

Bench To Bedside

Optimising Medical Research in Scotland
through Collaboration

Together we will beat cancer



CANCER
RESEARCH
UK

CONTENTS

1. EXECUTIVE SUMMARY	3
2. INTRODUCTION	6
3. FINDINGS	7
3.1 LEADERSHIP, POLICY & COLLABORATION	7
3.2 FUNDING	11
3.3 INFRASTRUCTURE	15
3.4 WORKFORCE	17
3.5 PATIENT ACCESS TO CLINICAL TRIALS	19
4. CONCLUSIONS & RECOMMENDATIONS	22
5. REFERENCES	24


1. EXECUTIVE SUMMARY

Around 32,000 people are diagnosed with cancer every year in Scotland¹. 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 been a vital part of 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 Scotland 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 medical research stakeholders, 21 with Scotland-wide remits and 9 UK-wide.

Scotland has a strong research base for its size, significantly overperforming in competitive research funding per capita. For example, Scotland received €533 million in Horizon 2020 funding between 2014-2016. This equates to €55 per capita, higher than any other UK nation².

Whilst our respondents highlighted Scotland's strength in medical research, they emphasised a need for policy action to maintain and expand on this success in the medium and long term. It is becoming increasingly difficult for universities in Scotland to individually compete for research funding. Some actions have been taken to enable collaboration in Scotland's research environment and it's important that this work continues.



**MEDICAL RESEARCH
COLLABORATION IN
SCOTLAND NEEDS TO
BE FACILITATED TO
SECURE LONG-TERM
FUNDING AND
ENSURE PATIENT**

Additionally, our respondents emphasised that NHS workforce pressures and ways of working are impacting the ability of health professionals to engage in research, potentially restricting patient access to research in Scotland.

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

Scotland's basic research environment is performing well in funding gained from competitive sources. This is, in part, due to the historic strength of its universities and ongoing support from the Scottish Government, which has established significant policy direction for Scotland's medical research environment through a number of strategies including in life sciences³, health and social care research⁴ and cancer⁵.

Despite this, there are concerns about the ability of Scottish universities to compete with the increasing critical mass of

research expertise at larger research institutions in the UK and internationally. Increasing collaboration within Scotland is a solution to this and would enable researchers in Scotland to compete more effectively for major research funding.

The Scottish Funding Council (SFC) is currently consulting on its Scottish Research Pooling Initiative including the work of the Scottish Universities Life Sciences Alliance (SULSA). It is crucial that this consultation looks at how such research collaboration can be increased⁶.

RECOMMENDATIONS

- Universities, the Chief Scientist Office (CSO) and the Scottish Funding Council (SFC) should work together to maximise the impact of the Scottish Research Pooling Initiative and explore further mechanisms to support collaboration between research teams from multiple universities. This could include financial support for meetings where collaborative grant applications could be developed.

FUNDING

The levels of Quality-related (QR) funding awarded to universities by the Scottish Funding Council (SFC) is high, more than twice that awarded in England per capita. However, there are concerns about how this funding is distributed. Whilst, the overall QR pot has grown by £6.5 million since 2014/15⁷, funding for some of Scotland's best performing universities fell and has reportedly affected the ability of some to maintain PhD student levels.

More serious concerns were expressed about the outlook for clinical research funding. Much of the available funding is provided through the Chief Scientist

Office's contribution to the National Institute for Health Research (NIHR) funding pools. However, the current arrangement only buys into four of the nine NIHR funding streams⁸ and there is a desire amongst researchers for this provision to be expanded.

Researchers and politicians are concerned about the impact of leaving the EU on research funding. Scotland is a major beneficiary of EU research funding and it is vital that the Scottish Government explores all options to minimise the impact of this potential loss.

RECOMMENDATIONS

- The SFC should engage with the universities ahead of the next Research Excellence Framework (REF) in 2021 and review how the changes have impacted medical research in Scotland's leading research Universities.
- The CSO should review the portfolio of clinical research funding available in Scotland, including access to NIHR funding and whether this can be expanded. The clinical research community should be consulted to ensure no gaps exist.
- The Scottish Government and Scotland's funding bodies 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

Our respondents identified Scotland's basic research infrastructure as world leading. However, there were some concerns about the levels of support staff in some institutions. There were also

positive responses about the interface between clinical and academic research, and ongoing efforts to perform clinical research across Scotland.

However, there are issues around accessing patient data which delay and prevent some clinical research projects. There is work ongoing into Scotland's data infrastructure through the Innovative Healthcare Delivery Programme (IHDP) and it is important that this continues⁹.

RECOMMENDATIONS

- The Scottish Government should continue to support and enable projects like IHDP that are seeking to link patient data to improve practices and outcomes.

WORKFORCE

Our respondents highlighted that Scotland's reputation for research is helping to attract early-career researchers but also expressed concerns about the retention of mid-level researchers.

Of most concern was the development and retention of clinical researchers. Our respondents highlighted the lack of opportunities for health professionals to engage in research. Currently, those who wish to take part in research only have one block of research time to nine for clinical practise. It is crucial that this research time is expanded to allow health professionals to take part in research.

It was highlighted that the number of CSO Clinical Academic Fellowships¹⁰ available is lower than the NIHR Academic Clinical Fellowships, limiting the number of health professionals that can take part in research.

