Bench To Bedside

Enhancing the Competitiveness of Medical Research in Northern Ireland

Together we will beat cancer

CANCER RESEARCH UK

CONTENTS

1. EXECUTIVE SUMMARY

More than 9,250 people are diagnosed with cancer every year in Northern Ireland[1]. Today, around half of the people diagnosed with cancer will survive for more than 10 years. This figure has doubled in the last 40 years. Cancer Research UK's ambition is to accelerate progress so that three-quarters of people survive the disease by 2034. Research has played a vital part in this progress so far and is crucial to further improve outcomes for cancer patients.

This study was conducted to analyse the state of the medical research environment in Northern Ireland and to identify policy actions to optimise it. This report uses the term "medical research" to encompass basic, translational and clinical health research across all disease areas. While the findings are reflective of the broader environment, we have focused on cancer in some areas. The report combines analysis of available data and interviews with 17 Northern Irish and nine UK medical research stakeholders.

Overall, our respondents spoke of the negative impact of a challenging financial and policy environment for research in Northern Ireland. Basic researchers are struggling to compete for funding from UK and EU sources. Additionally, workforce shortages and infrastructure issues in Northern Ireland's Health and Social Care (HSC) Trusts are impacting on the clinical research opportunities available to patients.

However, there are examples where, through supporting areas of research strength, researchers are successfully attracting major funding, such as Queen's University Belfast's status as a Movember Centre of Excellence[2]. It is crucial that those involved in research continue to refine this focus, drawing on potential

NORTHERN IRELAND SHOULD FOCUS ON AREAS OF MEDICAL RESEARCH STRENGTH TO ATTRACT INWARD INVESTMENT AND ACCELERATE PATIENT BENEFIT

collaborations between universities, the HSC and Northern Ireland's life sciences industry, to create world leading areas of excellence.

FINDINGS

There are several factors that enable a high-quality research environment, including: leadership, policy and collaboration; funding; infrastructure; workforce; and patient access to research.

LEADERSHIP, POLICY & COLLABORATION

Research in Northern Ireland is operating within a challenging policy environment. With the NI Executive shutdown since January 2017, it has been extremely difficult, and in some cases impossible, to enact policy change.

One example is the unpublished life sciences strategy. Our respondents spoke about having worked with the NI Executive to create a strong strategy that is not able to be published. Northern Ireland has a small but strong biotech sector and our respondents emphasised the need to capitalise on this.

Northern Ireland is the only part of the UK without a published up-to-date cancer strategy. There are several issues across the HSC that are affecting the provision of cancer research and a comprehensive

strategy is needed to ensure patients get the best standard of care, including access to research. Falling behind on the internationally recognised standard of care could significantly impact on the ability to undertake cutting edge clinical research. Cancer Research UK strongly welcomes the DoHs[3] decision to commission a new 10 year cancer strategy and this needs to be put in place urgently to address these issues.

RECOMMENDATIONS

- The Department for the Economy (DfE) should act as a matter of urgency to publish the life sciences strategy. This strategy should contain actions to build upon the strengths of Northern Ireland's existing life sciences industry.
- The Department of Health (DoH) should urgently develop and implement a comprehensive cancer strategy. The strategy should contain actions to improve the clinical research environment, including:
    - That cancer data is effectively used to assess and inform the transformative improvement to cancer services.
    - Plans to embed research throughout the health and social care system in Northern Ireland, to foster a culture of research at all levels
    - An aim to increase the number of patients having a discussion about taking part in cancer research.

FUNDING

There is growing concern amongst the research community in Northern Ireland about a reducing pot of research funding. In 2011/12, the NI Executive gave £51m in research funding to Higher Education Institutions (HEIs)[4]. By 2017/18, this had fallen to £46.5m, a decrease of almost 9%. Universities rely on this underpinning Quality-Related (QR) funding for the infrastructure and workforce that enables researchers to win competitive grants from sources such as UKRI and charities.

This level of QR funding is more than 40% lower than Scotland per capita[5] and there is a significant need for new funding streams to bridge this investment gap. One potential new low-cost funding stream that could increase competitive research funding in Northern Ireland is the pump priming of innovative research projects. Such a stream would allow researchers to create stronger grant applications and boost the research funding entering Northern Ireland.

Researchers in Northern Ireland have benefitted from access to high levels of research funding (€113m) through the European Regional Development Fund (ERDF)[6]. It is crucial that any potential loss of funding from EU sources is quantified and urgently mitigated.

RECOMMENDATIONS

- The DfE should review the level of QR funding to Northern Ireland's universities with a view to increasing funding to comparable levels to other UK nations.
- The DoH and HSC Public Health Agency R&D should explore pump priming as a way to allow researchers to perform small, proof of principle studies that can leverage funding for larger studies.
- The DoH and DfE and should urgently quantify the impact of the potential loss of EU funds as the UK leaves the EU and seek funding sources – including UKRI and others – to mitigate against this loss.

INFRASTRUCTURE

Belfast is thought to have good infrastructure access for basic research. However, significant investment into research infrastructure is needed,

particularly relating to clinical research.

Whilst some investment has been made, such as in the £10m Centre of Excellence in Precision Medicine[7], our respondents highlighted a need to establish a biomedical research centre to enable translational research. There are ongoing efforts to establish a biomedical research centre as part of the Belfast City Deal[8] negotiations and such a facility would be a huge addition to Northern Ireland's research infrastructure.

There are also concerns about the ability of researchers to share data within HSC or across the UK. It is crucial that regulations are implemented to ensure that data sharing becomes the norm amongst Northern Ireland's researchers.

