BENCH TO BEDSIDE

BUILDING A COLLABORATIVE MEDICAL RESEARCH ENVIRONMENT IN WALES

CANCER RESEARCH UK

CONTENTS

EXECUTIVE SUMMARY

Around 19,000 people are diagnosed with cancer every year in Wales[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 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 Wales 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 16 Welsh and nine UK medical research stakeholders.

Overall, our interviewees thought that Wales has the potential to deliver high quality medical research due to a number of factors:

- its size – both in population and geography;
- the centralised structure of its health system; and
- the high quality of Wales' university research.

These factors create the opportunity to, through coordinated focus, foster areas of excellence that will allow Wales to compete for funding in the UK and internationally.

But there is concern that a lack of strategic thinking and coordination is affecting Wales' ability to attract funding and talent. It is vital that stakeholders come together to provide a single vision and leadership for the Welsh medical research environment.

WALES NEEDS A CLEAR VISION FOR A WORLD-CLASS RESEARCH ENVIRONMENT THAT BENEFITS CANCER PATIENTS

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

To better compete for UK and international medical research funding, Wales must focus on its areas of strength. However, interviewees were concerned that the Welsh Government lacked a coordinated approach for its strategic priorities.

Oversight of medical research sits across two Welsh Government departments – Economy and Infrastructure, and Health, Wellbeing and Sport. Each funds areas of the medical research environment through public bodies: universities through the Higher Education Funding Council for Wales (HEFCW), and; clinical research through Health and Care Research Wales (HCRW). And this landscape is changing. The forthcoming Tertiary Education and Research Commission for Wales (TERCW)[2] will replace HEFCW and a new organisation, Research Innovation Wales, will be created as part of the TERCW structure. In a complex and changing environment, clear mechanisms for coordination are vital.

The Welsh Government has, since 2017, published several commissioned reviews of the research environment, such as the Reid[3] and Diamond[4] Reviews. It is important that the Welsh Government prioritises acting on the recommendations of these reviews.

The Welsh Cancer Delivery Plan 2016-2020 committed to developing an all-Wales cancer research strategy. It is important that this strategy is developed as a priority and acts to align priorities and improve cooperation in cancer research.

RECOMMENDATIONS

- The Welsh Government should put in place mechanisms to ensure better coordination and planning for the medical research environment. Any mechanism should link the work of all of the bodies that influence medical research in Wales – including HCRW, TERCW and HEIW - to ensure the Welsh Government's medical research priorities and targets are achieved.
- The Welsh Government should implement the recommendations in the Reid and Diamond Reviews.
- The Wales Cancer Research Strategy being developed under the Cancer Implementation Group should be completed as a priority. The strategy should set out clear roles for the key actors in the ecosystem, the ecosystem's interdependencies and how they can be optimised to leverage the most impact. The strategy should include:
  a. A set of key strengths and priorities for cancer research in Wales.
  b. An all-Wales infrastructure plan to maximise access to the most advanced equipment for researchers across Wales and ensure a sustainable funding approach.
  c. A plan to harness the strengths of Wales in big data, such as SAIL and HealthWise Wales, which provide an opportunity to carry out population level research in Wales.
  d. Proposals to extend the availability of clinical trials to patients across Wales.

FUNDING

The Welsh Government set a target in 2011 to achieve the same level of competitive funding as the other UK nations[5] but little progress has been made in medical research. Since 2011, Welsh institutions have increased their Medical Research Council (MRC) grant funding by just 0.51%[6].

Quality-related (QR) research funding from HEFCW to Welsh universities has been flat since 2012/13[7]. Universities rely on QR funding for the infrastructure and workforce that enable researchers to win competitive grants. The Diamond and Reid Reviews both recommend increasing QR funding, and it's important that this is done urgently.

Researchers and politicians are concerned about the impact of leaving the EU on research funding[8]. Wales is the biggest recipient of European Union (EU) structural funds of any UK nation[9] and EU funds have been crucial to the Sêr Cymru[10] programme. It's vital that the Welsh Government explores all options to minimise the impact of this potential loss.

The UK Government's ambition for 2.4% of GDP to be spent on R&D and the formation of UK Research and Innovation (UKRI) present new funding opportunities. The Welsh Government needs to engage with UKRI and support researchers to optimise access for any new funding opportunities.

There have been welcome increases in investment clinical research with HCRW's funding of clinical research increasing by 22% over the last 5 years[11]. However, interviewees raised concerns about access to National Institute for Health Research (NIHR) funding. The Welsh Government currently only invests into 5 of the 11 NIHR funding streams, restricting the range of funding that is available to researchers.

RECOMMENDATIONS

- The Welsh Government should increase QR funding to Welsh Universities in 2019/20, to enable researchers to compete for funding at the UK-level in the long-term.
- The Welsh Government and Wales' 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 other sources – to mitigate against this loss and ensure the Sêr Cymru programme's continuation.
- The Welsh Government and HCRW should review the portfolio of funding available to clinical researchers in Wales, considering all funding streams from Welsh bodies, the NIHR and other funders such as Cancer Research UK. The clinical research community should be consulted to ensure no gaps exist.

INFRASTRUCTURE

The infrastructure for both basic and clinical research has many strengths, with access to a wide range of advanced equipment and techniques. This is due in part to the Welsh Government funding projects such as the Cardiff University Brain Research Centre.

However, interviewees stated that access to equipment and support staff for research is reducing and there are concerns about the Welsh Government's commitment to support infrastructure in the long-term.

Patient data collected and made available to researchers, such as in the SAIL research database, is a hugely valuable resource However, concerns were raised about the future-proofing of data and ensuring that the data infrastructure meets evolving research needs. The new Health Data Research UK (HDRUK) body also presents the Welsh Government with opportunities and resource to improve health data linkage.

RECOMMENDATIONS

- The Welsh Government should work with universities to identify opportunities to expand infrastructure access, either through existing funding mechanisms or a new specific fund.
- The Welsh Government should assess the possibility of working with HDRUK and other stakeholders, to link NHS data and rapidly deliver value to patients, healthcare professionals, and the wider NHS – as the Scottish Government has done with the Innovative Healthcare Delivery Programme.

WORKFORCE

While there is an established medical research workforce, some believe Wales could be more effective in attracting world-class talent and creating research leaders.

The Cymru programme was established to address this. This programme has been extremely successful, bringing in more than 190 research fellows and PhD students, and over £67 million in funding to Wales between 2011 and 2017[12].

There are, however, worries about the impact of leaving the EU on the research workforce. It is crucial that the UK and EU to reach a deal that protects the rights and movements of researchers.

Interviewees expressed concerns about the lack of capacity in the NHS workforce. Increasing staff time pressures mean that they are less able to engage in research. Whilst this is not an issue unique to Wales, giving patients the opportunity to access clinical research is an important part of driving improvement. It's crucial that the NHS workforce is well resourced to allow staff to take part in research.

There are also concerns about the availability of funds for research time for clinical staff. In 2017, only 7 Research Time Awards were given to clinicians. It would be

hugely beneficial to clinical research to expand this programme.

RECOMMENDATIONS

- The Welsh Government should publish the ongoing evaluation of Sêr Cymru by 2020 and regularly evaluate schemes aiming to increase research workforce capacity in Wales. This evaluation should include recommendations for Welsh research institutions to capitalise on the increased research workforce from Sêr Cymru and to increase the proportion of competitive medical research funding they attract.
- Welsh Government, HEIW and HCRW 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. This should include HCRW extending its Clinical Research Time Awards.

PATIENT ACCESS TO CLINICAL TRIALS

Despite several recent examples of clinical trials in Wales being successful in recruiting patients. 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.

The Cancer Patient Experience Survey (CPES) reports that the number of patients having a research discussion fell from 29% to 23.1% between 2013[13] and 2016[14].

Reported pressure on staff time means clinicians are less able to assess what research is available to their patients, affecting patient recruitment. There are trial databases which effectively advertise clinical trials to patients and clinicians, including Cancer Research UK's trial database and the UK Clinical Trials Gateway. However, there is a need for these databases to be adjusted for clinicians' requirements. It's important that the Welsh Government and HCRW optimise the processes for clinicians to find potential research opportunities for their patients.

The 2016 CPES[15] showed significant regional variation in the accessibility of trials. Gaps exist between NHS Health Boards and Trusts in the number of patients having a conversation about research. HCRW has made structural changes to address this but further work is needed.

Our interviewees reported that bureaucracy is causing delays in opening clinical trials. The UK nations are working with the Health Research Authority to streamline trial administration processes and it is vital that this is prioritised to enable efficient patient access to trials.

RECOMMENDATIONS

- NHS Wales, HCRW and the Welsh Government should work with clinicians and patients to optimise the tools and infrastructure that support clinicians to quickly find suitable research opportunities for their patients.
- HCRW should continue to support measures to expand the number of research studies available to patients across Wales, evaluating the effectiveness of the hub and spoke model. They should assess the processes and infrastructure of NHS Trusts and Boards where the percentage of patients who reported a discussion about research is very low. This assessment should include involvement of patients locally to discover issues and possible solutions before targeting additional resources to these bodies.
- The Welsh Government should continue to work closely with other UK nations to ensure that permission streamlining work of HRA is realised and operates smoothly.

1. INTRODUCTION

Around 19,000 people in Wales were diagnosed with cancer in 2015[16], and it has been projected that this figure will rise to around 25,000 by the year 2035[17].

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 Wales. From 2010-15, an estimated £77.6M was spent by funders such as Welsh Government, research councils, charities and industry on cancer research alone in Wales[18].

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 Wales 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, which includes research 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 Welsh medical research environment, competing and collaborating as a part of 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 [19]. 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 reserved matters for 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 Wales. The aim of this approach is to establish where there is potential opportunity and where there are areas of concern in the Welsh medical research environment.

To conduct the interviews, Cancer Research UK commissioned DJS Research to perform structured telephone interviews with 16 stakeholders based in Wales 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.

2. FINDINGS

2.1 LEADERSHIP, POLICY & COLLABORATION

The governance of research has been a devolved policy area since 1999. In recent years, the Welsh Government has led a major shift in the policy landscape for science. They have created a number of priorities for medical research across a number of strategic documents published in the last 5-10 years, while seeking to review and develop the governance and funding of research and innovation.

In addition to the complex and changing policy landscape in Wales, the external policy context influences the quality of research that can be performed. Evolution in the UK-wide research landscape, including changes in strategy, have resulted in shifts in the medical research environment in Wales. For example, the formation of UK Research and Innovation (UKRI) and the UK Government's ambition for 2.4% of GDP to be spent on research and development (R&D) could potentially bring new funding to Wales. The Life Sciences Industrial Strategy identifies how to improve research and innovation in the UK, including in the NHS, and how this will improve productivity and drive economic growth[20]. The Industrial Strategy has the potential to create new avenues for research funding. As the UK leaves the EU, the nature of how UK-based researchers collaborate internationally may also be affected.

Despite the impact of these external factors, the Welsh Government, its funding bodies, Welsh universities and NHS Wales all have a significant role in influencing the policy landscape for medical research. While Welsh researchers receive a great deal of funding from UK-wide funding bodies, basic and clinical research in Wales is largely under the oversight of Welsh bodies. This includes underpinning research funding, infrastructure, workforce development and research governance.