Our respondents highlighted that challenges in the wider NHS workforce

were beginning to impact clinical research. It is crucial that these gaps are addressed to allow patients to take part in research.

RECOMMENDATIONS

- The Scottish Government should increase its support for clinical academic development through increasing the funding of the CSO Clinical Academic Fellowship scheme.
- The Scottish Government, NHS Health Boards and CSO should work with the medical research community to develop sustainable approaches to ensure health service staff have sufficient time to develop, undertake and participate in research.

PATIENT ACCESS TO CLINICAL TRIALS

The results of the Scottish Cancer Patient Experience Survey (CPES)¹¹ show that less than a quarter of patients in Scotland had a discussion about taking part in research, low compared to the average across the UK.

The Scottish Government is working to increase public participation in health research through the NHS Research Scotland (NRS) research networks¹² which aims to increase the number of trials available to patients across Scotland. It is crucial that the CSO, NRS and the Scottish Government continue to take steps to increase research participation.

RECOMMENDATIONS

- The Scottish Government should continue to promote engagement in health research and should seek further opportunities to increase the number of conversations with patients about clinical research participation.

2. INTRODUCTION

Around 32,000 people are diagnosed with cancer every year in Scotland¹³, and it has been projected that this figure will rise to more than 40,000 by the year 2035¹⁴.

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 been a vital part of this progress to date and is crucial to further improving outcomes for cancer patients and reach this ambition.

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

However, cancer research doesn't happen in a silo. Therefore, Cancer Research UK has conducted a study to analyse the current state of the medical research environment in Scotland 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 Scottish medical research environment, as it competes and collaborates with 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 research¹⁵. This report discusses the first five features. 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 Scotland. 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 21 stakeholders based in Scotland 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. Consequently, this report sets out policy recommendations for optimising medical research.

3.1 LEADERSHIP, POLICY & COLLABORATION

The medical research landscape in Scotland is made up of several different actors, based within and outside of Scotland. In both clinical and academic settings, contributions are made by a range of organisations such as governments, universities, the NHS, industry and charities.

The governance of both basic and clinical medical research in Scotland is led by the Scottish Government. At the time of publication, this is currently divided between two departments. The Minister for Further Education, Higher Education and Science currently has the oversight for universities, science and STEM¹⁶. The Cabinet Secretary for Health and Sport oversees research and development in health and social care¹⁷.

The Scottish Government funds and oversees research funding and governance through two public bodies. For clinical research, the Chief Scientist office (CSO)¹⁸ is responsible for supporting and increasing the level of high-quality health research in Scotland. For basic research, the Scottish Funding Council (SFC)¹⁹ is responsible for the funding and governance of universities, including research. (More details about the organisations that influence research can be found below).

The Scottish Government have a number of strategies that provide overarching policy direction for research. In 2015, the Scottish Government published a five-year Health and Social Care Research Strategy - Delivering Innovation through Research²⁰. This strategy is used by the CSO and NHS Research Scotland to inform their support for research in NHS Scotland. Additionally, the Scottish Government published the Life Sciences Strategy for Scotland in 2017 which sets out the Government's aim to grow the industrial turnover of the sector to £8 billion from £4.2 billion in 2014²¹. Moreover, the Scottish Cancer Strategy sets out actions to increase the level of cancer research in Scotland²².

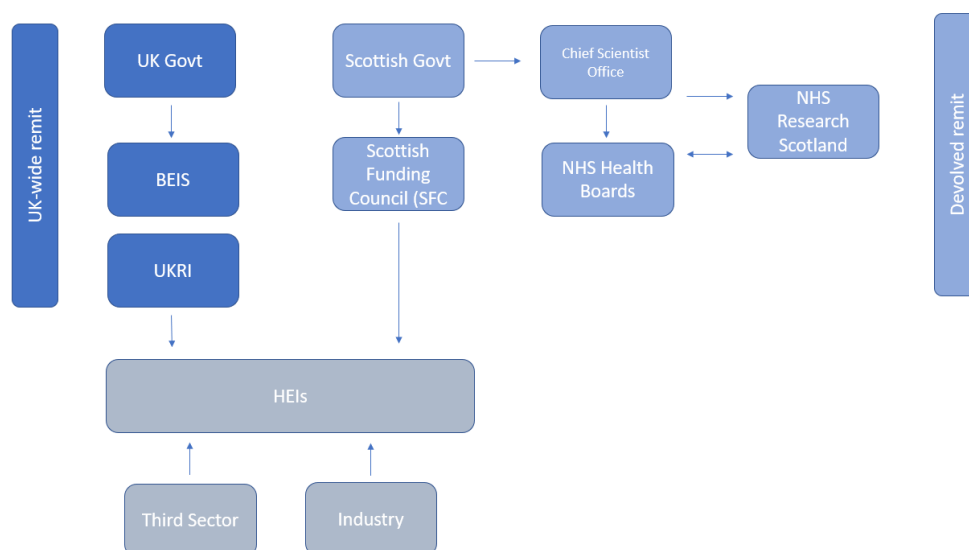


Figure 1: Organogram of organisations that influence medical research in Scotland

There is a growing need for national collaboration on medical research

The SFC is a major source of funding for Scotland's research institutions awarding more than £266 million in Scottish Government funding in 2017/18²³.