RECOMMENDATIONS

- Northern Ireland's universities, industry, the HSC and the third sector should work collaboratively with the UK Government and Belfast City Council to establish the iREACH biomedical research centre as part of the Belfast Region City Deal.
- The NI Government should urgently implement the Health and Social Care (Control of Data Processing) Act (Northern Ireland) 2016 to enable data sharing for medical research.

WORKFORCE

Northern Ireland's Universities are currently working effectively in recruiting and training PhD students. However, there is concern that a lack of opportunities for post-PhD development is causing many talented researchers to leave.

Interviewees were also concerned about the ability of research institutions to attract and retain research leaders. Whilst Northern Ireland is seen to perform well in terms of its intellectual capital compared to its size, there is a need for a greater focus of talent in areas of research excellence to increase the resilience of the research environment.

Significant issues also exist in the training and retention of clinical academics. Whilst clinicians have access to some all-Ireland and university-based fellowships, there is currently no central mechanism to protect clinicians' time for research, which is reducing the amount of clinical research available to patients.

RECOMMENDATIONS

- Northern Ireland's research institutions should work with the DfE to create a plan to ensure that Northern Ireland is able to attract and retain world class research talent.
- DoH should work with representative bodies to create mechanisms so that clinicians interested in engaging in research are able to.

PATIENT ACCESS TO CLINICAL TRIALS

Interviewees reported that it is becoming harder to recruit patients to trials in some areas such as cancer where advances in precision medicine approaches are making many trials more complex, leading to fewer patients being eligible.

Northern Ireland had the lowest reported level of patients having a research discussion of any UK nation in the Cancer Patient Experience Survey, a figure that fell from 18% in 2016[9] to just 15% in 2018[10].

Our respondents also reported that delays in the provision of drugs are preventing some trials opening. It is important that the DoH addresses these issues to allow patients to have timely access to research.

RECOMMENDATIONS

- The DoH, HSC and Health Trusts should put systems in place to signpost ongoing clinical trials to patients.

2. INTRODUCTION

More than 9,250 people are diagnosed with cancer every year in Northern Ireland[11] and it has been projected that this figure will rise to more than 13,000 by the year 2035[12].

Furthermore, half of the people diagnosed with cancer will now survive for more than ten years. This figure has doubled in the last 40 years from one in four. Cancer Research UK's ambition is to accelerate progress and see three-quarters of people surviving the disease by 2034. Medical research has played a vital part in this progress to date and is crucial to further improving outcomes for cancer patients.

Funding research into the prevention, early diagnosis and treatment of cancer has been a priority for a wide range of stakeholders in Northern Ireland: including the NI Government, research councils, charities and industry.

However, cancer research does not happen in a silo. Therefore, Cancer Research UK has conducted a study to analyse the current state of the medical research environment in Northern Ireland and identify possible policy actions that could optimise research. This report examines the external factors that affect cancer research as part of the wider medical research environment. In this report, the term "medical research" encompasses all basic, translational and clinical health research, including into the prevention, diagnosis, treatment and care of health conditions, as well as the delivery of medical services.

This report explores the strengths and challenges of the Northern Ireland medical research environment, as it competes and collaborates within the wider UK environment. There are several features in the research environment that provide the foundation for research to flourish including: leadership, policy and collaboration; funding; infrastructure; workforce; and patient access to research [13]. Regulation and governance are not discussed in detail in this report as policy oversight and competence for these areas currently are largely reserved to the UK Government.

The initial scoping phase for this report combined analysis of publicly available data with a series of detailed, anonymised interviews with key medical research stakeholders in Northern Ireland. The aim of this approach is to establish where there is potential opportunity and where there are areas of concern across the medical research environment.

To conduct the interviews, Cancer Research UK commissioned DJS Research to perform structured telephone interviews with 17 stakeholders based in Northern Ireland and nine UK-wide stakeholders. All interview responses have been anonymised. The information collated has been used in conjunction with available data to create a picture of the current environment for medical research. Based on this information this report sets out policy recommendations for optimising medical research.

3.1 LEADERSHIP, POLICY & COLLABORATION

Northern Ireland's medical research landscape is influenced by several different actors, based within and outside the nation. In both clinical and academic settings, contributions are made by a range of organisations such as: governments; universities; the Health and Social Care (HSC) board; industry; and charities. Much of the responsibility for the funding and governance of medical research is devolved to the NI Government and other public bodies. However, researchers in Northern Ireland do also have access to UK-wide funding through UKRI's funding streams.

During the current shutdown of the NI Executive, the governance of medical research is divided between two governmental departments. The Department for the Economy (DfE) leads science policy and life sciences and the development of higher level research students[14]. The Department of Health (DoH) oversees research in HSC[15] (figure 1).

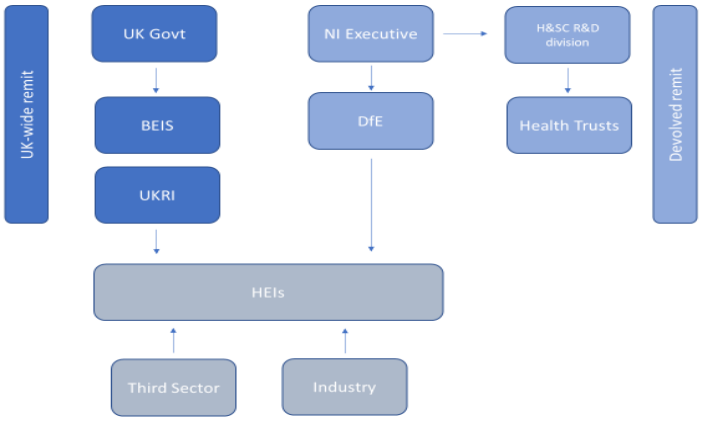


Figure 1: Organogram of organisations that influence medical research in Northern Ireland

The shutdown of the NI Executive is delaying crucial policy action

The policy environment for medical research in Northern Ireland is currently particularly challenging. The shutdown of the NI Executive places significant limitations on the actions that can be taken financially, and in a policy context to support medical research.

