring research impacts in the country. However, not even the SRC has a standard approach to measuring their own funding impacts, with a preference for evaluating the outputs and outcomes of specific funding programs in an ad hoc format. There has been great interest in approaches to measuring research impact in Sweden, with the SRC hosting two international meetings on the subject, and publishing reports based on the meetings.¹⁵⁶ In fact, in alignment with the initial meeting on research evaluation, the SRC and its Finnish counterpart jointly analysed the impacts of clinical research in universities in the two countries.¹⁵⁷ It is important to note that due to a lack of standard approaches to impact evaluation, assessing and comparing across disease states is very difficult for Sweden.

15.3.5 Knowledge products

With no standardised approach to monitoring and measuring research impact in Sweden or at the SRC, it is necessary to look at specific evaluation studies to identify impacts. For example, in medicine research, Swedish universities produce the highest output per capita in Europe, and Sweden is in the top 10 countries in the world for medicine and clinical medicine citations (as well as having a relative citation value for medicine that is above the world average). However, this citation value is decreasing relative to other countries, suggesting Sweden may lose its position in the top countries in the world for medical research.¹⁵⁸

15.3.6 Policy and Product Development

The SRC has a major role in informing policy on health issues in Sweden, with an explicit focus on research communication (including to policy development). The SRC is part of a group who organise an annual week for politicians to come and learn about new research findings, as well as running breakfast seminars to bring together policy makers and researchers.¹⁵⁹

While the SRC is focussed on basic research, Vinnova's role is in applied research, particularly in moving research towards industry and product development. While this is an explicit goal, and individual evaluations and impact analyses can shed light on what role Vinnova plays in this,¹⁶⁰ there is no consistent data maintained to provide overall lessons on the role Vinnova plays in product development (merely specific examples from individual evaluations).

15.3.7 Capacity Building

Capacity building in Swedish health research is a key part of the funding process. For the SRC, capacity building focuses on human resources, with funding for all stages of the research career: in particular, doctoral programs and junior researchers.¹⁶¹ Vinnova build capacity in Sweden in a different

¹⁵⁶ Cox et al. (2008); Gilbert (2009) *New Frontiers in Evaluation of Impacts of Medical Research: International Workshop 2009*. Stockholm, Sweden: Swedish Research Council.

¹⁵⁷ Academy of Finland and Swedish Research Council (2009). *Clinical Research in Finland and Sweden: Evaluation Report*. Helsinki, Finland: Academy of Finland.

¹⁵⁸ Academy of Finland and Swedish Research Council (2009).

¹⁵⁹ Swedish Research Council (2009). *Swedish Research Council: Financer of Basic Research*. Stockholm, Sweden: Swedish Research Council

¹⁶⁰ Vinnova (2008). *VINNOVA's Focus on Impact - A Joint Approach for Impact Logic Assessment, Monitoring, Evaluation and Impact Analysis*. Stockholm, Sweden: Vinnova

¹⁶¹ Swedish Research Council (2009).

way, by bringing together researchers and industry in order to facilitate effective applied research.¹⁶² The lack of a standard approach to assessing the impacts of funding at either the SRC or Vinnova means that it is very difficult to gauge the level of impact that capacity building activities have generally. However, specific evaluations do identify specific capacity impacts – such as the analysis of clinical research in Sweden and Finland that identified the issues facing junior researchers in Sweden who are not able to move on to further roles in the system due to a lack of mid-career funding.¹⁶³

15.3.8 Health and Health Sector

One impact area in which Swedish research evaluation seems to be lacking is the link of research to health and health sector benefits. This likely stems from a combination of the difficulty in attributing health outcomes to research, and also to the fragmented nature of the health research system in Sweden (since no one funder has any kind of direct link to changing health care in the country).

One study in Sweden did attempt to identify the health and health care impacts of Swedish health research. This study is predominantly one to assess the economic impact of health research, but it does so by estimating the impacts on health and the health system through: improved health outcomes, lower treatment costs, and higher health care infrastructure costs.¹⁶⁴ The linkage of research to these factors is not made explicit in the research however, only an assumption that research is responsible for 50% of health care costs and health improvements.