Concerns have been raised regarding the level of influence that the Scottish Government has over the SFC's governance of Universities. In 2018, the Scottish Government introduced Education (Scotland) Bill²⁴ to the Scottish Parliament seeking to merge the governance of the SFC with other funding councils primarily aimed at enterprise. It was defeated in Parliament but raised concerns from Scotland's medical research community.

"there is a risk of the Government getting too involved in university management. A lot of the academics are concerned about that." – Academic Researcher

"you could skew that research towards clinical research at the risk of the basic science" – Academic Researcher

Whilst there are potential benefits to enabling enterprise in the medical research sector, it is important that the Scottish Government ensures the independence of universities and protects the funding of basic research alongside clinical research.

Another issue that was highlighted by our respondents was the increasing power of some large research institutions outside Scotland. Some expressed concerns about Scotland's competitiveness for research funding in the long term.

"What attracts leaders is money and the critical mass of other high-quality researchers around them... I think Scotland does probably suffer slightly. I was involved in trying to recruit people to Glasgow and it's just not as easy as attracting people to Oxford, Cambridge and London" – Academic Researcher

One potential way to increase this critical mass is to increase research collaboration between Scottish institutions. There are worries that such collaboration does not happen regularly enough, and that it is currently easier to collaborate outside of Scotland.

"there's still probably too much competition among research groups and universities, which can mitigate against good joined up research activity" – NHS Representative

"It's no different for me whether the person's in Edinburgh or Manchester. I'll go with the right person... There are some impediments which mean that it is easier to get clinical trials opened in England than in Scotland at the moment." – Research Director

Other respondents highlighted the need to improve this collaboration to compete within the UK.

"I think that we have the ability, if we were all joined up, to be a really strong force, but we're just not there yet... I think that we should be collaborating more and becoming more just like a Scottish centre of excellence" – Clinical Academic

A strong example of this collaboration is the joint bid between Edinburgh, Aberdeen, Dundee, Glasgow, St Andrews and Strathclyde Universities for funding as a site for the Health Data Research UK project²⁵. This gave these universities access to a UK-wide pot of

£30 million funding and a potential £24 million in future funding schemes. It is important that HEIs and CSO work together to maximise the potential for collaboration within Scotland.

One funding stream that is currently in place to increase collaboration is the SFC research pooling funds²⁶. These 11 pools were “developed to support institutions to establish collaborative research pools with the aim of growing a critical mass of excellent research in Scotland, to compete effectively for funding, academic staff and research students both nationally and internationally²⁷”. This scheme was set up in 2004/5 and these pools have received over £140 million from the SFC along with over £300 million from institutions. However, the majority of the funding has come to an end and there is only a commitment of up to £112,500 a year for five years to support the continuation of successful pools. These pools include the Scottish Universities Life Sciences Alliance (SULSA) which works to enhance collaboration in life sciences²⁸. These pools are currently undergoing an independent review of their impact and it crucial that this review leads to the optimisation of these funds and that the SFC, CSO and the Scottish Government look at ways that they can further support research collaboration in Scotland.

The Life Sciences sector is a key strategic area for the Scottish Government

The life sciences industry is well established in Scotland and it has been estimated that the sector supports a Gross Value Added of £2 billion, employing over 37,000 people across 700 organisations²⁹. This sector is a key strategic area for the Scottish Government and the Life Sciences Strategy for Scotland, published in 2017, aims to grow the industrial turnover of the sector to £8 billion from £4.2 billion in 2014³⁰. Our respondents highlighted the potential of this sector and that collaboration between academia and industry could drive innovation in Scotland.

“at a national level we could negotiate more with larger companies to invest some money in Scotland” - Civil Servant

“one area where we can align the industrial strategy vision with the academic effort is a translational piece to develop our data science capabilities” – Research Director

However, there are worries that any increased focus on innovation and enterprise in life sciences research could introduce new bureaucratic barriers to research.

“I think that we're going to have to collaborate much more closely with industry and I think that will probably be another bureaucratic headache” – Clinical Academic

Cancer Research UK and other charities play a key role in enabling partnership working within the medical research environment. It is important that charities are included in any efforts to increase the level of partnership working within Scotland’s medical research environment.

The Chief Scientist Office is effective but needs more financial support

The CSO is part of the Scottish Government's Health Directorate and aims to support and increase the level of high-quality health research conducted in Scotland, supporting health science based upon the 2015 Health and Social Care Research Strategy³¹.

The CSO's policy is led by the Scottish Government strategy, however it works as a funder that is independent from Government. Our respondents highlighted both the benefits and drawbacks of this.

"I think [it's positive that] the CSO maintains an independent position from policy within government, so... we can pursue the research that's needed rather than the research that policy wants." – Civil Servant

"their links with policy, as in Scottish government policy, could be strengthened. The model of the operators is a responsive model. Researchers come to the committee with an idea and they ask for the funding, with a proposed, they don't operate a model of commissioned calls" – Academic Researcher

The independence of the CSO means that the work of the office is not tied to policy and can focus on funding and supporting the highest quality research. However, there are concerns that funding difficulties with NHS Health Boards has meant the provision of research is deprioritised by some.

"With the draw-down in finance to some of their health boards, there is an emphasis on clinical delivery and I think that research and innovation may suffer because of this." – Clinical Academic

It is crucial, with the limited scope of the CSO, that research continues to be supported by NHS Scotland Health Boards. It is important the Chief Medical Officer, along with the Chief Scientific Officer emphasises to NHS Scotland the crucial role of research as the best standard of care for patients across Scotland.