The strategic and policy environment

Welsh Government sees research and the life sciences as a strategic priority but could more effectively coordinate its strategic aims

The Welsh Government has recently published several documents which outline a range of priorities for medical research. These will be used by the Welsh Government, as well as bodies such as Health and Care Research Wales (HCRW) and Higher Education Funding Council for Wales (HEFCW) to make decisions about the funding and support of medical research.

The Welsh Government's current Programme for Government, *Taking Wales Forward*, outlines its commitments for 2016-2021[21]. Sitting underneath *Taking Wales Forward* is *Prosperity for All*, a national strategy which sets out how the Welsh Government will deliver the Programme for Government's commitments[22]. The strategy highlights the need to foster a thriving research environment, with commitments to bring together all research funding

and ensure that funding decisions reflect Welsh priorities, including the needs of regional and national economies.

The strategies focus on research was warmly received by one interviewee:

> "Prosperity for all certainly recognises the role of research and I think that's a good thing." [Academic researcher]

As part of *Taking Wales Forward* the Welsh Government also published *A Healthier Wales*[23], their plan for Health and Social Care in Wales. In the proposals, the Welsh Government recognised the importance of research in bringing about change and improvement in the health and social care system.

Science For Wales

Science For Wales, first published in 2011, set out the Welsh government's vision for science, and outlined the strategic agenda and key initiatives.[24] Reports on progress are published annually, with success measured against four key themes:

- Strengthening University Science
- Promoting Business Innovation and the Exploitation of Science
- Increasing the Science and Engineering Talent Pool
- Improving Delivery in Government

The two overarching ambitions of the strategy are to increase the share of UK Research Council funding to Wales and increase performance of Welsh universities in the Research Excellence Framework (REF) assessment.

Life sciences and health were chosen as one of three Grand Challenge priority areas. The Grand Challenge sectors build on areas where Wales already has a track record of excellence, and where the route from research to commercialisation is reasonably clear. By focusing on the Grand Challenges, the Welsh Government aimed to concentrate efforts and increase its prospects for success.

This strategy to focus on specific areas of excellence is explicitly echoed in *Science For Wales 2017*:

> "We are a small nation: we can't succeed at everything and, therefore, we need strategic focus and agility to achieve our full potential"[25].

This was also emphasised by a Welsh Government representative in our study:

> "Wales cannot be excellent at research in absolutely every area with a population of our size. Our strategy is to build on areas of excellence that Wales has that map onto areas of significant health need in Wales… things like cancer, like ageing, dementia, and mental health. They would be examples where we have centres in those areas." [Government representative]

In *Science For Wales*, one of the stated aims was for:

> "the proportion of research achieving 3* and 4* quality and impact levels in Welsh universities to reach the highest UK level (55% achieved by England), or its equivalent, in the new Research Excellence Framework (REF)."

This increasing focus on areas of excellence has influenced decisions with regards to how funding is allocated; prioritising projects within these areas. Many of our interviewees agree with this approach and feel that organisations within Wales are now concentrating on these. This is largely due to acknowledgement that the size of Wales means it is impossible for research institutions to maintain excellence across a wide range of areas.

> "I think the way the HCRW has set about things... I think it's addressing issues strategically, based on a competitive process with an emphasis on research excellence." [Research Director]

However, other interviewees discussed the lack of research centres for some important health areas.

> "the notable gap if you look at the health priorities for Wales was that… there's no research unit or centre in cardiovascular research when it is one of the major killers in Wales. Health and Care Research Wales' response was that we didn't get any excellent bids and were still about funding research excellence" [Research Director]

This issue highlights the conflicting nature of the Welsh Government's priority to address areas of significant health need, with the priority to focus upon areas of research excellence.

It is positive that the Welsh Government sees life sciences as a key strategic area and has set out a number of priorities for science and medical research. However, there is a need for greater coordination of the range of priorities that they have set out across their multiple strategy documents.

Questions about the focus of the Welsh Government point to a lack of clarity of the Government's vision for medical research within the research community. This suggests that greater coordination of the medical research environment would be beneficial and that it is crucial that the Welsh Government creates established mechanisms for the coordination of its priorities.

Several reviews of research and innovation call for greater support for research

In the last three years, the Welsh Government has published 3 commission reviews looking at the landscape for scientific research as a whole and have influenced significant changes in the governance of research. Whilst these reviews look at scientific research as a whole, this report is analysing their potential impacts of medical research specifically.

Hazelkorn Review

Published in March 2016, the *Hazelkorn Review*[26] looked at the regulation and oversight of post-compulsory education and training in Wales, with a specific focus on the role of the HEFCW.

Amongst the recommendations was a call to establish a single new authority for oversight of the post-compulsory education sector, and a shift in research provision from a market-demand driven system to a mix of regulation and competition-based funding. In January 2017, the Welsh Government accepted the recommendations of the report and

subsequently announced the establishment of Tertiary Education & Research Commission of Wales (TERCW) and Research and Innovation Wales.

The *Hazelkorn Review* also recommended a strategic review of research capacity and capability in Wales, which was then actioned in the *Diamond Review*.

Diamond Review

In 2017, an independent review of higher education funding and student finance arrangements led by Sir Ian Diamond was published[27]. *The Diamond Review* contained several recommendations for research funding. Amongst these were calls to:

- maintain the level of QR funding at the current level of £71 million in real terms over the next five years;
- in partnership with universities, create an annual award of 150 scholarships for up to three years to postgraduate researchers in addition to any current HEFCW funding;
- ensure financial provision is made for HEFCW's strategic development fund, which has been cut significantly in HEFCW's 2017/18 budget.

Reid Review

Following *the Diamond Review*, *the Reid Review of Government Funded Research and Innovation in Wales* was commissioned by the Welsh Government in 2017 to look at research and innovation. The review had scope to examine how research can be best developed within its research institutions and businesses[28]. The review was published in June 2018 and set out recommendations to support research and innovation (Box 1[29]).

The review highlighted the opportunities that increased UKRI funding levels present to research in Wales. But it highlighted that this funding is competitive and to ensure that Welsh researchers can access a greater amount of these funds, the Welsh Government needs to invest in the research environment.

An all-Wales strategic vision for cancer research is needed

The findings of our interviews suggested that there is a particular need for a long-term strategy to support cancer research and the Welsh Government's commitment to create a cancer research strategy presents a unique opportunity for long-term planning in this specific disease area.

There are worries from some involved in cancer research in Wales that it has been left behind in the Welsh Government's focus on research excellence. This is despite the identification of cancer as an area of research strength in *Science For Wales*.

> "I think cancer research in Wales is too isolated away from what's happening elsewhere. They need to link in, for instance, with higher education institutions, universities, and academic research outside of Wales." [Research Director]
>
> "I think cancer has been a bit of a loser because (Wales has) lost a little bit of focus on specifically cancer research… Effectively, we've lost the role of Cancer Research Network that used to run aside the Clinical Service Network." [Research Director]

Within the 2016 Welsh Government's Cancer Delivery Plan[30] was a commitment to "develop a Welsh Cancer Research Strategy, reflecting the priorities and ambitions of patients, charities, NHS organizations, Universities, pharma and Welsh Government, which will provide a common goal for cancer researchers in Wales for the next 10 years." While this commitment has been made, progress towards producing the strategy has been slow.

Many interviewees highlight the opportunity of a cancer research strategy to address some of these issues.

> "I think I'd probably go back to where I started, which is to come back to look at the strategy for cancer research… We've got to think about the strengths we have, what things we do well, what the things we could do well, and where we want to put resources. Then, where are the gaps?" [Clinical academic]

> "I think there needs to be more alignment with research leadership and policy. I think we all need to have a shared strategy of what success looks like and be very clear on that for cancer." [Research Support Manager]

Many interviewees underlined where greater leadership in Wales' cancer community would be beneficial.

> "I think that's a fundamental thing we need to do. The Welsh government, agencies, and coordinating groups all need to get together with the research community to develop a research strategy for Wales that's fit for purpose." [Research Director]

> "I'd like to see an overarching strategy for cancer research in Wales that has commitment with funding that would allow that delivery. A sort of multi-model of funding, not just through Welsh government, but other funders… and combines a sustainability of leadership and skill base to deliver the research." [Research Support Manager]

The opinion of those involved in cancer research is that a strategy is needed to assess and bring together the expertise in Wales. There is a strong desire amongst the community for any strategy to encompass an all-Wales approach due to the recognition that cancer research is too siloed across Welsh institutions.

> "Wales is too small to have three separate silos... We need to tie the whole thing together in the Wales Cancer Research Centre" [Clinical Academic]

The UK cancer research funding environment includes an increasing amount of competitive calls for large grants. In this context, Wales' research institutions do not individually have the critical mass or infrastructure to compete with the UK's larger institutions alone. To compete at this level, collaboration between Welsh universities could be beneficial.

> "We need to stop having too many people doing little things and have a few more of them morphing them together into something bigger." [Clinical Academic]

Creating an all-Wales cancer research strategy would also help to align priorities and drive greater coherence to the delivery of cancer research. A process led by researchers and involving government officials, industry representatives, NHS representatives and the

Charities, would allow for a process of assessing Wales' strengths in research that encompasses the range of stakeholders involved in cancer research.

The strategy should include a clear vision of the best approach for Wales to deliver world-class research that benefits cancer patients. This would involve looking at how the pipeline of research in its totality from discovery research, through translational to clinical can optimise the delivery of these benefits.

Box 1 – The recommendations of the Review of Government Funded Research and Innovation in Wales

1. I recommend that the Welsh Government increases the visibility and influence of Welsh research by creating a new Welsh Research and Innovation London Office (WRILO).
2. I recommend that the Welsh Government strengthens the Welsh research base and enables Welsh researchers to attract a greater share of UK-wide funding by implementing Diamond's recommendation for QR funding and creating an additional Future of Wales Fund specifically to incentivise Welsh researchers to win funding from outside Wales.
3. I recommend that the Welsh Government increases the visibility, coherence and impact of research and innovation in Wales by creating a single overarching brand for its innovation activities: the St David's Investment Fund. This should be worth some £35m yearly in the first instance but with the potential to grow to £100m

Governance Structures and Research Leadership

The medical research landscape in Wales is made up of several different actors, based within and outside of Wales. In both clinical and academic settings, contributions are made by a range of organisations such as governments, universities, industry and charities. Much of the responsibility for the funding, coordination and promotion of medical research is devolved to the Welsh Government and other Welsh public bodies. However, the UK Government is still highly influential through the UK Department for Business, Energy and Industrial Strategy (BEIS) (See Figure 1)

The work of bodies specific to fields of basic and clinical research (HCRW and HEFCW) allow for strategic leadership over research and facilitate short lines of communication between the Welsh Government and researchers. However, this system of governance has created a number of issues with regards to the overall coordination of medical research.

Medical research benefits from a diverse range of research funding sources

Funding for medical research in Wales comes from multiple streams, including the Welsh Government, UK Research Councils, industry, the charities and the EU. This diversity of sources is beneficial to the medical research environment as it provides long term financial stability, reduces risk and draws on different expertise to create a more competitive and high quality medical research environment[31 32].