15.3.9 Broader Social and Economic Benefits

As identified above, one recent study does attempt to provide an overview of the economic impact of Swedish health research. In that study, health and health care costs and benefits combine with GDP gains and improved productivity. As with the UK approach to measuring Return On Investment from health research, costs and benefits are combined to identify net benefit of research. In the Swedish study, the net benefit was identified as 1.08, representing an 8% rate of return on clinical research investment.¹⁶⁵

The research funders themselves also identify some economic benefits from their researchers, with evaluations looking at issues such as spin out company development, intellectual property and leveraged international funding. In one study for Vinnova, the evaluation identifies impacts on sales, spin off companies and established companies of Vinnova funding for innovative medical technology.¹⁶⁶ The findings are very specific however, so are not reproduced here. In general, without a standard approach to measuring and monitoring the economic and social outcomes in Sweden, it would require a meta-evaluation of all Swedish health research evaluations to identify comparable data for benchmarking.

¹⁶² See: <http://www.vinnova.se/en/About-VINNOVA/>

¹⁶³ Academy of Finland and Swedish Research Council (2009).

¹⁶⁴ Roback, Dalal and Carlsson (2011). *Evaluation of Health Research: Measuring Costs and Socioeconomic Effects*. *International Journal of Preventive Medicine*. 2(4): 203–215

¹⁶⁵ *Ibid.*

¹⁶⁶ Hellman, McKelvey and Johansson (2009). *Analysis of Chain-linked Effects of Public Policy: Effects on research and industry in Swedish life sciences within innovative food and medical technology*. Stockholm, Sweden: Vinnova

15.4 Canada

In 2009, Canada spent \$6.4bn on health research funding, with the vast majority of that funding coming from the public sector (federal government, provincial government and higher education).¹⁶⁷ Research is predominantly performed in higher education establishments (including teaching hospitals), and although the private sector still accounts for around a third of the health R&D performed in Canada, the proportion has dropped since 2006 (potentially due to re-direction of pharmaceutical R&D spending outside of Canada).¹⁶⁸ The government of Canada's S&T strategy in 2007 set out a need to build excellent research, to translate that research into practical applications, and to strengthen the pool of skilled individuals. This shows an emphasis on impacts (knowledge, practice and capacity) that is mirrored in government health funding plans such as the CIHR Roadmap.¹⁶⁹

15.4.1 Cancer

Cancer research funding in Canada comes from a variety of sources. While there is significant funding through Canadian Institutes of Health Research (CIHR) (Figure),¹⁷⁰ and in particular the CIHR Institute of Cancer Research, there is also funding through numerous charitable, not for profit and government bodies and departments. In 2008, the total funding to Cancer research in Canada was \$446.2m. Of this money, the largest single funder was CIHR (with \$119m).¹⁷¹ Funding was essentially split between three types of funders: Government at \$352m (mainly federal, mainly CIHR); Voluntary sector at \$83m (mainly the Canadian Cancer Society); and multi-funder at \$11m (through research alliances and initiatives).¹⁷²

¹⁶⁷ Statistics Canada (2010). *Science Statistics: Estimates of Total Spending on Research and Development in the Health Field in Canada 1998 to 2009*. Ottawa, Canada: Statistics Canada.