Recommendations

- Universities and the Chief Scientist Office should collaborate to explore further mechanisms to ensure that research teams from several institutions are able to collaborate to obtain funding from major research initiatives. This could include offering financial support to organise meetings where collaborative grant applications can be developed.

3.2 FUNDING

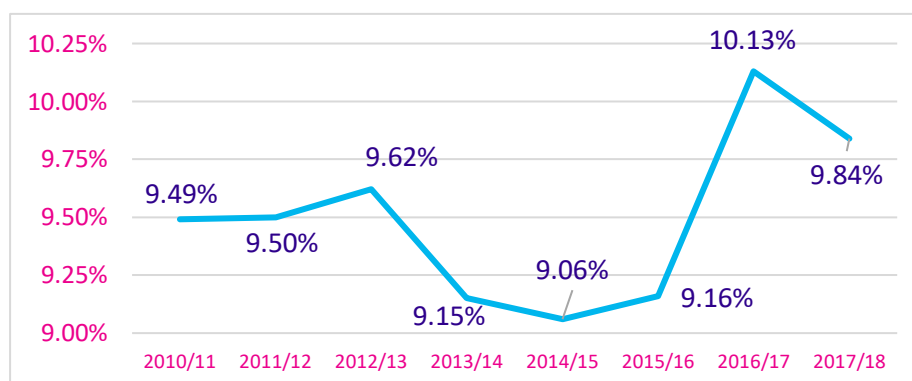
Scottish university funding from the Medical Research Council is healthy and increasing

Home to five of the world's top 200 universities, pioneering in high quality research, Scotland has been able to attract considerable funding from the Medical Research Council (MRC), which forms part of the UKRI. In 2017/18, Scotland received more than £80 million in research funding from the MRC³², with Edinburgh and Glasgow universities within the top 10 recipients of MRC funding and a further seven institutions within the top 100.

This figure has increased in recent times in line with the MRC's increasing budget, as shown in table 1. In the year 2010-11, Scotland received 9.49% of the MRC's overall funding and this is currently 9.84% (The percentage of MRC's research spend each year can be found in graph 2). This figure is significantly above Scotland's per capita population share of 8.7%.

Year	2010/11	2011/12	2012/13	2013/14	2014/15	2015/16	2016/17	2017/18
Total MRC funding	£73,560	£70,015	£74,088	£80,296	£72,624	£84,987	£76,483	£80,099

Table 1: MRC funding to Scotland institutions, by year, since 2010/11³³. Figures in £000s.



Graph 1:
Percentage of the
MRC's research
funding received by
Scotland
institutions from its
total research
grants.³⁴

There have been changes to the allocation of QR funding

The SFC awards funding to universities from the Scottish Government. It is a major source of funding to Scotland's research institutions, with more than £266 million awarded in 2017/18³⁵, an increase from the £243 million awarded in 2010/11. The majority of this fund is provided through the award of QR funding (known as the Research Excellence Grant (REG)) based upon the performance of Universities in the Research Excellence Framework (REF) assessment and is awarded as an annual block grant.

There are concerns within Scotland's universities about the distribution of the REG funding. Of the eight universities that were within the top 100 of the REF UK-wide, Edinburgh, St Andrews, Dundee and Aberdeen had their REG funding reduced between 2014-15 and 2018-19³⁶ (see Table 2). Our respondents identified flaws in the system which bases funding on improvements in performance and a perception of punishing universities who are already performing at a high level.

"things are averaged out so that the money that comes through the research exercise framework is more allocated equally among the universities" *Academic Researcher*

“focus on excellence, and recognise its importance if we're going to compete, this drive around redistributing is in nobody's interests” *Research Director*

As funding from competitive sources are increasingly concentrated to large institutions, it is important that Scotland's areas of research excellence are funded to allow them to compete at a UK and EU level. The SFC needs to engage with researchers across Scotland to ensure the QR funding formula optimises the level of external research funding attracted.

Institution (£millions)	2014-15	2018-19
Aberdeen	21.14	20.13
Abertay Dundee	0.53	0.72
Dundee	20.86	19.80
Edinburgh Napier	1.55	1.71
Edinburgh	84.02	76.94
Glasgow Caledonian	1.83	2.77
Glasgow School of Art	1.87	1.19
Glasgow	44.79	46.76
Heriot-Watt University	9.93	12.46
Highlands and Islands	1.37	2.47
Queen Margaret University	0.36	0.83
Robert Gordon	1.89	1.26
Royal Conservatoire of Scotland	0.15	0.26
SRUC	0	3.47
St Andrews	17.73	17.48
Stirling	5.29	7.32
Strathclyde	16.43	18.95
West of Scotland	0.91	1.49
Total	230.66	235.99

Table 2: QR funding to Scotland institutions in 2014/15 and 2018/19³⁷.

Chief Scientist Office needs to increase the level of funding researchers can access

As part of its mission to support and increase the level of high-quality health research, the CSO has a budget to fund research. Whilst our respondents were positive about the work of the CSO, they were concerned with the level of finances available to maintain this.