Our respondents reported that the absence of the Executive is making it difficult to create policy that supports medical research. One example of this is the development of a new life sciences strategy. There had been a great deal of collaborative work to produce a strategy that our respondents were happy to participate in. However, this strategy has yet to be published due to the shutdown, frustrating those involved in the process.

> "There has been work on a life sciences strategy which was ready when the Assembly collapsed. I would like to see that strategy published which was developed through an effective multi-stakeholder development process." – *Industry Representative*

A life sciences strategy would allow for the identification of key areas of research strength in Northern Ireland. The strategy could then support these areas through focussed financial and infrastructure support.

More specifically for cancer research and care, Northern Ireland has not published a cancer strategy since 2008. Such a strategy is crucial to the coordination of not only clinical services, but also medical research through shared infrastructure. Our respondents highlighted the impact that the lack of this strategy has had:

> "There needs to be a clear cancer strategy with research embedded… I think that we really need to… expand our research capacity and give as many people as possible an opportunity to be in research." – *Academic Researcher*

There are now plans in place to commission the development of a new 10-year cancer strategy[16]. This strategy should be developed urgently and improve medical research through: creating an emphasis on providing research within HSC; improving the data infrastructure for research; increasing workforce numbers in key areas to allow clinicians to take part in research; and improving the speed of access to treatments that would enable certain clinical trials to be run (these areas will be discussed in detail throughout this report). It is crucial that the DoH urgently produces a cancer strategy that embeds research within cancer care and addresses these areas.

Northern Ireland's HEIs need to focus on areas of excellence

To compete for funding in the long term, the medical research environment in Northern Ireland would benefit from a focus on specific areas of research excellence. This focus should then be used to drive investment in infrastructure and grant funding to further develop these areas. Our respondents identified a number of these areas that have been responsible for major funding to Northern Ireland including: molecular pathology; epidemiology; cell biology and; personalised medicine.

> "There are certain peaks of excellence that have been recognised by different players across the UK." – *Research Director*

> "[There are a] number of major programmes that we are leaders on because we've shared our talent, data and platforms." – Research Director

To maximise impact, areas of research excellence need to be identified by those involved in the governance and funding of research with funding and support focused into these areas. The delay in publishing the life sciences strategy due to the NI Executive shutdown has prevented a key opportunity to introduce this focus. It is crucial, when a life sciences strategy is published, that it identify areas of research strength and contains actions to optimise these areas.

Northern Ireland should seek to capitalise on its homegrown biotechnology industry

One of the strengths of the medical research environment highlighted by our respondents is its biotechnology sector and its relationship with academic institutions.

> "Northern Ireland companies have performed exceptionally well at a global level, particularly in diagnostics… global collaborations are not just being attracted, but are also being led from Northern Ireland." – *Industry Representative*

Collaborations between universities and these companies have impacted positively on medical research, including Almac's support of QUB's research infrastructure.

> "There has been good investment in the bench facilities. We have very good links between QUB, and a major company, Almac." – *Research Support Manager*

Northern Ireland's strength in this area was widely celebrated by our respondents who emphasised the need for greater support to further boost this sector.

> "We have some really excellent companies and the sector needs to grow to be able to support those who are not going to go for the academic route." – Academic Researcher

The presence of these local industry leaders potentially provides a hub of world leading infrastructure and expertise to draw from. Universities, HSC and the DfE need to work together to capitalise on this hub and explore how industry collaborations can create new research funding avenues.

Recommendations

- The Department for the Economy (DfE) should act as a matter of urgency to publish the life sciences strategy. This strategy should contain actions to build upon the strengths of Northern Ireland's existing life sciences industry.
- The Department of Health (DoH) should urgently develop and implement a comprehensive cancer strategy. The strategy should contain actions to improve the clinical research environment, including:
    - To ensure that cancer data is effectively used to assess and inform the transformative improvement to cancer services.
    - Plans to embed research throughout the health and social care system in Northern Ireland, to foster a culture of research at all levels
    - To aim to increase the number of patients having a discussion about taking part in cancer research.

3.2 FUNDING

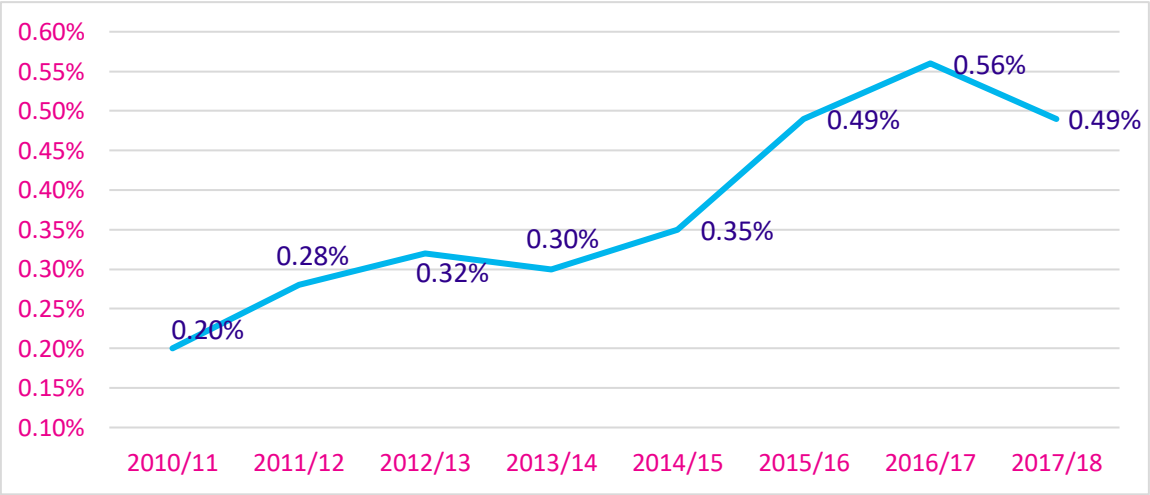
Northern Ireland's universities are struggling to compete for Medical Research Council funding

There was significant concern amongst our respondents that Northern Ireland's smaller population, and the challenging funding and policy environments are affecting the ability of researchers to compete for research funding.