¹⁶⁸ *Ibid*

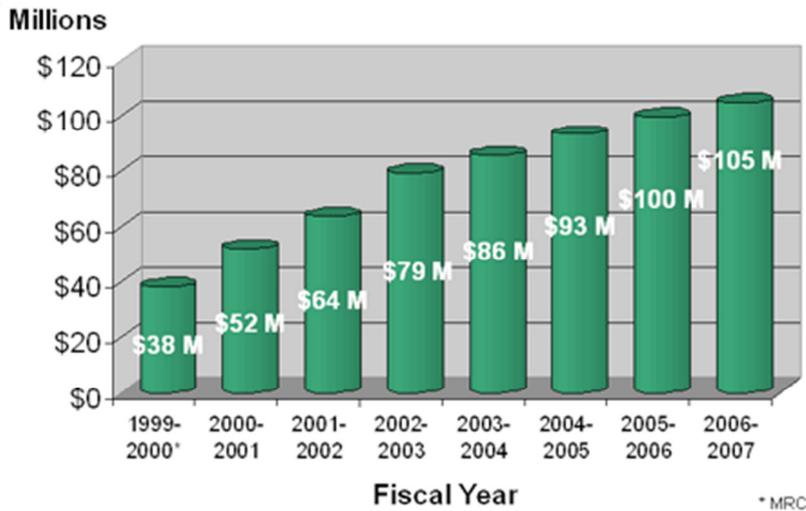
¹⁶⁹ CIHR (2009). *Science Statistics: Estimates of Total Spending on Research and Development in the Health Field in Canada 1998 to 2009*. Ottawa, Canada: CIHR.

¹⁷⁰ CIHR Institute of Cancer Research (2008). *Bar Chart: CIHR Cancer Research Funding over the last 8 fiscal years*. Available at: <http://www.cihr-irsc.gc.ca/e/35623.html>

¹⁷¹ Canadian Cancer Research Alliance (2011). *Cancer Research Investment in Canada, 2008: The Canadian Cancer Research Alliance's Survey of Government and Voluntary Sector Investment in Cancer Research in 2008*. Toronto: CCRA.

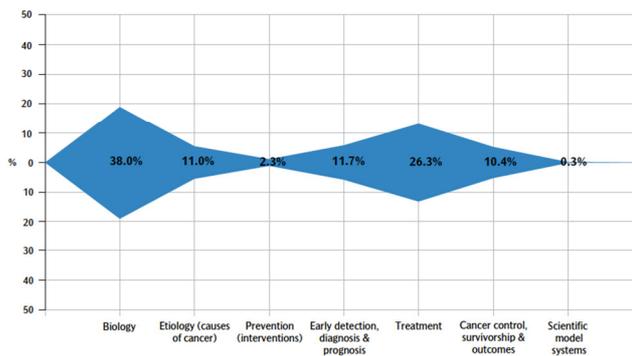
¹⁷² *Ibid*.

Figure 5: CIHR Cancer research funding in Canada: 1999-2007 (CIHR Institute of Cancer Research; 2008).



As we see in Figure , the funding for cancer research in Canada has been increasing in terms of government-led funding through CIHR, and has increased across all funders (except multi-funder initiatives). Funding has been split between the different stages of health research as shown in Figure .

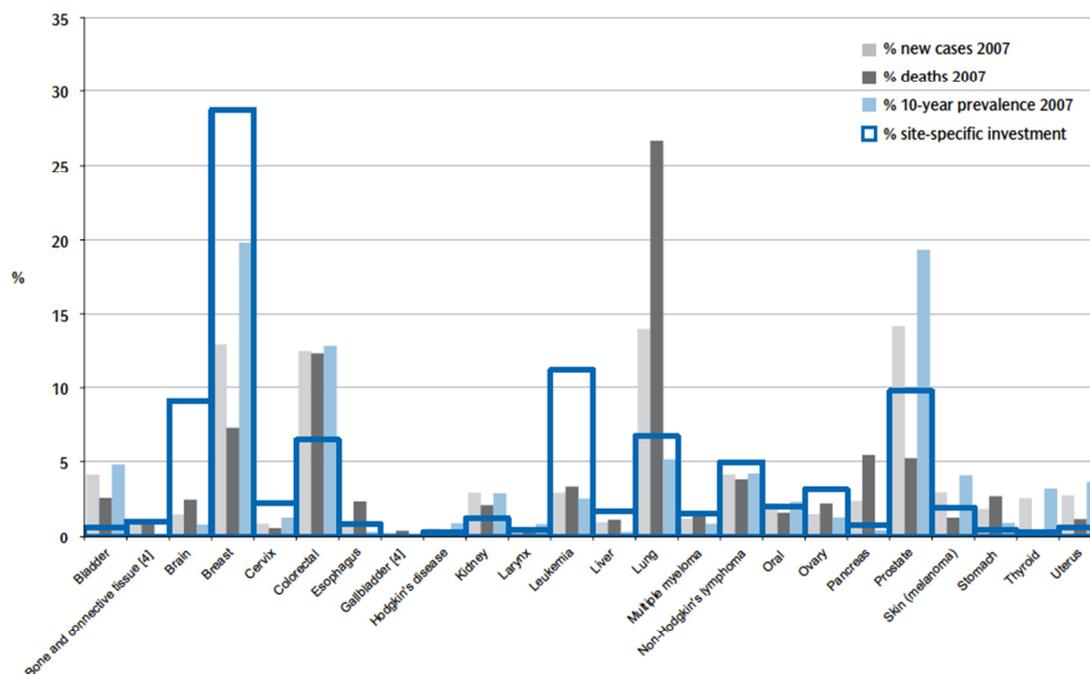
Figure 6: Distribution of 2008 cancer research funding by Canadian Common Scientific Outcomes category (Canadian Cancer Research Alliance, 2011).