“we have strong coordination from the CSO. The issue is that there are cash constraints... the CSO's networks could be strengthened with greater infrastructure support from the government” – Clinical Academic

The lack of funding was highlighted in the provision of clinical research, where the CSO is unable to provide the level of support to researchers, through fellowships and grant funding, that is provided in England by the NIHR.

“there needs to be an increase in funding from the Scottish Government because the level of CSO funding... is nowhere near even proportionately near to what NIHR funds.” – Academic Researcher

The CSO has an annual budget of around £69 million to directly grant fund research³⁸ and this support are highly valued by the research community. Demand for CSO grants are high - with over 150 applications per year of which only 20% are successful.

The CSO also works to obtain funding for clinical research in Scotland by contributing to the National Institute for Health Research (NIHR) funding pools exceeding £100m annually³⁹. Our respondents recognised that the current system only enables Scotland to buy into four of NIHRs main funding programmes⁴⁰. This is fewer programmes than can be accessed by researchers in both England and Wales.

“there's some UK wide money that Scotland can't go for, for instance some of the NIHR grants. We can't [apply] for the NIHR clinical academic fellowships, nor can we go for the programme research grants” *Academic Researcher*

“We are excluded from some of the major funding opportunities, which mean that some of the big money doesn't always come to us.” *Academic Researcher*

Limited access to the NIHR funds is a major concern for clinical research in Scotland. Whilst the CSO offers some alternative funding streams, our respondents highlighted that the level of funding is significantly lower than is available to researchers in England. It is crucial that CSO addresses this discrepancy and should conduct a formal review, involving clinical stakeholders, to assess the costs of not signing up to all available NIHR funding streams and work with NIHR to negotiate access to all streams that are found to be valuable.

Scottish Researchers Receive a Significant Level of Funding from EU sources

Scotland's Higher Education Institutions (HEIs) also receives substantial funding from the European Union. Scotland received €296 million of the €2.7 billion awarded to the UK through the Horizon 2020 research programme ending in 2016⁴¹. This represents 11.2% of total UK funding, and the highest per capita - €55 compared to the UK average of €40.

Scotland's HEIs also benefit from the EU's structural funds. It has been estimated that HEIs currently receive around £5.5 million a year from European Regional Development Funds (ERDF) and around £1 million in European Social Funds (ESF)⁴² and that, between 2007 and 2013, Scottish universities were the lead partners in ERDF projects worth over £62.5 million.

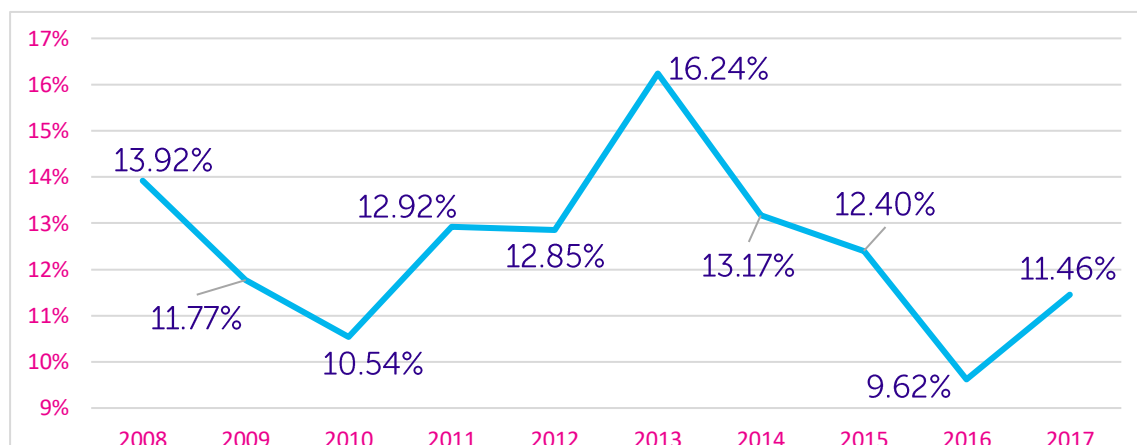
Evidence suggests that collaborative research on an international level is 1.4 times more impactful than research within national boundaries⁴³. It is crucial that the Scottish Government works with the UK Government to reduce the impact of losing these funding streams and to ensure continued access to the future EU framework programmes.

The Charity Sector is a crucial source of research funding

Medical research charities play a vital role in bringing the patient voice to collaborations, including those with universities, industry, regulators, funders and others. They often fund high-risk research into areas that might not be supported otherwise. Promising results from this research can be taken forward by industry, reducing the risk of high value investments.

Charities are a major funder of medical research in Scotland. The Association of Medical Research Charities (AMRC) have estimated that AMRC charities awarded over £146 million in grant funding for medical research alone in 2017⁴⁴, a higher contribution than the MRC.

The funding of medical research in Scotland by charities represents 11.46% of the total grant funding awarded by AMRC member charities across the UK. However, this has fallen in the last 10 years, in 2008 this figure stood at 13.82%. Graph 2 demonstrates the amount of funding received by Scottish institutions between 2008 and 2017.



Graph 2: Percentage of AMRC charities' research funding received by Scottish institutions⁴⁵.