In the 2014 Research Excellence Framework assessment of UK-wide research quality, more than 70% of university research in Northern Ireland was considered as internationally excellent or world leading[17]. However, this is the lowest figure of any UK nation. 76% of overall UK research was considered internationally excellent or world leading. This performance is reflected in its universities struggling to attracting funding from the UK's research councils.

In 2017/18, Northern Ireland's research institutions received around £4m in funding from the Medical Research Council (MRC)[18]. Queen's University Belfast (QUB) was in the top 50 recipients of research funding. Whilst this figure has also significantly increased in recent years - in 2010/11, Northern Ireland received only £1.5m from the MRC – it is significantly below the UK per capita average. The £4m MRC awarded in 2017/18 represented just 0.49% of its total research spend, against 2.87% of the UK population. (table 1 and graph 2 below)

This discrepancy suggests that the research environment needs greater support to allow Northern Ireland to compete at a UK level. However, these changes are difficult to enact during the current NI Executive shutdown.



Graph 2: Percentage of the MRC's research funding awarded to Northern Ireland institutions from its total research grants[19].

Year	2010/11	2011/12	2012/13	2013/14	2014/15	2015/16	2016/17	2017/18
Total MRC funding (£000s)	£1,575	£2,052	£2,435	£2,663	£2,841	£4,564	£4,233	£3,971

Table 1: MRC funding to Northern Ireland institutions, by year, since 2010/11[20].

Changes to Quality-Related (QR) funding are needed to support basic research

QR funding is an important segment of university research income in the UK and forms part of the dual support system that universities rely upon to fund research. It is often used by universities to fund essential infrastructure and workforce, enabling them to compete for project grants from competitive sources, such as Research Councils, charities and industry.

Universities are also reliant upon the dual funding system in the UK, as many grants from Research Councils, industry and charities do not cover the full economic costs (FEC) of research – such as infrastructure or staff costs. A Russell Group report on the scale of this funding gap[21] found that even when Research Council funding and capital funding are combined, universities only recover around 90% of the FEC of research. This figure is even lower when money has come from other funders, such as the EU and charities.

In 2018/19[22], the DfE awarded more than £46.5m to Northern Ireland's two universities. QUB was the biggest recipient, receiving more than £32.5m, whilst the University of Ulster received £14m. There has, however, been a gradual reduction in this funding in recent years. In 2011/12[23], almost £51m was given to Northern Ireland's universities. Our respondents mirrored this picture, with a number stating that it has become more difficult to obtain funding in recent years:

> "I think the availability of funding has actually not developed. It's actually declined." - *Academic Researcher*

This level of funding is significantly below that seen in some other UK nations. Whilst comparable to Wales, it is significantly lower than Scotland - just under £25 per capita compared to almost £43 in Scotland[24]. It is vital that the DfE act to increase the level of QR funding to allow medical researchers to compete for further competitive funding.

One further action proposed by our respondents to potentially enable greater attraction of major funding from competitive sources would be for the DoH and DfE to provide smaller "pump priming" grants to researchers in Northern Ireland, allowing them to perform proof of principle studies that might then leverage additional funding from other sources.

> "I'd like more research funding to be made available for pump priming and making sure that developments between laboratories and clinical research are available." – *Academic Researcher*

Such grants would allow medical researchers in Northern Ireland to strengthen their grant applications for larger funding grants and could support an increase in the funding gained from competitive sources such as the MRC.

There is increasing financial support for clinical research

In 2017/18, HSC R&D spent £15.84m on research & development[25]. Some £10.3m of this was allocated funding from the DoH, with an additional £1.58m gathered through bids to the department, and a further £0.4m from other sources. In addition, DoH's £3.53m contribution to the NIHR Evaluation, Trials and Studies Coordinating Centre (NETSCC) provides NI researchers access to NIHR funding opportunities.

A 2015 report on life and health sciences in Northern Ireland highlighted the benefits of HSC R&D funding [26]. Not only does every £1 of HSC R&D funding leverage an additional £4.14 from elsewhere, but one in five publicly funded studies positively impacts on increased length or quality of life. The report also pointed out that, at £7.63 per capita, HSC R&D's budget was significantly lower than the rest of the UK and less than half of the per capita spend in England. Our respondents also highlighted this lack of funding for clinical research.

> "There isn't funding available. It's a struggle to get a few thousand pounds to do a bit of seed research." – *Clinical Academic*

However, the figure spent on clinical research has increased in recent years, up from £10.32m in 2011/12 (see table 2). This increase in support is welcome and will certainly help to build the clinical research that is available to patients in Northern Ireland.

Financial Year	2011/12	2012/13	2013/14	2014/15	2015/16	2016/17	2017/18
Total R&D spend (£m)	£10.32	£10.85	£12.18	£15.06	£15.34	£16.37	£15.84

Table 2: Total HSC R&D research and development spend per year[27].