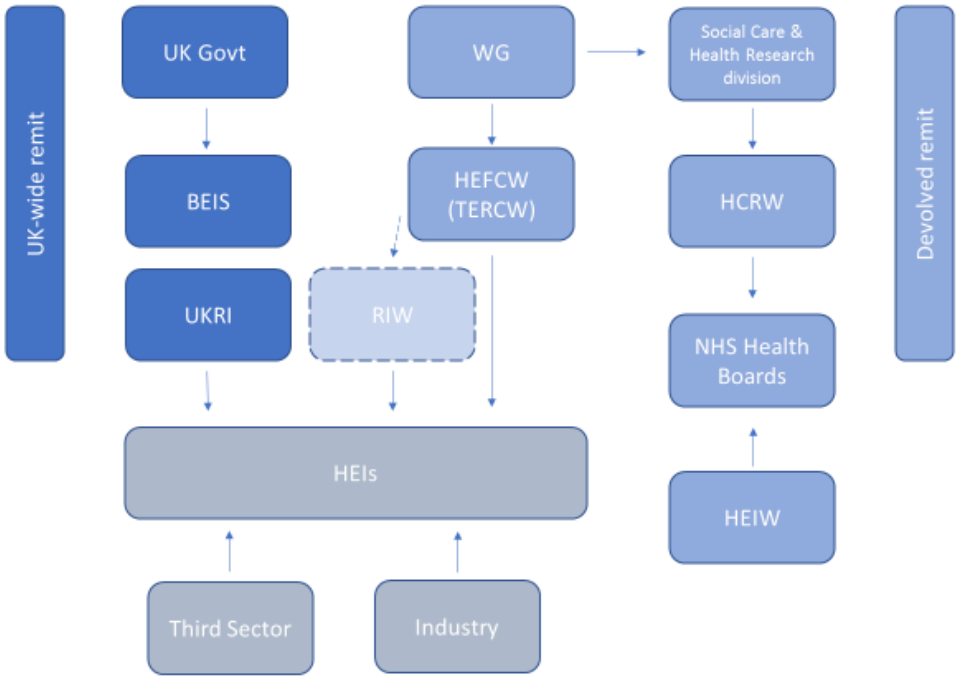


Figure 1: Organogram of organisations that influence medical research in Wales (TERCW and Research and Innovation Wales (RIW) are still to be definitively placed at time of writing).

One example of this benefit is the dual support system of university funding, unique to the UK. Universities receive government funding for research via two main routes: Quality-Related (QR) funding from the devolved Funding Councils (currently HEFCW in Wales), and response mode grant funding from UK Research Councils and Innovate UK (part of UKRI).

QR funding provides a stable, un-hypothecated income stream for institutions that is often used to cover some of the basic infrastructure needed to undertake research. Universities are awarded QR funding based on the quality and quantity of their research outputs.

Response mode grant funding from UKRI (and charities) to Wales is awarded on a competitive basis, providing grants for discrete research projects. The dual funding system assumes that these response-mode grants will not cover the full economic costs (FEC) of research and that the remainder of these costs, the indirect research costs, will be met by other funding streams including QR funding. Therefore, it is clear to see that both types of funding play vital roles in supporting research.

UKRI delivers most of the UK's public spending on R&D. It provides UK-wide research funding through the seven Research Councils and Innovate UK[33]. The increased investment of £7 billion over five years[34] that is being distributed through UKRI from the UK Government creates the potential for increased funding for medical research projects in Wales.

There is also a pathway for new funding to be channelled through interdisciplinary schemes rather than directly through Research Councils. Current and planned schemes include;

- the Industrial Strategy Challenge Fund,
- the Strength in Places Fund and
- the Strategic Priorities Fund[35].

The Governance of research is undergoing significant change

The oversight of both basic and clinical medical research in Wales is led by the Welsh Government. At the time of publication, this is currently divided between two Governmental departments. The Cabinet Secretary for Economy and Infrastructure has the oversight for science policy, life sciences, research and innovation and the development, retention and attraction of higher level research students for Wales. The Cabinet Secretary for Health, Wellbeing and Sport oversees research and development in health and social care (see Appendix 1).

The Welsh Government appoints a number of people to advise and provide leadership to research, namely a Chief Scientific Adviser, a Chief Scientific Adviser for Health and a Chief Medical Officer (see Appendix 1). In addition to the team of advisers, the Welsh Government has established a cross-portfolio group - the Expert Committee on Life Sciences and Health (ExCoLSH), who develop and support strategic initiatives[36].

As shown in Figure 1, the Welsh Government uses two main funding bodies to oversee research. These are currently HCRW and HEFCW, which govern clinical and basic research respectively, although the oversight of both is undergoing significant change.

In basic research, HEFCW is currently responsible for funding research in Higher Education Institutions (HEIs). Welsh universities are responsible for 84% of all published research in Wales and are responsible for nearly half of all expenditure on research and development in the nation[37]. This means that the roles that HEFCW plays in delivering un-hypothecated QR funding is crucial to medical research.

However, HEFCW is due be replaced by the TERCW[38]. TERCW's formation was proposed in the 2016 *Hazelkorn review* which recommended a single regulatory, oversight and coordinating authority for the post-compulsory sector. As part of this restructure, a new body will be created, Research and Innovation Wales (RIW). RIW will be a statutory committee within TERCW, which will act to promote Welsh Government strategy aligned with research and innovation activities.

There are also ongoing changes to the oversight of clinical research. HCRW is the Welsh Government funding body which supports clinical research in Wales. HCRW is overseen by the Welsh Government's Division for Social Care and Health Research, which commissions, funds and manages HCRW's research infrastructure.

HCRW sets its agenda and funding against the Welsh Government's strategic priorities, which are currently set out in *Prosperity for All*[39] and *A Healthier Wales*[40]. The overall vision of HCRW is for 'Wales to be internationally recognised for our excellent health and social care research that has a positive impact on the health, wellbeing and prosperity of the people in Wales. (More detail about HCRW's aims, role, and infrastructure is set out in Appendix 1.)

HCRW is currently reviewing its strategic plan[41]. The current strategic plan was created for 2015-2020 and this review will examine at how it can best support the delivery of infrastructure and research funding schemes beyond 2020.

Alongside this, Higher Education and Improvement Wales (HEIW), launched in October 2018, has been created to act as a single body within NHS Wales to oversee the training and education of health professionals in Wales. HEIW now has oversight of strategic workforce planning and the NHS careers services. This has the potential to change development pathways for clinical research staff.

The communication is strong but there is a need for a more coordinated approach to medical research governance

The research community in Wales benefits from relatively direct lines of communication with the Welsh Government, enabled by bodies such as HCRW led by, and consulting with, research leaders.

Several interviewees highlight the positive impact of having these short lines of communications to decision-makers.

> "We also have short lines of communication with government, compared to England... It's a very different relationship. We have a closer relationship. I think that's very good."
> [Clinical academic]

> "There's a lot more accessibility to the decision makers than there is in England. Because it's a small country, we have pretty good access to politicians and key decision makers, so we can actually get to speak to people relatively easily."
> [Academic Researcher]

These communication lines are a significant advantage of the size of Wales and can enable the research environment to be reactive to the emerging concerns of those who work within it, as well as changing external research environments.

However, other interviewees highlighted some of the challenges that the close connection between the Welsh Government and HCRW has created. There is a perception that although the leadership of HCRW is strong at an individual level, it is often influenced by short-term political considerations. As a result, some interviewees argue that research priorities are being determined according to short-term clinical outcomes rather than long-term considerations about the strength of the research environment.

> "I think that (Welsh Government priorities) are aimed at getting good headlines and not thinking about the long-term future of research in Wales… They are purely about delivering clinical changes." [Academic Researcher]

> "There's very much an emphasis on quick wins from the politicians. They're wanting to see immediate clinical impact of research that happens, which is entirely fine and reasonable. When you have to prioritise, it's completely understandable, but that does tend to rather neglect the long-term and the research that's not immediately clinical relevant now but would be in 10 or 15 years' time if it were conducted."
> [Research Director]

> "I think there is a gap in understanding at the civil service level [about] what the real needs are in research… They see research as being just one government department." [Clinical academic]

Other interviewees argue that one consequence of these spending priorities is that less is being spent on basic research.

> "We feel that it ... particularly in terms of Welsh Government, that we are not being supported. We feel that effectively there is a short-sighted view that all funds should be directed into the sort of clinical end of the translational pipeline, because that will produce the immediate results. But that is at the risk then of neglecting what is going on at the basic end of things." [Academic Researcher]

Despite some of these concerns within the research environment, a Welsh Government representative indicated a willingness to understand issues in the medical research environment.

> "I think there's a strong will within government to help and support, and from my perspective it's making sure that all the colleagues within the Welsh government get the research agenda as well." [Government representative]

The proposed creation of RIW under the oversight of TERCW will give basic research a strategic body to oversee research and innovation and may help address these issues. This has not previously been the case within the structure of HEFCW.

However, due to the significant change made to research governance, some believe that the Welsh Government is struggling to address the strategic issues faced across the Welsh medical landscape. The Welsh Government needs to coordinate the delivery of research priorities across Wales. This would help to address some of the concerns held in the medical research community.

Accordingly, the Welsh Government should seek to create a mechanism to ensure better coordination and planning across the medical research pathway. The environment benefits from a number of bodies, such as HCRW, HEIW and TERCW, that plan the funding and coordination of research within the different stages of the research pathway.

There is a need, however, for a new mechanism to ensure that the Welsh Government's priorities are reflected across basic, translational and clinical research. It should also work to ensure any future research strategy links and promotes the work of researchers across the research pathway and across Wales.

Having a such a mechanism to provide coordination across medical research could open up discussion and support greater collaboration in the medical research environment. Such collaboration is key to allowing the Welsh Government to maximise the success of their policy priorities.

Collaboration

The creation of UKRI means expanding Wales' UK-wide research collaboration and influence is critical

In the *Reid Review*, the establishment of UKRI was highlighted as a major opportunity for research in Wales. The significant increase in the budget for UK Government funded research following the amalgamation of the Research Councils into UKRI (£7 billion over five years[42]) means that researchers have access to a much larger pot of funding.

However, the review suggests that the influence of Welsh research on the governance of the Research Councils and UKRI is limited. Its analysis shows that only 1% of individuals on the committees of Research Councils are affiliated with Welsh Institutions – this is compared to 12% from Scotland. The governance board of UKRI also only has 1 member of 12 who is based outside of England.

To increase the visibility of Welsh research across the UK, the review recommends that the Welsh Government creates a new Welsh Research and Innovation London Office (WRILO). WRILO would act on behalf of the Welsh Ministers to identify and promote funding opportunities, attract talent and investment to Wales, and increase the visibility of Welsh research outside Wales[43].

This would not be unprecedented. The Scottish Government have four 'innovation and investment' hubs in Dublin, Berlin, Brussels and London[44]. Pursuing a similar model could enable Wales to compete more effectively within the UK for not only research funding, but for positions in the UK-level research governance.

In addition to the funding of research, effective coordination of regulation and governance across the UK and further afield could allow more research opportunities to be available to patients in Wales. The establishment of the Health Research Authority (HRA) has helped to make progress in streamlining UK-wide clinical research. Regulation also plays an important role in non-clinical research, including research carried out using animal models. There needs to be safe and proportionate regulatory frameworks in place across the research pipeline. However, as much of this regulation is regulated on a UK-wide level to enable effective coordination, it is not a focus of this report.

Investment is crucial to catalyse industrial research and development

The life sciences sector in Wales is home to more than 360 companies, with a £2 billion turnover and more than 11,000 employees, and is one of the three Grand Challenge areas identified in *Science For Wales* (2012). Its vision is to grow the sector and establish Wales as one of the best environments in the world for Life Sciences innovation, delivering at least £1 billion of extra value in the sector by 2022.