Recommendations

- The SFC should engage with the universities ahead of the next REF in 2021 and review how the changes have impacted medical research in Scotland's leading research Universities.
- The CSO should review the portfolio of clinical research funding available in Scotland, including access to NIHR funding. The clinical research community should be consulted to ensure no gaps exist.
- The Scottish Government and Scotland's funding bodies 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

Research infrastructure refers to the equipment and processes used by researchers to support research and promote innovation. This includes the facilities, equipment and computer framework used by the scientific community.

In Scotland, much of the research infrastructure is held within universities and NHS Scotland. Advancements in research techniques, through developments in areas such as genomics and data science, mean that medical research is becoming increasingly expensive. New, specialised techniques mean new equipment is needed. Therefore, long-term strategic support for this infrastructure is crucial to medical research.

Basic researchers have access to world leading infrastructure

Our respondents indicated that while the access to research infrastructure in Scotland's large research universities is particularly strong; this access is not equal across all Scottish institutions.

"Scotland punches well above its weight in its research infrastructure and I think that it is not all just in Glasgow and Edinburgh" *Government Representative*

"[Scotland's basic research infrastructure] is very variable and talking about Scotland as a whole in terms of equipment or infrastructure it may be a little misleading because it'll come down to individual institutions" *Academic Researcher*

Some respondents, also highlighted that greater support, through the provision of support staff, is needed for researchers to be able to scale up projects.

"If you're going to scale up your work you need outstanding support staff from management staff, administrative staff and secretarial staff... this is an area where we're quite often struggling to recruit outstanding individuals" *Research Director*

Basic research is becoming increasingly concentrated into large institutes and it is vital that infrastructure is established across Scotland to encourage collaboration across institutions.

Scotland's NHS is well structured for clinical research, but greater support is needed

The CSO provides funding for clinical research infrastructure through NHS Research Scotland⁴⁶ with over £42 million allocated to the NHS Boards to maintain the infrastructure which delivers clinical research⁴⁷. However, our respondents noted that whilst the CSO is helping to foster collaboration, a lack of financial support for research infrastructure is limiting its effectiveness.

"we have strong coordination from the Chief Scientist Office... The issue is that there are also cash constraints, so that support could be strengthened with greater infrastructure support from the government" *Clinical Academic*

"the CSO really has very limited capacity to fund infrastructure... there's probably much more we could do to make sure that we've got the right estate, the right equipment, and the right resources to do the best research" *Academic Researcher*

Our respondents stressed the lack of biomedical research centres and units in Scotland compared to the provision of these centres in England, funded by NIHR.

“In Scotland, we don't have access to the research design service that NIHR provides, and Chief Scientist Office doesn't provide such a service to us for that” *Civil Service*

“we don't have all the same infrastructure things that England does in terms of the NIHR funded biomedical research centres and units.” *Research Director*

It is crucial that the Scottish Government enables the CSO to expand its support for infrastructure. Our respondents were positive about the projects and schemes run by the CSO, but the reach of these projects is limited by the funding available.

Ongoing work to improve the data infrastructure is helping to create an environment that fosters innovative research

A significant benefit of Scotland's unified health service is the potential ability to access a large amount of patient data for research.

“We have a number of assets here: One, our size. Two, the fact that we have the unique personal identifier, the CHI number, which every patient in Scotland has. So, we have the potential to link data using that mechanism.” *Research Director*

“There are very good data, patient data level available and we have good mechanisms that protect patient privacy but that do allow us access to data.” *Academic Researcher*

Nevertheless, there are some issues currently with the sharing of data between Health Boards preventing its use in research.

“My observation is that we have loads and loads of data sitting in the health service, in primary and secondary care. It is linkable, but linking it is not easy.” *Research Director*

Respondents did note that some areas of research have engineered greater data access and the ongoing work to improve data access more widely. The Innovative Healthcare Delivery Programme (IHDP)⁴⁸, funded by the Scottish Government through its cancer strategy, is working to improve data access and linkage and there is optimism about the progress that is being made.

“We have identified a technology called data visualisations, which means that you don't have to move the data from one silo to another to be able to link it with other data.” *Research Director*

It is important that this work to improve data access continues. If developed, Scotland's NHS has the potential to be a world leading location for clinical research and allowing efficient access to patient data for research is an important step in unlocking this potential.

Recommendation

- The Scottish Government should continue to support and enable projects like IHDP that are seeking to link patient data to improve practices and outcomes.

3.4 WORKFORCE

The workforce for basic and clinical research is vital to the production of better, kinder treatments and the improvement of patient care. In basic research, this spans from research leaders who set the research agenda, through to the support staff who are crucial to the effective operation of a research lab. In clinical research, this includes the consultants who lead the trials, the nurses and support staff that enable the trials to happen and the diagnostic staff needed to screen for eligibility in any given trial.

Universities are able to train and recruit high-quality researchers, but there is increasing competition for research leaders

Scotland's universities have a strong reputation for research worldwide and a considerable number of undergraduate and postgraduate researchers are trained in the nation. Between 2013/14 and 2017/18, over 300,000 students studied life sciences in Scotland⁴⁹, which represents 10.6% of the UK total. This is increased further in those studying postgraduate research degrees alone, where 11.2% studied within Scotland.

In addition to the numbers of researchers being trained in Scotland, our respondents emphasised that the reputation of the universities is helping to attract high quality students.