Cancer prevalence in Canada is also generally on the rise, attributed in part to an aging population.¹⁷³ There have been improvements in two cancer areas, cancers of the larynx and cervix, but there were large increases in prevalence in liver and thyroid cancers. Research investment generally matched levels of prevalence, incidence and deaths for cancers in Canada (Figure).

¹⁷³ Ellison, L. and Wilkins, K. 2012. Canadian trends in cancer prevalence. Health Reports, Vol. 23(1). Statistics Canada. Catalogue no. 82-003-XPE

Figure 7: Canadian cancer funding against incidence, prevalence and deaths (by cancer type) (Canadian Cancer Research Alliance, 2011).



- [1] Source for new cancer cases: CANSIM Table 103-0550 New cases for ICD-O-3 primary sites of cancer (based on the July 2010 CCR tabulation file), by age group and sex, Canada, provinces and territories, annual. Canadian Cancer Registry - 3207.
- [2] Source for cancer deaths: CANSIM Table 102-0522 Deaths, by causes, Chapter II: Neoplasms (C00 to D48), age group and sex, Canada, annual (number). Vital Statistics - Death Database - 3223.
- [3] Represents site-specific prevalence for patients diagnosed with cancer since 1997 who were alive on January 1, 2007. Data are available from Canadian Cancer Society's Steering Committee on Cancer Statistics, *Canadian Cancer Statistics, 2011* (Toronto, Canadian Cancer Society, 2011).
- [4] Prevalence data were not available for gallbladder and bone and connective tissue cancers.

With a multitude of funders, it is perhaps unsurprising that there is no single approach to measuring the impact of Canadian research into cancer. CIHR uses an approach modelled on the payback framework (but this is still in its early stages of application so does not have specific reported results). Other provincial funders use versions of the CAHS model of research impact (again, based on the payback model), while charity funders such as the Canadian Cancer Society use examples of impacts (anecdotes).¹⁷⁴ The National Cancer Institute (funded by the Canadian Cancer Society and Terry Fox Foundation) has also performed a bibliometric analysis of the research they fund.¹⁷⁵

¹⁷⁴ http://www.cancer.ca/Canada-wide/Cancer%20research/Progress%20we%20ve%20made.aspx?sc_lang=en

¹⁷⁵ Campbell et al (2008). *Science Statistics: Estimates of Total Spending on Research and Development in the Health Field in Canada 1998 to 2009*. Montreal, Canada: Science-Metrix; Campbell et al (2009). *Bibliometric Analysis of Research Supported by the National Cancer Institute of Canada—Phase II*. Montreal, Canada: Science-Metrix; Campbell et al (2010). *Bibliometrics as a Performance Measurement Tool for Research Evaluation: The Case of Research Funded by the National Cancer Institute of Canada*. *American Journal of Evaluation*. **31**:66