Two thirds of the life sciences companies in Wales produce medical technologies and the majority are SMEs: 93% have fewer than 250 employees.[45]

Wales has a substantial number of ongoing commercial research studies, with the HCRW research portfolio listing 84 ongoing commercial studies in July 2018[46].

In the pharmaceutical sector specifically, the ABPI Cymru Wales Industry Group (WIG) has a membership of over 25 ABPI member companies, including both major global and smaller companies with a strong presence in Wales.[47] However only 8% of all published research in Wales originates from the commercial sector.[48]

Many interviewees highlighted the benefits of strong links between academia and industry:

> "I think we still need to develop infrastructure to have better relationships with the commercial sector to allow them to invest in treatments and technology, and to pilot and develop those in Wales." [Research Director]
>
> "[Industry links] is one of the areas which Welsh government actually needs to continue to invest in… Wales is the sort of place, which if we get the environment right, could really be spectacularly good." [Clinical Academic]

The Diamond Review highlights the need for support in linking academia and industry. The review recommends the Welsh Government "develop a funding framework aimed at supporting knowledge transfer that reflects volume and industry engagement"[49]. This would create a small number of hubs, based around areas of research excellence, to promote and manage university-industry relationships and enable effective translational technology transfer activity. The fund would also support universities, in collaboration with industry, to bid for support for specific project funding.

The Reid Review also supported this aim of fostering academic-industry links by suggesting the creation of three industry-led innovation hubs. The review also recommends the establishment of the St David's Investment Fund – a £35 million fund designed to "consolidate the planning and presentation of support for innovation in business and the public sector from across Welsh Government and public bodies in Wales"

RECOMMENDATIONS

- The Welsh Government should put in place mechanisms to ensure better coordination and planning for the medical research environment. Any mechanism should link the work of all of the bodies that influence medical research in Wales – including HCRW, TERCW and HEIW - to ensure the Welsh Government's medical research priorities and targets are achieved.
- The Welsh Government should implement the recommendations in the Reid and Diamond Reviews.
- The Wales Cancer Research Strategy being developed under the Cancer Implementation Group should be completed as a priority. The strategy should set out clear roles for the key actors in the ecosystem, the ecosystem's interdependencies and how they can be optimised to leverage the most impact. The strategy should include:
  a. A set of key strengths and priorities for cancer research in Wales.
  b. An all-Wales infrastructure plan to maximise access to the most advanced equipment for researchers across Wales and ensure a sustainable funding approach.
  c. A plan to harness the strengths of Wales in big data, such as SAIL and HealthWise Wales, which provide an opportunity to carry out population level research in Wales.
  d. Proposals to extend the availability of clinical trials to patients across Wales.

2.2 FUNDING

Welsh universities are struggling to compete for Medical Research Council funding

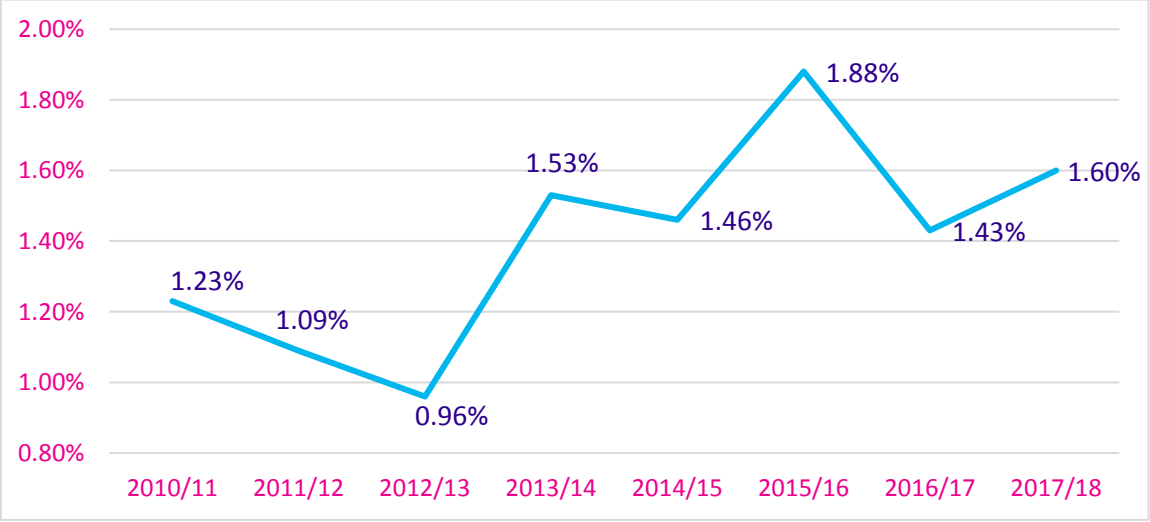
In 2017/18, Welsh research institutions received funding of almost £13 million from the Medical Research Council (MRC), which forms part of UKRI[50]. Of these, Cardiff University was the biggest recipient, receiving almost £9.5 million – the 22nd biggest in the UK. Three other Welsh Universities – Swansea, Bangor and Aberystwyth – received MRC funding, though at significantly lower levels than Cardiff.

The MRC is a major source of medical research funding in Wales, but there has been a large reduction in recent years[51]. The £13 million received in 2017/18 contrasts with almost £17.5 million received in 2015/16. This can be explained in part by an overall reduction in MRC funding between 2015/16 and 2017/18: from £927m to £814m[52]. Nonetheless, across the same year Wales saw a reduction in the proportion of MRC funding it receives, from 1.88% to 1.6%[53]. (More details can be found in table 1 and graph 1 below)

However, Wales has historically performed better in attracting competitive research funding across all 7 of the UK's Research Councils than from the MRC. In 2015/16, Welsh research institutions received 2.17% of all Research Council funding. But, unlike funding from the MRC alone, the proportion of funding from all 7 Research Councils has fallen in recent years, from 2.23% in 2010/11.

Year	2010/11	2011/12	2012/13	2013/14	2014/15	2015/16	2016/17	2017/18
Total MRC funding to Welsh institutions	£9,509	£8,025	£7,406	£13,414	£11,729	£17,446	£10,818	£13,008

Table 1: MRC funding to Welsh institutions, by year, since 2010/11[54]. Figures in £000,000s.



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

As outlined in *Science For Wales*, the Welsh Government set a target[55] to increase its share of UK Research Council funding from 3.3% in 2009/10 to 5%. Taking Wales' percentage of the UK population as a baseline (4.9%), it set its aspiration to "exceed that percentage of UK Research Council and other competitive research funding [within five years]."

To meet this target, the Welsh Government has initiated several schemes including: the Sêr Cymru research talent Programme; and the establishment of National Research Networks (NRNs) including a Life Sciences Research Network. Recruits from Sêr Cymru have, as of 2017, brought in £67.1 million in competitive research funding[56] (further detail on Ser Cymru is on page 49).

Despite these initiatives, the Welsh Government calculated that Wales received 3.6% of the funding from the Research Councils in 2015/16[57]. This represents only modest success and falls significantly short of the 5% target set out in *Science For Wales*[58]. Although this target had no end date, there has been little progress towards it between 2009/10 and 2015/16.

Quality-Related funding has fallen in real terms

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, which enables them to bid successfully for project grants from competitive sources, such as Research Councils, Charities and industry.

Universities are 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[59] 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.

This shows the importance of QR funding for the completion of research at universities by helping to cover the FEC. In the *Reid Review*, (more information on page 7) the benefits of such un-hypothecated funding streams were listed (see Box 2 for a summary[60]).

QR funding is vital to allow universities to compete for grant funding. Without up-to-date equipment and the staff trained to run them, universities are not able to compete for funding with other centres in the UK.

The reduction in this funding is being noticed by researchers:

> "what we are seeing is not only a lack of investment, but a disinvestment in what is going on in preclinical and basic research" [Academic Researcher]

However, some feel that it can be covered by other sources:

> "they've funded slightly less of the basic science research… that can be funded by the MRC and Wellcome… I don't think it means that they don't recognise it's important, just that they recognise that there not the only funder and they're picking their niche" [Research Director]

Box 2 - Benefits of un-hypothecated research funding, from the Review of Government Funded Research and Innovation in Wales:

- meet the cost of entering financial partnerships (sometimes at short notice) with other organisations;
- accept research grants from funders that do not meet the full economic cost of research. Such funders include Research Councils, medical research charities and the EU;
- nurture researchers at early stages of their careers who are not yet ready to win research funding competitions;
- provide stable careers (rather than short-term contracts) for leading researchers in an environment where even the strongest teams will encounter gaps between competitively awarded research grants; and
- **support** adventurous explorations at the frontiers of knowledge where exciting discoveries lay the foundations of research funding programmes.

While this is true of the direct funding for research, it is crucial that the research infrastructure is in place to attract competitive funding from these sources. It is important that Welsh universities receive continued support for research through the QR funding stream to allow them to compete for research funding nationally and internationally. An example of this importance is the use of QR funding in the creation of the Cardiff University Brain Research Imaging Centre (CUBRIC), which has received a large amount of external funding (more information in Box 3[61]).

The increased investment from UK Government in R&D, being delivered through UKRI[62] [63], presents a significant opportunity for researchers in Wales to gain further funding. However, without changes in the environment and greater Welsh Government support to improve the ability of Welsh researchers to compete on a UK-wide basis, Wales could miss out on winning a share of this new funding.

Box 3 – Impact of QR funding of CUBRIC at Cardiff University

£17 million of QR funding has been central in establishing and scaling up the Cardiff University Brain Research Imaging Centre (CUBRIC), which is set to become one of Europe's foremost facilities in this field. The centre's first incarnation – CUBRIC 1 – was established in 2006, supported by investment from Research Councils and QR. The purpose-built, three-floor facility offered state-of-the-art brain-scanning technologies, including MRI and EEG equipment.

This investment built and sustained a critical mass of around 60 staff who drove the initiative forward and attracted £23 million of external grant income in the centre's first seven years. Further cementing its reputation for excellence, CUBRIC was expanded and relocated in 2016, with QR funding leveraging over £27 million of external funding from various partners including Wellcome, the Medical Research Council and the Wolfson Foundation.

In the *Diamond Review*[64], (more information on page 6) one of the key recommendations was to maintain the level of QR funding at the current level of £71 million, in real terms, over the next five years. The report highlights the importance of QR funding to universities:

> *"*QR funding is crucial in providing the baseline investment that enables the long-term strategic development of research and the creation of a critical mass of research capability. The certainty and predictability of QR funding is important given the long planning horizons that university research strategies have to address*."*

The Welsh Government has accepted this recommendation, but it is important that they look to increase QR funding significantly, rather than just maintain current levels. The opportunity presented by the increased UKRI budgets means that quick investment in university research could have a significant and lasting impact.

The Reid Review[65] also supported the importance of maintaining and increasing QR funding, naming it as the highest priority from the *Diamond Review*. The *Reid Review*, however, went further. The review proposed an additional funding stream called the Future of Wales Fund. The fund would begin with an initial £30 million, given to institutions based on the research funds they attract from competitive sources, above a benchmark figure.

This would reward institutions and researchers who are able to gain competitive research funding, building on centres of excellence in Welsh research. An additional benefit of such a fund would be to reduce the reliance of Welsh universities on Research Council funding.

One issue highlighted by our interviewees was that institutions saw funding from charities and industry sources as less valuable than that from Research Councils.