“we're able to attract international PhD students... because our universities are seen as world-leading” – Academic Researcher

Despite this success in recruiting and training early-career researchers and attracting many world leading researchers, our respondents highlighted concerns about competing with larger institutions for research leaders. The greater resource and critical mass of larger institutions is reportedly increasingly drawing researchers out of Scotland.

“What attracts leaders in the field is money and the critical mass of other high quality people... I think Scotland does probably suffer slightly” – Academic Researcher

“There are a few examples where [recruiting research leaders] has happened but in general it is quite difficult to recruit very senior successful people”- Clinical Academic

These apprehensions show why increased collaboration between Scotland's HEIs could provide a significant boost to its research potential in the long-term. Greater collaboration between institutions would expand critical mass of researchers in any given research area, increasing Scotland's competitiveness with large research institutions.

Scotland's Health system is well structured for clinical research, but greater support is needed

Our respondents identified the strength of Scotland's health professional training but acknowledged a range of issues that are preventing health professionals from engaging in research. They particularly emphasised the lack of time that consultants have to engage in research. In Scotland, many consultants are contractually allowed one session of supporting professional activity (SPA) – which includes research – for every nine clinical sessions. This is having a significant impact on the ability of doctors to take part in research.

“I would like to see more opportunities for NHS Clinicians to participate in research and I think the current 9 plus 1 contract is very damaging” – Clinical Academic

Between December 2010 and December 2011, it was reported that 63% of the consultants appointed were on 9:1 contracts⁵⁰. Comparatively, the standard contract in England is for consultants to spend 7.5 sessions a week on direct clinical care and 2.5 on other activities. As a result, health professionals in Scotland are disadvantaged and it is vital that the Scottish Government, CSO and NHS Scotland work to create time to contribute in research.

These issues are being compounded by a lack of career pathways for those wanting to develop a career in clinical research. As part of its wider research infrastructure, NHS Research Scotland currently spends £12.7 million to meet the time of staff and £2 million for R&D Office staff⁵¹. Numerous respondents indicated the lack of opportunities for development subsequently preventing the development of clinical research leaders, predominantly in Nursing, Midwifery and Allied Health Professionals.

“if you are a clinical academic who's on an NHS salary... the time to develop applications and write grants is largely on your own time. That's where I think we could fund more NHS time” – Clinical Academic

“in terms of [NMAHPs], it is not set up to encourage and support developing future leaders... there are little to no schemes for those kinds of professionals to undertake funded PhD research” – Civil Servant

Fellowships are available to clinicians through the CSO Clinical Academic Fellowships⁵² and clinical research time (2 sessions) can be bought out through the NRS Career Researcher Fellowship⁵³. However, our respondents expressed that the support offered was not equivalent to that given in England and open for too narrow a field of clinicians.

“The fellowship schemes were not as generous as other funders... and we certainly felt a disadvantage compared to those available through NIHR” – Academic Researcher

“There needs to be much more focus on bringing in a broader group of professions... The number of schemes that the CSO offers to non-medics is relatively limited” – Academic Researcher

These difficulties are significantly affecting the ability of health professionals in Scotland to engage in research and it is crucial that the Scottish Government, CSO and NRS work together to expand both the number of health professionals supported by clinical fellowships and the number of roles that are able to access this funding.

Recommendations

- The Scottish Government should increase its support for clinical academic development through increasing the funding of the CSO Clinical Academic Fellowship scheme.
- The Scottish Government, NHS Health Boards and CSO should work with the medical research community to develop sustainable approaches to ensure health service staff have sufficient time to develop, undertake and participate in research.

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 are able to take part in appropriate research trials. For these reasons, it's imperative to highlight issues around patient access to clinical trials.

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

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 are 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 many “targeted” medicines and the identification of more clinically actionable genetic mutations. 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 Scottish medical research environment. The growing specificity of trials mean that they are now often run across many sites. The reporting of these trials onto public databases seldom specify where the trials are currently open across these sites, making it difficult to create an accurate picture of clinical trial participation in Scotland.

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

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 NHS to carry out clinical research⁵⁴.

Despite positive attitudes towards clinical research, in the 2015/6 Scottish CPES⁵⁵, only 22% of respondents stated that someone had discussed whether they would like to take part in research. This figure is lower than that in both the Welsh and English CPES results (all of the figures can be seen in Table 3 below).

There are several possible attributing factors to this low figure. One significant factor may be pressures on the health service. A total of 31,331 new cases of cancer were diagnosed and registered amongst the resident population of Scotland in 2016. This is an 8.4% increase of 2,432 more cases in 2016 compared with ten years previously⁵⁶.

Nation	% of interviewees who had research discussed with them		
	2013	2015/6	2017/8
Wales	29% ⁵⁷	23.1% ⁵⁸	N/A
England	32% ⁵⁹	27.4% ⁶⁰	29.5% ⁶¹
Scotland	N/A	22% ⁶²	N/A
Northern Ireland	N/A	18% ⁶³	15% ⁶⁴

Table 3: Percentage of Cancer Patient Experience Survey interviewees who had research discussed with them by nation.

Oncologists are seeing an increasing number of patients, adding constraints on time spent during each consultation resulting in fewer opportunities to discuss research with their patients. Additionally, if fewer consultants are able to engage in research themselves due to growing NHS pressures, they might be less active in communicating about research to their patients.