EU Funding through the ERDF is important for supporting medical research in Northern Ireland

Researchers in Northern Ireland also receive funding from EU sources, including €43m from the Horizon 2020 programme in the years up to 2016. Northern Ireland receives 1.6% of the total funding received by the UK[28], significantly lower than the UK average per capita.

Northern Ireland does, however, benefit from a large amount of funding via the European Regional Development Fund (ERDF) stream which supports economic development with the aims of reducing inequalities and increasing cohesion. Between 2014 and 2020 Northern Ireland is set to receive €113m in funding for research and innovation projects from the ERDF. This amounts to €60 per capita, substantially above the UK average of €23.

It is crucial that DfE and DoH investigate the potential impact of the loss of these funds due to the UK exiting the EU and seek alternative funding sources – including from outside the NI Government agencies. This includes ensuring access to UK-wide substitutes for this funding, such as the proposed UK Shared Prosperity Fund.

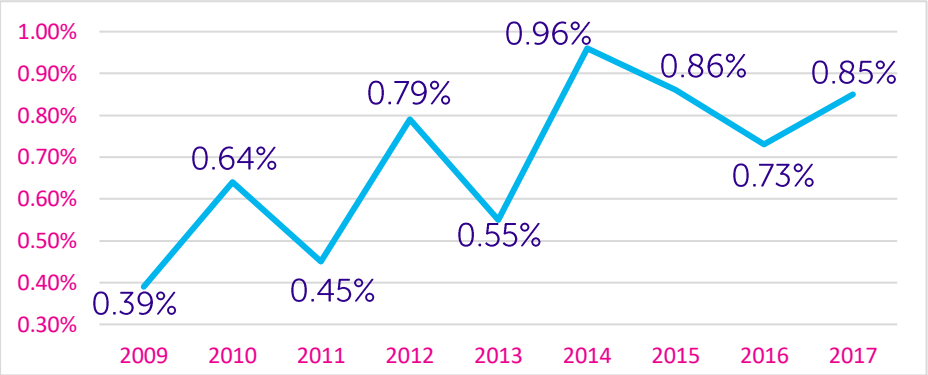
Medical charity investment in Northern Ireland is low but growing

Charities are a major funder of medical research in the UK, funding more than £1.6 billion across the UK in 2016[29]. Medical research charities also play a vital role in bringing the patient voice to collaborations with universities, industry, regulators and others. They often fund higher-risk research into areas that might not otherwise be supported. Promising results from this research can be taken forward by industry with reduced risk on their investment.

The Association of Medical Research Charities (AMRC) have estimated that medical research charities awarded almost £11m in grant funding for medical research in Northern Ireland in 2017[30]. This funding covers a wide range of areas. However, their support in Northern Ireland represents only 0.85% of the total grant funding awarded by AMRC member

charities across the UK, significantly below Northern Ireland's per capita 2.87% share of the UK population. This figure has, however, more than doubled in the last 10 years from 0.39%. (Graph 1)

Despite this increase, Northern Ireland is still significantly behind other UK nations. These difficulties highlight the need for greater focus and collaboration in Northern Ireland medical research to increase the level of research funding that Northern Ireland attracts.



Graph 1: Percentage of the AMRC charities' research funding received by Northern Irish institutions[31].

Recommendations

- The DfE should review the level of QR funding to Northern Ireland's universities with a view to increasing funding to comparable levels to other UK nations.
- The DoH and HSC Public Health Agency should explore pump priming as a way to allow researchers to perform smaller, proof of principle studies that can leverage funding for larger studies.
- The DoH and DfE and should urgently quantify the impact of the potential loss of EU funds as the UK leaves the EU and seek funding sources – including UKRI and others – to mitigate against this loss.

3.3 INFRASTRUCTURE

Collaboration between universities and industry has created a strong infrastructure for basic research in Northern Ireland

Despite the lower levels of funding available to researchers, our respondents felt that they had access to a wide range of research equipment and techniques. This has, in part, been supported through QUB partnering with Northern Ireland's biomedical industry.

> "In terms of our university, we have a number of core technology units, so we have the genomics' unit, the mass spectrometry unit, and our bioinformatics unit, which are all supported by the university." – *Clinical Academic*

> "The university has been very good at supporting that and local industry has supported [the universities] in this." - *Industry Representative*

Whilst this infrastructure support within QUB is encouraging, it's crucial that the NI Government and universities continue to work with Northern Ireland's industry to facilitate collaboration and to source funding for further laboratory research infrastructure.

Infrastructure for clinical research has been impacted by long term funding issues

Northern Ireland has a range of facilities[32] to enable clinical research including the NI biobank, NI Clinical Trials Unit and the Experimental Cancer Medicines Centre (ECMC)[33]. These facilities are crucial to the provision of clinical research in Northern Ireland.

However, our respondents suggested that the clinical research infrastructure has been negatively impacted by the cumulative effect of lower levels of funding compared to other UK nations. Our respondents emphasised the need for significant investment to improve the infrastructure to a point where more competitive funding can be attracted.

> "We don't need to match Scotland and Wales, we actually need to overtake in percentage contribution simply because we have been suffering from years, decades of underinvestment in medical research." - *Research Director*

> "Not having a proper cancer clinical trials unit has really given some limitations to our capacity for trials, and also our ability to open trials quickly." – *Clinical Academic*

One specific example where a lack of infrastructure is potentially limiting the availability of clinical research is the lack of a biomedical research centre. There was consensus amongst respondents that this posed a major issue for the provision of clinical research.