> "there is still a perception, I think, that charity funded grants are of less value than Research Council funded grants, because they don't come with full economic costing." [Academic Researcher]

A fund of the kind suggested by the *Reid Review* would allow researchers to pay research, technical and admin staff from the non-Research Council grant. It would allow researchers to be less reliant on Research Council funding and look to sources such as Life Sciences SMEs to fund their work, with some of the overhead costs of doing this work being funded by the match fund. This could help build a critical mass for medical research, enabling Wales to better compete for funding.

To do this, Wales' research institutions need to be given sufficient capital to enable them to create an infrastructure and workforce that can attract this funding. It is important that the Welsh Government recognises the importance of these funding streams to achieve their own targets.

The Higher Education Funding Council for Wales (HEFCW) awards funding from the Welsh Government to Wales' universities. In 2017/18, the overall funding budget for the HEFCW stood at £99.3 million. This is a dramatic reduction from the budget for the previous year[66]. In 2016/17, universities received £127.6 million from the HEFCW in total to support teaching and research. This cut, however, has not affected the research funding, with the money taken from the strategic funding budget.

This is attributed to the changes in the student fees system, with a reduction in Government's direct contribution to universities. The Welsh Government has stated that the future financial settlements for HEFCW can be expected to increase in each financial year for the lifetime of the current Assembly Government[67]. However, there is concern amongst universities about their budgets.

In 2017/18, HEFCW gave over £80 million to fund research in Wales' Universities[68]. This is done through four main funding streams:

QR Funding

The award of QR funding in Wales is based upon the performance of universities in the 36 units of assessment in the UK-wide REF assessment, which evaluates quality, volume, and the 'subject cost relativities'[69]. In 2017/18, HEFCW gave £71 million to Universities in QR funding. Of this, over £30.5 million was spent on life and medical sciences research.

This £30.5 million investment represents a recent uplift for medical research. In 2014/15 medical research only received around £18.5 million. Following the 2014 REF assessment, strong performance in the Allied Health Professions, Dentistry, Nursing and Pharmacy, and Psychology, Psychiatry and Neuroscience units saw an increase in QR funding (table 2 below).

REF 'Unit of Assessment'	2012/13[70]	2013/14[71]	2014/15[72]	2015/16[73]	2016/17[74]	2017/18[75]
Clinical Medicine (and related units pre-REF unit change)	£6,801,750	£6,801,750	£6,945,200	£6,707,753	£6,707,753	£6,707,753
Public Health	N/A	N/A	N/A	£1,072,631	£1,072,631	£1,072,631
Allied Health Professions, Dentistry, Nursing and Pharmacy	£6,359,300	£6,395,849	£6,531,619	£10,114,327	£10,114,327	£10,114,327
Psychology, Psychiatry and Neuroscience	£1,716,123	£1,794,285	£1,707,698	£8,075,858	£8,075,858	£8,075,858
Biological Sciences	£3,787,040	£3,835,208	£3,787,525	£4,598,285	£4,598,285	£4,598,285
Total	£18,484,142	£18,827,092	£18,972,042	£30,568,854	£30,568,854	£30,568,854

Table 2: HEFCW allocations to universities in Wales by REF 'Unit of Assessment' from 2012/13 – 2017/18

However, the same increase has not been seen in the clinical medicine REF Unit of Assessment. Despite the overall increase of money allocated to life and medical sciences, the amount given to clinical medicine research fell following the 2014 REF assessment. For the 2014 REF assessment, several previous units were amalgamated into one – clinical

medicine. When this happened, the amount given to Welsh universities for clinical medicine fell from £6.95 million in 2014/15 to £6.7 million in 2015/16. This is despite Cardiff University ranking 8th in the UK for this unit[76].

More widely than the life sciences, the overall amount of QR funding available sits at £71 million and has not increased since 2012/13[77], when QR funding was reformed. This represents a significant real terms decrease over this decade. It is also a much lower level than is seen in some other nations.

For example, the Scottish Government, through the Scottish Funding Council, gave universities almost £232 million through its Research Excellence Grant (REG) scheme - the equivalent of Wales' QR system[78]. This is more than three times the level of funding that universities in Wales receive. In recent years, the REG system has also had a steady year on year increase in investment, that has not been given to Welsh universities. In 2012/13, Scottish universities were awarded £223 million and this figure has increased year on year[79].

The current levels of QR funding in Wales do not match the support that is given in other nations and this support is crucial to the environment for basic research (As discussed on page 23).

While some areas of medical research have received extra funding following the 2014 REF assessment exercise, the lack of investment in overall QR funding over a number of years poses a potential threat to medical research in the long-term.

Postgraduate Research funding

This stream supports the training that higher education institutions provide for postgraduate research students. In 2017/18 just under £5.2 million will be allocated to universities. There is a cap on the set amount that can be distributed to each postgraduate student for the university[80].

The amount given to universities for postgraduate training has not increased since 2012/13[81], representing a decrease in real terms in support for postgraduate research students. This creates issues in terms of the workforce capacity in the Welsh research environment. Many grants from Research Councils and other sources do not include funding for students, therefore this funding stream is important in creating the critical mass of research staff, which allows research groups to compete for competitive research funds.

Sêr Cymru

Sêr Cymru[82] is a Welsh Government initiative that aims to build strengths in areas of existing excellence and to develop emerging strengths (further detail on Ser Cymru is on page 49).

The original initiative, aimed at research leaders and networks was funded by a £50 million investment from the Welsh Government with a further £11.2 million from the HEFCW, all of which is match funded by the Welsh Higher Education Institutions. This programme has been successful so far in attracting external research funding to Wales. It has been reported that these networks have brought in the region of £67.1m in additional Research Council grant income to Wales[83].

The second phase of the initiative was launched in 2015, with a commitment of £60 million from the Welsh Government, the European Union and the Welsh Higher Education Sector.

Strategic Development Fund

Strategic development funding[84] has been used by Welsh universities to support both collaborative and individual initiatives. Among the uses of this funding was to 'pump prime' research infrastructure projects and to "contribute to funding proposals involving other parties such as Welsh Government partners, the Research Councils and major charities, or other UK-wide agendas."

In 2017/18, this funding was cut from over £21 million in the previous year to just £2.25 million due to HEFCW budget restrictions[85] [86]. This loss of funding could potentially impact the Welsh medical research environment in the long-term.

The *Diamond Review* recommended that "financial provision is made for HEFCW's strategic development fund, which has been cut significantly in HEFCW's 2017/18 budget"[87]. This is important to encourage collaborative working within Wales, with organisations in the UK, and those abroad.

Increasing support for clinical research

HCRW provides funding for local support and the delivery of research through the R&D departments in Wales' seven Health Boards and three all-Wales Trusts – Velindre, Public Health Wales and the Ambulance Service[88]. They also fund central support for research through the HCRW Support Centre and Research Delivery Staff.

Overall, HCRW allocated almost £16.5 million in 2017/18 to these bodies (table 2)[89]. This figure represents a £3 million increase on the previous year. Before this, the overall funding had remained static at around £13.5 million since 2012/13.

Funding Stream	2012/13	2013/14	2014/15	2015/16	2016/17	2017/18
Direct NHS Trust and Health Board Funding	£13,125,737	£12,760,997	£12,809,651	£12,896,049	£12,278,352	£14,963,863
Centralised NHS Support Costs	£399,263	£704,003	£655,349	£568,951	£686,648	£950,472
Clinical Research Fellows and Specialty Leads	-	-	-	-	£500,000	£500,000
Total	£13,465,000	£13,465,000	£13,465,000	£13,465,000	£13,465,000	£16,414,335

Table 2: HCRW funding for clinical research by stream 2012/13 – 2017/18[90].

In 2017/18, almost £15 million of this allocated funding was Activity Based Funding (ABF)[91]. ABF is awarded to Health Boards and Trusts based on the type of clinical research carried out by each Health Board or Trust, the number of patients recruited in each Trust or Health Board, as well as the number of research active staff in each Board or Trust.

The increase in support from HCRW and the Welsh Government is really welcome and will help to build a larger clinical research base across Wales. In addition to the HCRW R&D

grants, researchers are also able to apply to 5 of the 11 NIHR funding programmes due to contributions made by HCRW to the NIHR[92]. These streams are currently:

- Efficacy and Mechanism Evaluation;
- Health Technology Assessment;
- Health Services and Delivery Research;
- Invention for Innovation;
- and Public Health.

The interplay between these two sources of funding was highlighted during our interviews:

> "We buy into a range of different funding schemes run by the NIHR, which I think is good for the environment in Wales, and we also run our own schemes, which are focused more on capacity-building in Wales, so things like studentships, fellowships [as well as grants] on government priority areas, so for example we had a recent themed call around health inequalities and around Prudent Healthcare" [Government Representative]

The Welsh Government invests in NIHR funding streams to provide grant funding for clinical research, while the ABF system seeks to support NHS Trusts based upon the research they do, and to pay for the training and support of research staff. Some interviewees were positive about this dual funding system from the NIHR and HCRW, and emphasised the importance of NIHR funding in Wales:

> "What the Welsh government do for us at the moment, in terms of grant funding, is that they buy us into all the Department of Health and NIHR funding which is really quite important for us to be able deliver then research on the ground for patients in Wales" [Research Director]

However, some commented that it was insufficient that researchers have access to only 5 of the NIHR funding streams:

> "The fact that, in Wales, we have access to some NIHR funding and not others depending on which pots Welsh government wants to put money into just doesn't make sense" [Research Director]

> "I think the biggest challenge will be the lack of funding opportunities. The fact that we don't subscribe to some of the UK wide schemes, like the NIHR programme grant. Although we've got similar things in Wales, they are not funded at the same level, or they are not as frequent so there's less opportunity." [Academic Researcher]

HCRW also funds research through a series of funding schemes[93]. These schemes give opportunity for individuals from both a clinical and academic background to engage in clinical research, or to lead their own research projects (more detail about clinical fellowships and awards can be found in the Workforce chapter, page 41).

Widespread concern at the potential loss of EU funding

Funding from the EU also plays a valuable role in supporting medical research in Wales. This comes through competitive research grants such as the Horizon 2020 programme, as well as EU structural funds, which are used to fund projects that increase research and innovation

capacity. These funding streams currently play a crucial role in the research funding landscape and the potential loss of these funds, once the UK has left the EU, could have a major impact on research in Wales. The UK Government has made commitments to underwrite UK researchers' successful funding bids from the EU until the end of 2020, for the lifetime of projects[94]. However, there is no guarantee that UK researchers will be eligible to apply for EU funding after exit day, nor what the arrangements will be for UK participation in future EU funding programmes. However, in UK-EU negotiations there has been openness to agree UK participation in EU funding programmes until the end of 2020, as well as willingness from both sides to explore UK participation in the next framework programme, Horizon Europe[95].

Sêr Cymru

The European Commission is giving a great deal of support to the second phase of the Sêr Cymru initiative. It is co-funding 90 fellowships through the Horizon 2020 Marie Skłodowska-Curie Actions (MSCA) COFUND scheme and the Welsh European Funding Office (WEFO) under the European Regional Development Fund (ERDF). This represents a £23 million contribution to the £61 million pot of Sêr Cymru[96], and the programme is an important part of the Welsh Government's plan to increase the amount of competitive research funding that is gained. However, this stream of funding is under threat following the UK's departure from the EU. It is crucial that the Welsh Government and HCRW investigate the potential impact of the loss of these funds and seek alternative funding sources for this initiative – including from outside the Welsh Government. This includes ensuring Wales has access to UK-wide substitutes for this funding, such as the proposed UK Shared Prosperity Fund that aims to support regions in a similar way to the ERDF (for more detail about the Ser Cymru scheme, see box 4 on page 49).