Our respondents expressed their satisfaction with the systems in place to signpost patients to clinical trials where the CSO gives funding to Health Boards R&D offices based on their patient recruitment

“I think there are very strong monitoring systems in place and there is an active drive to recruit patients of the prime target” – Civil Servant

“I think the Chief Scientist Office rewards health boards appropriately for recruiting patients into trials by essentially rewarding R&D offices by payment by results, and number of patients proved financially” – Clinical Academic

There are also a number of trials databases that effectively advertise the clinical trials available to patients. Examples of this are Cancer Research UK’s clinical trial database⁶⁵ and the NIHR UK Clinical Trials gateway⁶⁶. These services offer patients and clinicians extremely valuable information about the trials that are available in their area. This information is presented to them in lay language, allowing them to make decisions about whether research is correct for them.

These recruitment systems and incentives are being supported by NHS Research Scotland’s SHARE initiative⁶⁷. SHARE was created to establish a register of people interested in participating in health research and who agree to allow the use of coded data in their NHS computer records to check whether they might be suitable for health research and clinical research studies. As of April 2019, more than 250,000 people have signed up and our respondents were positive about the potential of this initiative.

“I think that (SHARE) is huge evidence of the willingness of the population to engage in clinical trials and I think going forward that is going to be a huge resource we gain for matching patients to the appropriate clinical trials.” – Civil Servant

Despite the positive responses about patient recruitment, the ability of small cancer centres to run clinical trials was identified as a barrier.

“The bureaucracy and the expense of running trials can be a bit of a barrier, particularly to participation in smaller units across the country. It comes back to money available for infrastructure to support particularly small units that might want to enter just one or two patients a year to a given trial.” – Civil Servant

NHS Research Scotland are working to improve access to clinical trials throughout Scotland in a wide range of disease areas – with NRS supporting research across 27 research areas⁶⁸. For example, as an area of Scottish Government strategic priority, clinical research in cancer is being supported through the NRS cancer network. This network, led by Cancer Research Champion Professor David Cameron, aims to support the recruitment of cancer patients into clinical research. It does this through increasing the number of trials available and facilitating access to clinical trials outside of Scotland’s main cancer centres. It is important that this work continues and has a focus on funding clinical trial support staff and services.

UK-wide work of the Health Research Authority is working to streamline clinical trial approval

Our respondents highlighted other issues about the approvals of trials by Health Boards but recognised that this was being addressed as part of wider UK efforts through the work of the Health Research Authority (HRA). HRA is working to harmonise the approval systems of each UK nation. 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 across the UK.

Such harmonisation would be incredibly valuable for patients. Quick approval of research in Scotland, 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 their trials to the rest of the 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 CSO and NHS Research Scotland work closely with their UK counterparts to ensure that this harmonisation provides as much benefit to patients as possible.

Recommendation

- The Scottish Government should continue to promote engagement in health research and should seek further opportunities to increase the number of conversations with patients about clinical research participation.

4. CONCLUSION AND RECOMMENDATIONS

Scotland has a strong reputation for delivering world class medical research which has benefited from ongoing support from the Scottish Government. However, as UK and international research infrastructure and intellectual capital is concentrated into large centres, researchers in Scotland would profit from increased collaboration to continue to compete for funding.

Whilst Scotland has the highest per capita level of university QR funding in the UK, there are concerns about how this funding is used to support research excellence. There are also worries about the level of funding that is given to researchers at the clinical end of the research pipeline through the CSO. Addressing these funding challenges would future-proof Scotland's reputation as a home for world leading research.

Health professionals who want to engage in research require additional support - current career and contractual structures limit the time available to do so. There is an urgent need to address barriers they face to pursuing careers as clinical academics or to engage in research alongside their clinical work.

These issues are having some effect on the accessibility of research to patients in Scotland, with the signposting of research lower in Scotland than in other parts of the UK. Moreover, reported bureaucratic issues in setting up trials that are delaying some trials from opening. It is vital these issues are addressed to allow as many patients as possible to take part in suitable clinical trials.

Scotland has a strong reputation for research and attracting research funding. It is important that efforts are made now to improve the cooperation and coordination of the medical research environment to ensure the long-term strength of medical research in Scotland.

LEADERSHIP & COLLABORATION

- Universities and the Chief Scientists Office should work together to explore further mechanisms to support collaboration between research teams from multiple universities to obtain funding from major research initiatives. This could include financial support for researchers to organise meetings where collaborative grant applications can be developed.

FUNDING

- The SFC should engage with the universities ahead of the next REF in 2021 and review how the changes have impacted medical research in Scotland's leading research Universities.
- The CSO should review the portfolio of clinical research funding available in Scotland, including access to NIHR funding. The clinical research community should be consulted to ensure no gaps exist.
- The Scottish Government and Scotland's funding bodies 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

- The Scottish Government should continue to support and enable projects like IHDP that are seeking to link patient data to improve practices and outcomes.

WORKFORCE

- The Scottish Government should increase its support for clinical academic development through increasing the funding of the CSO Clinical Academic Fellowship scheme.
- The Scottish Government, NHS Health Boards and CSO should work with the medical research community to develop sustainable approaches to ensure health service staff have sufficient time to develop, undertake and participate in research.

PATIENT ACCESS TO CLINICAL TRIALS

- The Scottish Government should continue to promote engagement in health research and should seek further opportunities to increase the number of conversations with patients about clinical research participation.

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