15.4.2 Diabetes

Funding for diabetes research in Canada is predominantly through CIHR, with other smaller funders and provincial funding bodies also playing a role. At CIHR, diabetes is mainly funded through the Institute for Nutrition, Metabolism and Diabetes (INMD), who in 2010 managed to pull in over \$100m in CIHR funding for its affiliated researchers.¹⁷⁶ While this total is not all diabetes research, the part of it that is (not identified in reports) represents a 2.4 fold increase in diabetes research funding in the ten years of INMD existence. In addition to CIHR, the Canadian Diabetes Association (CDA) also fund research and in 2010 funded nearly \$7m worth of diabetes research.¹⁷⁷

Diabetes in Canada is on the rise, with between 4-5% of individuals self-reporting as diabetic.¹⁷⁸ While the morbidity due to diabetes may be increasing, mortality has been decreasing (a common trend for chronic diseases). The cost of diabetes in Canada is high, with an estimated cost to the Canadian healthcare system in 2020 at nearly \$17bn a year.¹⁷⁹

While INMD and CIHR have standard impact measurement approaches, there is no standard approach for funders such as CDA, who in fact use an anecdotal approach that identifies their best researchers from any given year of funding.¹⁸⁰

15.4.3 Mental Health

In Canada there are two main organisations involved in mental health issues across the country – the Canadian Mental Health Association (CMHA) and the Mental Health Commission of Canada (MHCC). While both of these groups provide some research funding, the majority of funding is still provided through CIHR (and in particular its Institute for Neuroscience, Mental Health and Addiction – INMHA). The MHCC receive large amounts of funding from Health Canada (over \$240m over ten years) but it is difficult to identify how much of this is applied to research on mental health issues.¹⁸¹ As the majority of this funding comes through federal government grants, funding is subject to government audit (but not impact evaluation). CIHR research funding for mental health is assessed using the CIHR impact framework, although mental health research is only clearly identifiable when it is linked to INMHA (as general CIHR grant research is not easily linked to disease categories). In general, it is much harder in Canada to identify mental health related research funding inputs and impacts, than it is for other more established and discrete clinical research areas such as cancer.

Mental health in Canada is a significant health issue; with estimates that one in five Canadians will experience mental illness at some point in their lives.¹⁸² The economic cost of mental illnesses in Canada was estimated to be at least \$7.331 billion in 1993 and it is likely to have increased since then.¹⁸³ With such an important issue, it is not surprising the government chose to develop the MHCC

¹⁷⁶ Institute for Nutrition, Metabolism and Diabetes (2011). *Internal Assessment for 2011 International review*. Ottawa, ON: CIHR.

¹⁷⁷ Canadian Diabetes Association (2011). *Annual Report: Financial Statements*. Ottawa, Canada: Canadian Diabetes Association

¹⁷⁸ See: <http://www.statcan.gc.ca/pub/82-229-x/2009001/status/dia-eng.htm>

¹⁷⁹ See: <http://www.diabetes.ca/diabetes-and-you/what/prevalence/>

¹⁸⁰ Canadian Diabetes Association (2011) *Research Report 2011*. Ottawa, Canada: Canadian Diabetes Association

¹⁸¹ See: <http://www.hc-sc.gc.ca/ahc-asc/pubs/audit-verif/2011-11/index-eng.php>

¹⁸² Health Canada (2002). *A Report on Mental Illnesses in Canada*. Ottawa, Canada: Health Canada

¹⁸³ *Ibid.*

in order to produce a cohesive strategy for mental health across Canada. The MHCC is funded until 2017 and the strategy should be in place by then.