> "We are disadvantaged by not having a BRC, biomedical research centre; I think that the government need to commit to a centre like that." - *Clinical Academic*

> "We could invest in a biomedical research centre which puts us at least on paper on a level par with other regions we are trying to compete with." – *Research Director*

A biomedical research centre would allow Northern Ireland to develop more clinical research from the range of academic and commercial research that is undertaken in the

nation. There are efforts to establish a biomedical research centre as part of the Belfast City Deal that is being negotiated[34]. As part of this deal, an Institute for Research Excellence in Advanced Clinical Healthcare (i-Reach) has been proposed as part of the Global Innovation Institute (GII). Such a facility would be a huge addition to the research infrastructure.

Increasing access to patient data could enhance research opportunities in Northern Ireland

The small population size of Northern Ireland presents a potential opportunity to researchers in Northern Ireland for population level research. Crucial to this, however, is the availability of linked data from HSC.

> "People who are generally born in Northern Ireland, they live in Northern Ireland and they die in Northern Ireland. So that gives us quite a very rich access to what we call epidemiological data and it's a data about these patient's lives." – *Clinical Academic*

> "[NI's] 1.8 million population is actually a very attractive population to work with, particularly with a single health system, but you need to enable the use of the samples and the data that's generated from that." – *Academic Researcher*

This data availability was reported to be an issue by our respondents. The sharing and linkage of HSC patient data was identified as an area where improvement is needed.

> "I think our availability in sharing data is quite poor. I think that could be improved greatly." – Clinical Academic

> "We're still using multiple different patient systems, we've only just got an electronic health record in, but it's not been approved for use in research." – *Clinical Academic*

Our respondents highlighted that work is ongoing amongst researchers to ensure that data sharing is becoming the norm amongst researchers. However, the absence of a devolved parliament has stalled legislation enabling the secondary use of data. Despite receiving Royal Assent, regulations to implement the Health and Social Care (Control of Data Processing) Act (Northern Ireland) 2016 are still not drafted or agreed. Without this legislation, there are difficulties in sharing data across the NI health service. It is also not possible to integrate cancer data with other UK nations or undertake comparative research.

Where the sharing of data has been made possible, some teams within Northern Ireland have attracted major research funding. Examples of these include the Cancer Research UK accelerator in digital pathology, the Movember Centre of Excellence for prostate cancer and the MRC/CRUK Escort Programme. Such awards and programmes highlight the potential for research in Northern Ireland, especially as a partner in wider projects with larger research institutions.

Recommendations

- Northern Ireland's universities, industry, the HSC and the third sector need to work collaboratively with the UK Government and Belfast City Council to establish the iREACH biomedical research centre as part of the Belfast Region City Deal.
- The NI Government should urgently implement the Health and Social Care (Control of Data Processing) Act (Northern Ireland) 2016 to enable data sharing for medical research.

3.4 WORKFORCE

The research workforce is vital to the development of treatments and the improvement of patient outcomes. In basic research this spans from research leaders to the administrative and technical staff who make up a research team. In clinical research this includes the clinicians, nurses and allied health professionals that enable trials to happen.

There is a shortfall in the basic medical research workforce

Our respondents reported that the numbers of students at Northern Ireland's universities was strong. From 2013/14 to 2017/18, more than 54,000 students in Northern Ireland studied medicine and allied subjects[35], representing almost 3.1% of UK students, slightly above NI's UK population share. However, concerns were raised about the capacity for postgraduate training.

> "We have a good pool of talented PHD and undergraduate students… but getting PHD students funded is always difficult." – *Academic Researcher*

> "There are talented people coming through the ranks that have been trained in Northern Ireland. The one weakness that that system probably has is critical mass. There is a limit to the number we can nurture in Northern Ireland." – *Research Director*

This concern is reflected in the numbers of students undertaking postgraduate research study. From 2013/14 to 2017/18, the Northern Ireland percentage of UK postgraduates was just 2.3%. This suggests that fewer undergraduates are going on to postgraduate study in Northern Ireland than other parts of the UK and this could be due to issues in the funding of postgraduate positions, resulting in many researchers leaving for opportunities elsewhere. Our respondents suggested that there needs to be growth in the research sector overall to allow talented researchers to develop and build Northern Ireland's research portfolio, focussing on areas of strength where better support systems for researcher development exist.

> "[The attraction and retention of researchers] has the right support in the peaks of excellence. Outside the peaks of excellence, the support is significantly weaker." – *Research Director*

> "Our reputation is good and growing. I worry that the size of the sector needs to grow. That's what needs to happen over the next five years." – *Academic Researcher*

Further along the research career pathway, our respondents felt that Northern Ireland's intellectual capital performs well in its areas of strength, but both the lack of critical mass and workload pressures are impacting the effectiveness of research leaders.

> "[Northern Ireland] has punched above its weight in terms of the intellectual capital in our clinical and academic communities." – *Industrial Representative*

> "There is [grant writing] support, but it's not as much as you would like, and it's not driven by the Government to increase research funding." – *Academic Researcher*

To enable Northern Ireland's research leaders in its areas of excellence to maximise the impact of their work, universities and other bodies need to provide the best possible infrastructure and support to nurture and retain research leaders.

Pressures on the health service are affecting the ability of clinicians to take part in research

Increasing clinical pressures on the health service and a lack of dedicated infrastructure are significantly impacting the ability of health professionals to take part in clinical research.

> "When it comes to actually running the trial, the level of pharmacy and nursing support can be difficult to find, because they're often prioritised for front line services, or for general NHS work. It can be difficult to get the support." – *Clinical Academic*

> "The issue really comes down to the support from the Trust. I would say that they're under pressure for waiting lists... It's very difficult to get nursing and pharmacist support for the purposes of trials." – *Industry Representative*

In addition, workforce shortages are impacting the ability of Health Trusts to open trials, or to do so in a timely manner, and it is crucial that the Department of Health takes action to address these in any new life sciences or cancer strategy. They also noted that these delays are affecting the retention of clinical academics.