Horizon 2020

In addition to the European Commission funding given to the Sêr Cymru initiative, Welsh universities also receive direct funding from the European Union through the Horizon 2020 programme. In 2017, research by the Technopolis group[97] showed that Wales received €55 million from the programme in the years up to 2016. This represents only 2% of the total Horizon 2020 funding received by the UK.

When these figures are calculated per capita of the population, Wales receives the least of any UK nation, at €18 per person, compared to the UK average of €40 per person. This suggests that Wales is not able to effectively compete as effectively as the rest of the UK for EU competitive research funding.

European Regional Development Fund (ERDF)

Conversely, Wales receives the highest level of funding per capita of any UK nation via the ERDF stream, which aims to support economic development in regions across the EU, with the goal of reducing inequalities and increasing cohesion. Between 2014 and 2020 Wales is set to receive €388 million in funding for research and innovation projects from the ERDF. This amounts to €125 per capita, significantly above the UK average of €23. €121 million of this has gone to both public and private research centres.

Access to EU research funding programmes is a key issue in the ongoing negotiations on United Kingdom's exit the European Union. EU funding streams are crucial as they account for a significant proportion of UK research funding. In 2014/15, the UK received £120 million of funding for clinical medicine from the EU and £90 million for biosciences[98].

During its inquiry into the potential impacts of the United Kingdom's exit the European Union on Wales[99], the Welsh External Affairs Committee highlighted the importance of EU funding to research. The Welsh Government response[100] stated that the *Reid Review* was, in part, looking at the potential impacts of United Kingdom's exit the European Union on Welsh research funding.

The *Reid Review* suggests that one major effect of United Kingdom's exit the European Union on research funding would be the shift of funding from EU structural funds to the increased competitive funding of UKRI. This point places greater emphasis on the previous recommendations of the review to increase the competitiveness of Wales at a UK-wide level.

Our interviewees highlighted the importance of replacing EU funds following the UK departure from the EU:

> "(replacing potential funding from EU sources) is absolutely essential that we get that in Wales" [Clinical Academic]

> "In terms of finance, I would like to remain optimistic that mechanisms will be found where we will have access to European funding, if not to EU funding necessarily. I would like to think that's going to be less damaging than one fears it could be" [Research Director]

It is important that the Welsh Government calls on the UK Government to encourage UK researchers to strengthen their international collaborations and to ensure they have continued access to infrastructure and funding such as Horizon Europe. The UK Government should endeavour to shape the future of these programmes to ensure they align with UK priorities and are awarded based on scientific excellence.

Other Funding Sources

Industry

In recognition of its potential, the growth of the life sciences sector is a Welsh Government priority. The life sciences sector is one of the three grand challenge areas identified in *Science For Wales*[101]. Its vision is to grow the sector and establish Wales as one of the best environments in the world for life sciences innovation, delivering at least £1 billion of extra value in the sector by 2022.

Industry is becoming an increasing focus in UK-wide policy. In November 2017, the UK Government committed to working with industry to boost spending on R&D to 2.4% of GDP by 2027[102]. This represents a substantial increase in R&D spend. The figure in 2016 stood at just 1.67%[103]. This suggests that there is a shift in focus happening on a UK level, looking to the commercial sector to boost R&D spend and productivity.

To enable this sector to thrive in the research environment and Welsh economy, the Welsh Government should explore ways to help universities partner with industry to invest in research. In the *Reid Review*, a number of suggestions were made to improve links between

researchers and industry. Among these, is a £35 million investment fund to "consolidate the planning and presentation of support for innovation in business and the public sector from across Welsh Government and public bodies."[104] Other suggestions in the *Reid Review* to improve industry links include:

- creating three industry-led innovation hubs;
- a new productivity roadmap;
- and measures to help innovation in rural areas.

Charities

Medical research charities play a vital role in bringing the patient voice to collaborations, including those with universities, institutes, industry, regulators, funders and others. They often fund exploratory and 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 the high investment.

Charities are a major funder of medical research in Wales. Medical research charities funded more than £1.6 billion across the UK in 2016[105]. This is a higher contribution than either the MRC or the NIHR.

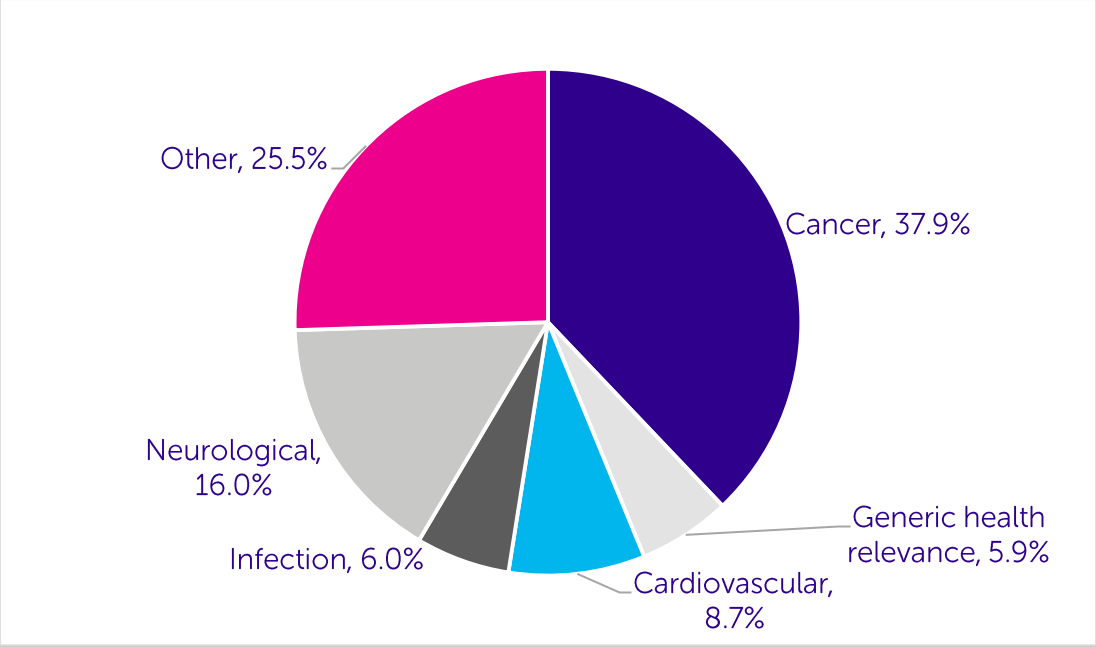
The Association of Medical Research Charities (AMRC) have estimated that medical research charities awarded over £16 million in grant funding for medical research in 2017[106]. In total, 29 AMRC member charities funded research in Wales in 2017, representing 1 in 5 of the AMRC's members[107].

This funding covers a wide range of areas. Across the UK, the biggest recipient of this funding is cancer research, which received 37.9% of the total funding in 2014. The second largest recipient was neurological research, receiving 16% in the same year. The figures for other fields can be seen in Graph 2 below. The Wales Cancer Research Partnership has also estimated that between 2010 and 2015 charities funded £45 million[108] of cancer research.

Medical research charities play a key part in the UK's uniquely diverse funding base for life science research.

While charities are a major funder of medical research in Wales, their support represents just 1.26% of the total grant funding awarded by AMRC member charities across the UK. This has fallen in the last 10 years, in 2008 this figure stood at 1.91%. The figure for 2017 represents the lowest proportion of the total AMRC grant pot awarded to researchers. Graph 3 below shows the amount of funding received by Welsh institutions in real terms between 2008 and 2017.

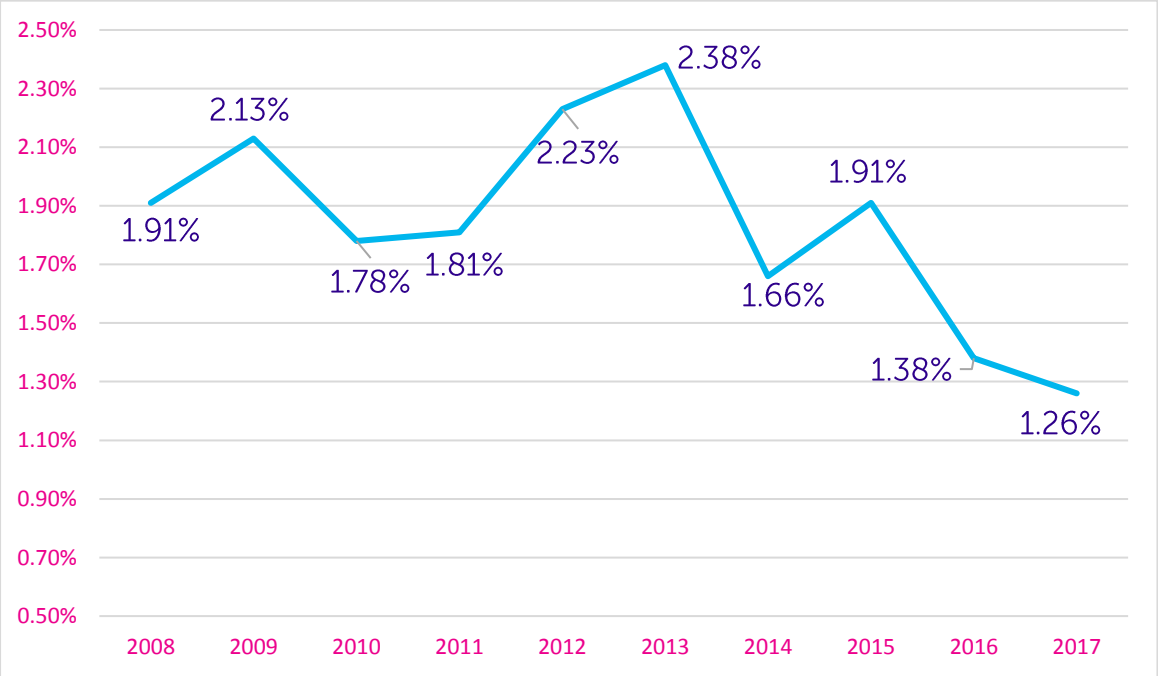
This decline in performance in attracting medical charity research funding is reflective of the issues previously discussed around Research Council funding. Issues with the Welsh Government's support of the research environment through QR funding are especially pronounced in obtaining funding from charities, who are often unable to provide the same support through their funding for research staff and infrastructure as grants from other sources.



Graph 2: Top research areas funded by charities in the UK (2014)[109]

In addition to the REF-based QR funding stream, £3.1 million of the QR budget is provided to help institutions meet the FEC of research funded by charities. This element was introduced in 2007/08[110] but has not been increased in the last 10 years, meaning that this support has fallen in real terms.

It is important that the Welsh Government continue to support vital research funded by charities through maintaining the charity element of QR funding. Additionally, as with funding from industry, the *Reid Review's* recommendation of a match fund for external investment could enable medical researchers to better utilise charity funding.



Graph 3: Percentage of the AMRC charities' research funding received by Welsh institutions[111].

RECOMMENDATIONS

- The Welsh Government should increase QR funding to Welsh Universities in 2019/20, to enable researchers to compete for funding at the UK-level in the long-term.
- The Welsh Government and Wales' 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 other sources – to mitigate against this loss and ensure the Sêr Cymru programme's continuation.
- The Welsh Government and HCRW should review the portfolio of funding available to clinical researchers in Wales, considering all funding streams from Welsh bodies, the NIHR and other funders such as Cancer Research UK. The clinical research community should be consulted to ensure no gaps exist.