To measure the impact of research on mental health, CIHR uses its payback-based framework (particularly through INMHA), while other major mental health research funders such as MHCC tend to produce evaluations of specific programs of research rather than having a defined framework. This means that there are pockets of information on the impacts of mental health research, such as bibliometric analyses of research on mental health in the workplace.¹⁸⁴

15.4.4 Impacts of health research funding

With a multitude of different funders in Canada it can be difficult to identify the impacts of any given piece of research, or indeed the work of an individual funder. This is partly due to the complexity of attribution in a multiple-funder environment, but it is also largely due to the difficulty in getting research funders to agree on a unified approach to measuring impacts (thus making impact assessments comparable). The Canadian Academy of Health Sciences (CAHS) did develop a framework and indicators that received funding and support from funders of health research across Canada (federally, provincially, from the not for profit and business sectors).¹⁸⁵ The CAHS report developed a framework for assessing the research impacts of any piece of health research conducted or funded in Canada, based on the payback framework. This framework is currently being built on or personalised by a number of funders to allow impact assessment of research funding that can be compared across funders. Since the framework is based on the payback framework it can be analysed easily for this study. However, the framework and its descendants are still at an early stage and therefore not used to provide good impact data.

15.4.5 Knowledge products

Canadian federal government and a number of other players regularly perform bibliometric analyses of health research in the country (either in specialist subject areas or by funder). In cancer research, recent analyses by the National Cancer Institute of Canada (NCIC) showed that research supported by NCIC was significantly higher quality than publications by cancer researchers in Canada when not supported by NCIC (based on highly cited papers [HCPs] and relative citation values), and also that Canadian cancer research was above the world average for impact (HCPs and relative citations) ranking second among the G7 countries for quality of cancer research.¹⁸⁶

In Diabetes, CIHR analysed endocrinology research conducted by their funded researchers and identified a high level of specialisation in the endocrinology field, as well as a Canadian relative citation value above the G7 average (in fact CIHR funded research was higher than the top G7 relative citation value).¹⁸⁷ For mental health research, Canada also performs better than the world average for relative

¹⁸⁴ Archambault, Côté and Gringras (2003). *Bibliometric Analysis of Research on Mental Health in the Workplace in Canada, 1991-2002*. Montreal, Canada: Science-Metrix.

¹⁸⁵ Panel on Return on Investment in Health Research (2009). *Making an Impact: A Preferred Framework and Indicators to Measure Returns on Investment in Health Research*. Ottawa, ON: Canadian Academy of Health Sciences.

¹⁸⁶ Campbell et al. (2008).

¹⁸⁷ CIHR Institute of Nutrition, Metabolism and Diabetes (2010). *Bibliometric Study of Obesity Research in Canada, 1998-2007*. Ottawa, ON: CIHR. Available at: <http://www.cihr-irsc.gc.ca/e/41601.html#2.2>

citation values, with Canada ranking third in the world behind only the USA and the UK.¹⁸⁸ More specifically in mental health, a study of mental health in the workplace in Canada showed large increases in the number of papers in the field from Canada (growing 50% faster than the world average).¹⁸⁹

15.4.6 Capacity Building

Building capacity is a major role of CIHR and its institutes. With institutes devoted to each of the three conditions under study in this report, it is possible to identify capacity building outcomes directly related to cancer, diabetes and mental health research funding. Since CIHR is the major funder in Canada, we have only identified their capacity building impacts here, but there would also be additional capacity benefits from other funders.

Cancer research capacity building has been built around the role of the CIHR Institute of Cancer Research (ICR), and in the 2011 International Review of its activities, ICR identified a number of capacity benefits including investments of \$20m in strategic training initiatives (targeted human resource development), fellowship style funding that increased leveraged research funding for PIs by over 6 times, and team-building funding. ICR has also improved network development and collaboration for cancer researchers in Canada.¹⁹⁰

For diabetes capacity building, INMD has supported team grants in multiple subject areas including diabetes that have produced long-term capacity development through employing students and post-doctoral researchers, as well as fostering inter-organisational collaborations. INMD has also been successful in building nephrology research in Canada.¹⁹¹

For mental health, INMHA has been involved in a number of team and strategic grants to build capacity, although these are not easy to link specifically to mental health research.¹⁹² There have also been developments in international partnerships in mental health research.