> "We're hopefully opening a trial this week that has taken me nearly two years to get open, whereas other centres I know were open within six months." – *Clinical Academic*

> "It's difficult to retain clinical academics as well, because there's always increasing clinical pressures." – *Research Director*

There are also concerns about the opportunities for health professionals to develop careers in research, and the short-term nature of many research roles.

> "I think that we need to invest in clinical academic programmes to allow clinicians to be academics, and to allow academics to continue to be clinicians because I think that's very important in all aspects." – Academic Researcher

Whilst some opportunities exist for clinical academic fellowships through university[36] and all-Ireland schemes[37], Northern Ireland is the only UK nation without a government funded clinical fellowship scheme. Without clear pathways and stable job opportunities for clinical academics, many will stop undertaking research or move elsewhere to find opportunities. It is crucial that the DoH works with Trusts to establish career pathways for clinical research.

Recommendations

- Northern Ireland's research institutions should work with the DfE to create a plan to ensure that Northern Ireland is able to attract and retain world class research talent.
- DoH should work with representative bodies to create mechanisms so that clinicians interested in engaging in research are able to.

3.5 PATIENT ACCESS TO CLINICAL TRIALS

The ability of patients to access clinical trials is an important area of any research environment. Clinical trials are crucial in providing the best possible standard of care to patients. There is a need to develop better, kinder treatments and to improve patient care and this relies on scientific progress. Therefore, it's vital that the right patients can take part in appropriate research trials.

We are using cancer as an example to illustrate the themes around patient access to clinical trials due to the availability of data from the Cancer Patient Experience Survey (CPES). Clinical trial enrolment data is difficult to use as a marker of changes in patient recruitment. This is partly a result of advances in precision medicine approaches to treatment, with the development of a greater number of "targeted" medicines and the identification of more clinically actionable genetic mutations limiting the number of patients suitable for some trials. This means that fewer patients may be eligible for any given trial, given the increasing stratification of patient populations according to results from genomic testing.

It is also difficult to find detailed data about the number of patients signing up for trials across the Northern Ireland medical research environment. The increasing specificity of trials mean that they are now often run across many sites. The reporting of these trials onto public databases often does not specify where the trials are currently open across these sites, making it difficult to create an accurate picture of clinical trial participation in Northern Ireland specifically.

The Cancer Patient Experience Survey provides an insight into how the NI HSC is engaging its patients in research and we are using this to highlight where systemic issues might exist in the recruitment of patients to clinical trials across the medical research environment.

The signposting of research to patients is lower than other parts of the UK and falling

Patients appreciate the opportunity to participate in clinical research. When asked, 89% of people said they would be willing to take part in clinical research, and 95% of people said they think it is important for the health service to carry out clinical research[38].

However, in the 2018 Northern Ireland CPES[39], only 15% of responders said that someone had discussed with them whether they would like to take part in research. This is the lowest figure of any UK nation and is lower than in 2016, when it was 18%. (Table 3 below).

These results suggest that the issues previously outlined in the leadership, funding, infrastructure and workforce for clinical research are having a significant impact on the ability of the health service to discuss clinical research opportunities with patients.

Nation	% of interviewees who had research discussed with them		
	2013	2015/6	2017/8
Wales	29%[40]	23.1%[41]	N/A
England	32%[42]	27.4%[43]	29.5%[44]
Scotland	N/A	22%[45]	N/A
Northern Ireland	N/A	18%[46]	15%[47]

Table 3: Percentage of CPES interviewees who had research discussed with them by nation.

There are several possible attributing factors to this low figure. One significant factor is very likely to be pressures on the health service. A total of 9,457 new cases of cancer were diagnosed and registered in Northern Ireland in 2015, 30% more than ten years previously[48]. Increasing time demands on oncologists means that they may not have enough time to discuss research with their patients. In addition, if fewer consultants can engage in research themselves due to growing workforce pressures, they might be less active in communicating about research to their patients more generally.

Our respondents highlighted the problems that are being experienced in recruiting patients to trials.

> "I would be lying if I said [trial recruitment] was easy, or that we have been successful overall. Recruitment to interventional trials has not exceeded 3.5% over the last couple of years… we've had a lot of success in terms of biomarker related studies, where maybe the level of recruitment increases to 18%." – *Research Director*

One exception to this is in prostate cancer research, where Northern Ireland performs well, and Belfast has been selected as a Movember Centre of Excellence in collaboration with Manchester.

> "We probably have the highest rate of recruitment to prostate cancer trials in the whole of the UK, per capita… We now have three clinical academics in prostate cancer… and because we've been successful in grant applications as well, in general we've got strong support to develop ideas for trials and then to push them through." – *Clinical Academic*

The success of this group of clinical academics in securing investment and recruiting patients demonstrates the potential for world leading medical research in Northern Ireland. However, this relies on a critical mass of research-interested clinicians in the same clinical field to recruit patients. It is important that patients have the best possible access to trials across the health service and the Department of Health and Health Trusts should consider how to ensure eligible patients are offered the opportunity to take part in clinical trials. This could include steps such as providing administrative support to identify eligible patients or adding the responsibility to signpost clinical trials into clinicians' contracts.

Issues in accessing new medicines are affecting the availability of trials

Another issue reported by our respondents that is reducing the availability of clinical trials to patients is the speed with which new medicines are approved for use in Northern Ireland.

They suggested that the slow uptake of new medicines is affecting Northern Ireland's attractiveness as a site for trials for experimental medicines.