2.3 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 Wales, much of the research infrastructure in basic and clinical research is held within the nation's universities and Health Service. 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 infrastructure such as equipment and data initiatives are crucial to those involved in medical research. This allows research institutions to effectively utilise emerging techniques.

With the increasing cost of infrastructure, there is a growing recognition that collaboration between institutions is vital to the provision of the most expensive equipment and techniques.

Stronger and more coordinated support is needed for basic research infrastructure across Wales

The provision of fundamental equipment for basic research is relatively strong in wales. Some of the interviewees found that they had access to the equipment they needed. This was common in Cardiff:

> "there could always be more, but we have a lot of good equipment and we have the opportunities to bid for new equipment" [Academic Researcher (Based in Cardiff)]

The biosciences department at Cardiff University[112] has access to a number of state of the art pieces of equipment including next generation sequencing and 3D printing.

However, it was highlighted that research infrastructure in mass spectrometry is lacking at Cardiff University. However, the interviewees noted that relationships with Bristol and Exeter mean researchers are still able to use these facilities.

> "we don't have as easy access to the sort of mass spectrometry that we'd like. But they have those facilities in Bristol… I think to some extent, we sort of include Bristol in how we operate, and also borrow from Exeter." [Academic Researcher]

Cardiff University is part of the GW4 collaboration[113] with 3 other universities: Bath, Bristol and Exeter. As part of this collaboration, researchers can access equipment across the universities.

Such collaboration is seen as an important factor for future competitiveness of Welsh medical research at UK-wide level. Institutions in Cambridge, Oxford and London have access to world leading equipment due to the strategic purchasing and sharing of equipment. A similar approach in Wales would allow researchers across the nation to have greater access to state of the art equipment.

This should be a key consideration for any future research strategy. An all-Wales approach to research equipment would allow for greater focus on areas of strength, targeting the procurement of equipment on what would best support research.

Despite the general positivity around equipment in the major research universities, our interviewees spoke of a reduction in support for basic research infrastructure in recent years.

> "we're not seeing any direct investment from the Welsh Government in infrastructure or in preclinical posts, research, I mean, well, it's decreasing, it's being cut" [Academic Researcher]

Some of those interviewed also suggested that, in addition to the investment, there is an increasing shortage of technical staff qualified to run some of the newest technologies and a lack of administrators to support research.

> "We could always have more sort of core facilities, people to actually provide services to run advanced up-to-date technologies... capital is not necessarily so difficult to find. It's salaries to run these sorts of things that are tricky." [Academic Researcher]

> "They don't want to fund the boring bits, which is to pay for an administrator" [Clinical Academic]

Such issues are, in part, caused by the recent evident reduction in QR funding (page 23). Universities use QR funding for strategic funding of equipment and support staff and the real terms reduction of funding to this stream are undermining the ability of medical researchers in Wales to compete on a UK-wide level.

Another issue raised within universities concerns access to some of the more expensive equipment, which is reliant on securing funding from Research Councils, industry or charities.

This was described as leading to a 'vicious cycle of access':

> "we're always being told to use the infrastructure because it's the way to get high impact papers… but you need to equipment to get the high impact papers to get grant funding. But you can't use the equipment because you haven't got the grant funding to get the high impact papers." [Academic Researcher]

This again suggests that cuts to QR funding are increasingly affecting Wales' basic research infrastructure. Universities are becoming ever more reliant on grant funding to pay for the maintenance, upkeep, and therefore use of research equipment. The dual support system of university funding in the UK depends on QR funding to fund the basic infrastructure needed to undertake research. Wales is currently struggling to compete on a UK-wide level for such grant funding and without support from QR funding, Wales risks being left further behind.

Some of our interviewees recognised the issues around research equipment in basic research as an indicator that the Welsh Government is prioritising translational and clinical research ahead of basic research:

> "there's been a significant change in how Welsh Government have asked for the funding to be used… they have asked for a major skew away from pre-clinical research, towards translational and clinical research." [Academic Researcher]

The Strategic Development Fund was launched in 2005 by HEFCW. The fund was intended to drive strategic change in universities through primarily collaborative initiatives[114]. As part of this fund's 'priorities' two streams included:

- 'pump priming' (increasing expenditure to increase output) the development of research infrastructure between institutions.
- contributing to funding proposals involving other parties such as Welsh Government partners, the Research Councils and major charities, or other UK-wide agendas - particularly where a small investment by HEFCW could help secure a much larger investment from other, especially UK-wide sources.

This investment was originally introduced to complement a funding stream known as the Reconfiguration and Collaboration Fund[115]. This fund ran from July 2002 until September 2011 and aimed to encourage major performance gains and increase the competitiveness of Welsh universities. Most notably, the first phase of the project supported the merger of Cardiff University and the University of Wales College of Medicine. An independent evaluation[116] found that "there can be little or no doubt that since the merger, the University's standing and ability to attract research funding has increased quite significantly." However, in 2011 a decision was taken to close the Reconfiguration and Collaboration Fund following the end to funding for the strategy that supported it.

At this point, the Strategic Development Fund focused entirely on funding the merge of higher and further education institutions and since 2011, this fund for research infrastructure has not been replaced.

A one-off investment of £1.7 million was made in 2015 research institutions were invited to bid for capital funding and in total, 9 pieces of equipment were funded. While this investment is welcomed it does not cover the recurrent funding streams that were previously available. This loss of recurrent funding for infrastructure and support for grant attraction may be affecting access to state-of-the-art equipment for researchers.

The reduction of this fund was highlighted in the *Diamond Review*. It is suggested that this fund should "drive sector-wide efficiencies or provide of seed corn funding in pioneering areas of activity." It is recommended that the fund is set at £50 million per annum, a larger sum that has previously existed in this area. The *Diamond Review* also suggested that any project funded by this money should be co-funded by universities.

A partnership funding model could be extremely beneficial to medical research. In particular, in cancer research where the proposed strategy – if developed on an all-Wales basis – could identify infrastructure gaps, with universities able to collaborate with each other and the Welsh Government to fund any projects.

Wales' clinical research infrastructure is well supported

Wales has a number of facilities and groups to support the delivery of clinical research, this infrastructure is laid out in Appendix 1 as well as figure 2[117] below. Our interviewees generally found that the provision of clinical research infrastructure is strong.

> "we've got the Health and Care Research Wales. They've kept that infrastructure, research centres and units… and they're starting to develop a coherent infrastructure." [Academic Researcher]

> "I think the funding for infrastructure has been very good for Wales," [Research Director]

As noted in the *Landscape* chapter, Wales has a good number of core trials facilities under the governance of Health and Care Research Wales. *Science For Wales 2017*[118] highlights clinical trials as a key area of strength for Cardiff University.

Clinical trials units are a key part of any clinical trials infrastructure, enabling the design, conducting, analysis and publishing of clinical trials. Wales currently has 3 UK Clinical Research Collaboration (UKCRC) registered clinical trials units, funded by HCRW, in Cardiff, Swansea and Bangor[119]. There is also a Cancer Research UK funded clinical trials unit at the Velindre Cancer Centre[120] which has been open since 1994.

Our interviewees noted that the establishment of the 4 Clinical Trials Units in Wales and the leadership of the HCRW has had a positive impact on the availability of trials for patients:

> "in the last three years, we've seen more early phase clinical trials coming into Wales, which has been quite a new initiative for Wales, where patients previously were travelling to Southampton and London." [Research Support Manager]

There is also an increasing network of infrastructure of equipment and facilities that are empowering researchers to undertake world-class research. These include the Cardiff University Brain Research Imaging Centre (CUBRIC)[121]. It was established in 2016 and houses state of the art equipment in Brain Imaging, including Europe's most powerful brain scanner.

> "there are often spectacularly good things here… CUBRIC, the brain imaging centre. We've got one of the best MRI scanners in Europe. For the research area that is linked to that would be a really big draw" [Clinical Academic]

As discussed previously in the *Funding* chapter, QR funding is an important source of funding for major research infrastructure projects such as CUBRIC. The establishment of such projects often drive further inward investment from external funders (as seen in Box 3). Thus, increased investment in the QR funding stream has the potential to drive further investment into the Welsh medical research environment.

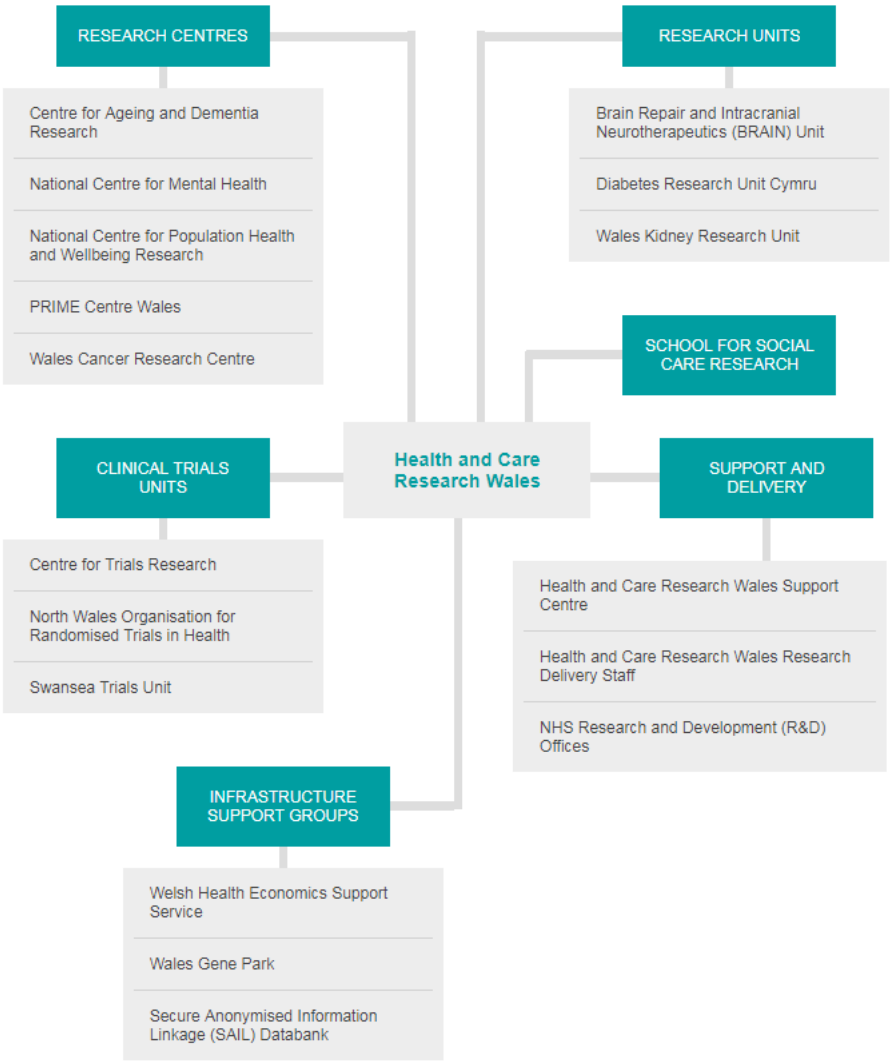


Figure 2: a map outlining the infrastructure for clinical research in Wales[122].