15.4.7 Policy and Product Development

ICR has been active in informing policy, with researchers involved in policy forums (with decision makers and the public). ICR research has also informed organisational policies such as those in palliative care.¹⁹³ ICR doesn't currently identify product impacts, but it has noted that there are likely to be research products around personalised medicine for cancer that are linked to the research of the Institute. For diabetes, INMD scientific directors have provided advice to the House of Commons committee on health around diet and obesity issues (including the links to diabetes), and played a lead role in the development of Canada's sodium reduction strategy.¹⁹⁴

¹⁸⁸ Lariviere et al. (2010). *Bibliometric Analysis of INMHA-related Research, 1997-2008*. Montreal, Canada: Observatoire des sciences et des technologies.

¹⁸⁹ Archambault, Côté and Gringras (2003).

¹⁹⁰ Institute for Cancer Research (2011). *Internal Assessment for 2011 International Review*. Ottawa, Canada: CIHR

¹⁹¹ Institute for Nutrition, Metabolism and Diabetes (2011). *Internal Assessment for 2011 International Review*. Ottawa, Canada: CIHR

¹⁹² Institute for Neuroscience, Mental Health and Addiction (2011). *Internal Assessment for 2011 International Review*. Ottawa, Canada: CIHR

¹⁹³ Institute for Cancer Research (2011).

¹⁹⁴ Institute for Nutrition, Metabolism and Diabetes (2011).

INMHA has been involved in developing policy in a number of mental health areas, including being integral to the development and on-going working of the MHCC, with high-level representation on MHCC advisory boards. This is helping to inform the mental health strategy for Canada. INMHA also has played a key role in developing evidence-informed approaches to workplace mental health in Canada.¹⁹⁵ INMHA does not have information on product development for mental health (although they do identify neuroscience products such as new stem cell lines).

15.4.8 Health and Health Sector

While CIHR's framework provides a space to collect information on health and health sector benefits, it is difficult for individual institutes to identify and claim health and health sector benefits. In cancer, ICR has identified specific impacts in palliative care approaches (such as online training in palliative care), improvements in treatment protocols for cancer in young people, and developing resources for cancer doctors to educate their patients.¹⁹⁶

Diabetes research through INMD has been involved in the development of clinical guidelines for improved type-2 diabetes care in relation to heart failure. The study itself also provided health benefits to those involved in the study by reducing mortality due to heart failure for those with type-2 diabetes.¹⁹⁷

Mental health benefits arising from INMHA research can be seen in relation to specific projects and programs, such as a program on addiction in Vancouver that shows reductions in risky drug taking behaviour and increase in the use of addiction programs.¹⁹⁸

15.4.9 Broader Social and Economic Benefits

Identifying specific economic and social impacts from Canadian research is complex, and despite the presence of a framework at CIHR to assess broader benefits, most research cannot yet allocate these kinds of impacts. For cancer research ICR hasn't yet identified specific impacts, but it has identified reduced health care costs and other economic costs of cancer (such as lost work days) as a major economic impact likely to arise.¹⁹⁹ Commercialisation and new jobs in biotech are also touted as future economic impacts.

While INMD broader impacts for diabetes are not currently identified, there are clear broader impacts in terms of public awareness around obesity (which is closely linked to diabetes), measured through a strong media profile around obesity. INMD does not identify any economic benefits arising from their research other than in additional research funds pulled in by diabetes researchers (at a rate of 2:1 for a specific research program in gastroenterology), which is considered a capacity building impact.²⁰⁰

Mental health social impacts from INMHA included increased awareness of mental health issues through the delivery of "Café Scientifiques" fora for the general public. Economic benefits of INMHA

¹⁹⁵ *Institute for Neuroscience, Mental Health and Addiction (2011).*

¹⁹⁶ *Institute for Cancer Research (2011).*

¹⁹⁷ *Institute for Nutrition, Metabolism and Diabetes (2011).*

¹⁹⁸ *Institute for Neuroscience, Mental Health and Addiction (2011).*

¹⁹⁹ *Institute for Cancer Research (2011).*

²⁰⁰ *Institute for Nutrition, Metabolism and Diabetes (2011).*

research are not yet identified (since they are likely to be long-term) but they are expected to be in the prevention, early intervention and early treatment of conditions and diseases.²⁰¹

²⁰¹ *Institute for Neuroscience, Mental Health and Addiction (2011).*