> "The cancer research network are having to turn away potential research collaborations from industry, because [of issues with accessing new medicines]. In other words, because patients in Northern Ireland are increasingly falling behind those in other parts of the UK in terms of being on the latest cancer medicines." – *Industry Representative*

Issues in approving new medicines are having a significant impact on the availability of not only the best standard of care for patients, but also on the availability of innovative trials of existing treatments. It is crucial that the Department of Health works to urgently ensure the swift adoption and regular commissioning of innovative, evidence-based medicines.

The Health Research Authority is working to streamline clinical trial approval

Our respondents highlighted other issues about the approvals of trials by Health Trusts but recognised that this was being addressed as part of wider UK efforts through the work of the Health Research Authority (HRA)[49]. HRA is working to harmonise the approval systems across all UK nations. This would allow for quick approval of trials across the UK, which would be a hugely attractive selling point to industry to conduct their work within the UK.

> "There are certain limitations whenever researchers are trying to get approvals in terms of ethical approvals, government approvals for research. The ethics is obviously where we tie in with the UK, the National Research Ethics Service in the UK, so we're part of that overarching system within the United Kingdom." – *Clinical Academic*

Such harmonisation would be incredibly valuable for patients. Quick approval of clinical research in Northern Ireland, for trials that are being led in other UK nations, would allow for a greater number of trials to be offered to patients. Researchers who set up trials in one UK nation may not open up their trials to other UK nations, where the burden of engaging with three extra approvals systems is too great. The harmonisation work of the HRA will hopefully allow more clinical trials to be available to patients in more parts of the UK. It is important that the Department of Health work closely with their UK counterparts to ensure that this harmonisation provides as much benefit to patients as possible.

Recommendations

- The DoH, HSC and Health Trusts should put systems in place to signpost ongoing clinical trials to patients.

4. CONCLUSIONS AND RECCOMENDATIONS

Cancer Research UK has undertaken this research to assess the strengths of the medical research environment in Northern Ireland and outline opportunities for policy action to enhance medical research in the country. The findings highlight the need for consolidation of resources into areas where Northern Ireland can be internationally competitive.

The current policy environment in Northern Ireland is creating challenges for medical researchers. The shutdown of the NI Executive restricts the actions that can be taken to support research. There is significant need for strategies to provide leadership to those involved in research across the pipeline – from a life sciences strategy to foster collaboration and focus to maximising the strengths of Northern Ireland's life sciences industry, to a cancer strategy which places research at the heart of NI HSC services.

There is also the need for an appropriate level of QR funding to support medical research in universities, particularly basic research. This funding provides crucial infrastructure and workforce that underpins research. Sufficient QR funding would enable researchers to better compete for funding from outside Northern Ireland.

This funding is needed to maximise the potential of the basic research infrastructure that Northern Ireland has developed through collaboration between academic and industry research institutions. Steps should also be taken to improve clinical research infrastructure, including the establishment of a biomedical research centre, and ensure that all possible steps are taken to facilitate and access to health data for research.

Our respondents highlighted significant concerns about the research workforce across the pipeline. In basic research, there are concerns about the opportunities for Northern Ireland's postgraduate research students to continue their career within the country, with many leaving for external opportunities, or leaving academia entirely. There are also concerns about the opportunities that exist for health professionals to take part in research. It is vital that mechanisms are put in place to ensure that health professionals are encouraged and supported to take part in research.

Such mechanism could help to increase patient access to appropriate clinical trials in Northern Ireland. However, it is important that, alongside such clinical mechanisms, systems are put in place to increase the signposting of clinical trials.

Whilst Northern Ireland is home to areas of international medical research excellence, the policy and funding environment means that researchers are struggling to compete at a UK and international level. Medical research needs greater support in Northern Ireland to build on the areas of research excellence.

LEADERSHIP & COLLABORATION

- The Department for the Economy (DfE) should act as a matter of urgency to publish the life sciences strategy. This strategy should contain actions to build upon the strengths of Northern Ireland's existing life sciences industry.
- The Department of Health (DoH) should urgently develop and implement a comprehensive cancer strategy. The strategy should contain actions to improve the clinical research environment, including:
  - That cancer data is effectively used to assess and inform the transformative improvement to cancer services.
  - Plans to embed research throughout the health and social care system in Northern Ireland, to foster a culture of research at all levels
  - A aim to increase the number of patients having a discussion about taking part in cancer research.

FUNDING

- The DfE should review the level of QR funding to Northern Ireland's universities with a view to increasing funding to comparable levels to other UK nations.
- The DoH and HSC Public Health Agency R&D should explore pump priming as a way to allow researchers to perform small, proof of principle studies that can leverage funding for larger studies.
- The DoH and DfE and should urgently quantify the impact of the potential loss of EU funds as the UK leaves the EU and seek funding sources – including UKRI and others – to mitigate against this loss.

INFRASTRUCTURE

- Northern Ireland's universities, industry, the HSC and the third sector need to work collaboratively with the UK Government and Belfast City Council to establish the iREACH biomedical research centre as part of the Belfast Region City Deal.
- The NI Government should urgently implement the Health and Social Care (Control of Data Processing) Act (Northern Ireland) 2016 to enable data sharing for medical research.

WORKFORCE

- Northern Ireland's research institutions should work with the DfE to create a plan to ensure that Northern Ireland is able to attract and retain world class research talent.
- DoH should work with representative bodies to create mechanisms so that clinicians interested in engaging in research are able to.

PATIENT ACCESS TO CLINICAL TRIALS

- The DoH, HSC and Health Trusts should put systems in place to signpost ongoing clinical trials to patients.

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