Cardiff University also houses the Wales Research and Diagnostic PET Imaging Centre[123], which enable clinical research into diseases like cancer, epilepsy and dementia. Such facilities underline the potential for Wales to undertake world leading research. They inspire novel and impactful research and trials with the use of state of the art equipment, which can play a role in attracting world-leading international researchers to Wales.

Other important facets of the research infrastructure include the five research centres and units. The remit of these centres is to support medical research of all types. The centres and units cover 8 areas that are the Welsh Government's priorities: diabetes, neurological disease, kidney disease, dementia, mental health, primary and emergency care, population health and cancer.

The centres can play an important role in facilitating research excellence in priority areas through their ability to coordinate the research in basic, translational and clinical research. Speaking about the Wales Cancer Research Centre, one of the 8 research centres, our interviewees were positive about its role of acting as a conduit between the three research stages:

> "Wales is too small to have three separate silos, three separate academic silos or more. We need to tie the whole thing together in the Wales Cancer Research Centre." [Clinical Academic]

Concerns about Welsh Government priorities and the long-term support of clinical research infrastructure

There are concerns among some researchers involved in basic and translational research that Government influence is pressuring the Wales Cancer Research Centre into moving funds towards clinical research to the detriment of early stage research:

> "[the Wales Cancer Research Centre' most recent funding bid] had too much laboratory science and they didn't like that. That's very telling, because actually laboratory science is very translational and very aimed at finding things relevant to patients" [Clinical Academic]

> "we've got something called the Wales Cancer Research Centre, and funding for the preclinical side of things has been actually ... It's being reduced by direct mandate from Welsh Government" [Academic Researcher]

To foster research excellence, the Welsh Government should look to its research centres, led by those involved in research, to identify and fund the best research possible. Basic research is crucial for the discovery of new treatments, and the support of the Research Centre infrastructure for the strongest research can help leverage further funding across the pathway.

Wales also benefits from taking part in the UK-wide Experimental Cancer Medicine Centre (ECMC) network[124]. The ECMC Network is a collaboration of world-leading scientists and clinicians who bring together expertise and techniques to drive the discovery, development and testing of new anti-cancer treatments and biomarkers in early phase studies and trials. The Cardiff ECMC centre, set up in 2006 and based in Cardiff, is funded in partnership by the Welsh Government and Cancer Research UK.

Researchers in Wales also have access to the Wales Biobank at Cardiff University. The Biobank stores up to 900,000 biological samples and plays a role in supporting eight disease specific biobanks, many of which also have links with the research centres and units:

- Archie Cochrane Biobank
- Acute Myeloid Leukaemia Bank
- Cardiff School of Dentistry Tooth Bank
- National Centre for Mental Health Biobank
- SWIFT (South Wales Initiative for Fetal Tissue) Research Tissue Bank
- Wales Cancer Bank
- Wales Kidney Research Tissue Bank
- Welsh Neuroscience Research Tissue Bank

This network of biobanks is a valuable resource for researchers. It allows them access to disease tissue to enable the researching of potential drugs and treatments on such tissues. Our interviewees suggested that one such facility, the Wales Cancer Bank, was vital to their work.

> "When we set up the Wales Cancer Bank, it was an absolute model for what could be done." [Clinical Academic]

> "I would say that we seem to benefit from a good cancer bank facility… we are fortunate that we have a reasonably well run and extensive cancer bank." [Academic Researcher]

> "There have been some major initiatives. The Wales Cancer Bank is a prime example because that was the first cancer bank of its type set up. A lot of other places around Europe and the UK followed." [Charity Representative]

Some, however, suggested that the initial investment in a world leading facility has not been followed by sufficient support to maintain the facilities level, causing biobanks elsewhere to move past Wales.

> "There's always an issue with sustainability of these large infrastructural projects. They're investments that you won't see a quick return on, but they are going to be vital for long-term success. Is the support there for these at the moment? I guess not as much as it should be." [Charity Representative]

Others considered this to be symptomatic of a wider issue with infrastructure. As the medical priorities of the Welsh Government shift, big research facilities are being underfunded:

> "There was a lot of investment in cancer. They then (change their focus to) other fields like dementia… (This means) things like [the Wales Cancer Research Centre] have level funding, a reduction in real terms. That's been happening now for the last five years." [Clinical academic]

> "We had significant infrastructure support with things like the Welsh Cancer Bank… but there are threats to that funding." [Research Director]

To create a thriving research environment, the Welsh Government needs to provide long-term support for the research infrastructure it creates. While it is right for the Government to change its focus based on what is best for the health of those who live in Wales, new investment shouldn't be to the detriment of funding for research facilities in other areas. Medical research often takes many years, or even decades to develop new treatments and long-term support for facilities is crucial to support these developments from bench to bedside.

The Welsh data infrastructure needs investment to effectively support research

In *Science For Wales 2017*[125], the Welsh Government highlighted data as a key area of opportunity for creating world leading research in Wales.

> "With its excellent relationship with its NHS, Wales is well-placed to bring together extensive health; genomic; educational and social media data to provide an unprecedented platform for research on diseases; treatment response and to performance of smart clinical trials in the future."

With 3 million people and a centralised NHS, many within the medical research environment see the use of patient data for clinical research as a unique area of potential strength for research in Wales.

> "I think we've got a huge opportunity in Wales to really major in big data and metadata because we're a closed cancer ecosystem in Wales because we're a country of three million people, and I think you can look at the totality of that healthcare system quite easily in terms of data relating to patients, their disease, their treatments and their outcomes." [Research Director]

Such research is extremely valuable in the development of new treatment and healthcare systems. If Wales can develop a data infrastructure that enables researchers to link patient data and study the effectiveness of medicines and technologies in the real world, it would be a unique selling point to attract funding from industry stakeholders.

SAIL Databank

The Welsh Government has begun the process of trying to set up this type of infrastructure. One major step in this is the establishment of the SAIL (Secure Anonymised Information Linkage) databank. Established in 2007 and based in Swansea University, SAIL is a national data 'safe haven' of anonymised health and administrative datasets about the population of Wales. Data safe havens provide access to health data and services to enable research while protecting the confidentiality of the data.

The databank allows researchers to link together data from a wide range of data sets, from primary and secondary care, as well as mental health, social services, education and national survey data. Between 2007 and 2017, over 250 projects and 350 researchers have been approved to work with the SAIL Databank[126], the Welsh Government has valued the research supported at £250 million[127].

This work has included a wide range of research methods, including: cohorts, case-controls, natural experiments and clinical trials and has researched a number of areas from prevention, reducing inequalities to reducing mortality.

Our interviewees were generally positive about the databank, and its potential.

> "I think the SAIL data bank is widely recognised as being ahead of the game in terms of what we've got, so building on that further is important, and making sure that we increasingly use routinely collected data to support our research work. I think the more we can move towards routine data, helping to generate follow-up assessments as part of research, the better." [Government Representative]

> "because you've got SAIL, there is actually the availability of data that is probably far better than it is in England" [Academic Researcher]

> "there's good research infrastructure in the sense that we've got the SAIL database at Swansea University" [Academic Researcher]

Others expressed fears about the long-term support and effectiveness of the databank.

> "I think we do have really good infrastructure in terms of the SAIL bank… but it could be better with more investment… if you look at it by how it is funded, it is funded by lots of different strands… which doesn't ensure its sustainability." [Academic Researcher]

> "[(SAIL) will be great if it works properly. I'm not sure that this is a question of funding… I think there was a lot of talk about the potential. We need to understand whether that potential is being realised as much as it should be for the amount of money that's gone into it." [Clinical Academic]

The ability to access large amounts of data is an increasingly essential part of medical research. The SAIL databank is potentially a huge asset to the medical research environment in Wales. A key issue raised by our interviewees is the heterogenous nature of clinical data.

> "routinely collected data often isn't formatted in a way that is easy to search, as perhaps clinical research data would be. So, there is often quite a bit of work to use it in a format that will actually generate the answers to the questions you want to ask it. So it's quite resource-intensive at the moment" [Government Representative]

Such barriers make it difficult for researchers to easily use the data held within the SAIL databank. This may put some researchers off in favour of other nations where such data can be more efficiently studies. Any changes that can be made to the recording of medical data to allow easier research would help to increase the impact of the SAIL databank, whilst also enabling the NHS to better monitor and evaluate the provision of services.

To ensure that the potential of SAIL is realised, the Welsh Government needs to ensure the databank is sufficiently funded in the long-term to meet the needs of an advancing technological landscape. They also need to ensure that local systems are up to standard and there is sufficient local capacity to do high quality data collection.

Our interviewees highlight a number of issues in the IT infrastructure of Wales including the storage of data and the availability of informatics systems.

> "As a matter of principle, there should be data warehousing, so that we increase the knowledge. Now, part of the restrictions on that is of course the IT infrastructure, because you need the right infrastructure to do that. I think it's not universal." [Clinical Academic]

> "In terms of the informatics systems as well, we could have bigger and better for the future. For example, for personalised cancer medicine you need good informatics systems that are flexible and allow you to collect this data." [Charity Representative]

> "the clinical informatics system in Wales is not good… We had a really good system, which was clunky but probably better than anywhere else. We've lost momentum in that. That really does need a serious input and a serious look." [Clinical Academic]

Given that data is integral to research and clinical practice, it is vital that the Welsh Government supports the development of an IT infrastructure that is fit for the future. This requires long-term planning and funding to support the development of this type of infrastructure.

The development of this infrastructure should focus on the ability for clinicians and researchers to easily link and study NHS data to deliver value rapidly to patients, healthcare professionals, and the wider NHS. This should be comparable to the work of the Innovative Healthcare Delivery Programme (IHDP) in Scotland. The Welsh Government should seek to create links with the new Health Data Research UK body to initiate a similar programme in Wales.

HealthWise Wales

HealthWise Wales (HWW) is a confidential research study, which aims to develop an in-depth knowledge of the health of Wales[128]. It aims to recruit 100,000 people over a five-year period (from 2015-2020) to the project. HWW has, at the time of writing, recruited over 20,000 patients to the project[129]. The Welsh Government is planning for those who sign up to HWW to firstly be members of a cohort with longitudinal data on health and lifestyle factors and record-linked to routinely available healthcare data. HWW will then support researchers through:

- providing opportunity for researchers, through HWW email, to advertise research opportunities to those who have signed up;
- allowing researchers to access data held in the HWW data repository, which can include routine healthcare data that is available in the Secure Anonymised Information Linkage (SAIL) databank;
- supporting data collection for studies by hosting questionnaire modules on the HWW Platform and linking participant data to healthcare records (SAIL).

It is hoped by some in the research community that this will enable researchers to draw from a large number of patients who are engaged in research, both now and in the future, when those who have signed up might become eligible for clinical trials and other forms of research.

> "HealthWise Wales is a new government initiative to get the general public to sign up to research, to be part of a pool of people to collect data and link up to research projects. Theoretically, within those patients who then go on to develop cancer, we could have an engaged group for research purposes." [Research Director]

Such initiatives could be valuable to the normalisation of research participation in the public. It also allows the creation of a pool of people who are willing to engage in research which researchers will be able to draw from. Over time, this could positively impact the number of patients who are recruited for research. The Welsh Government should continue to work with HCRW and NHS Wales to create opportunities for the Welsh public to engage in research.

RECOMMENDATIONS

- The Welsh Government should work with universities to identify opportunities to expand infrastructure access, either through existing funding mechanisms or a new specific fund.
- The Welsh Government should assess the possibility of working with HDRUK and other stakeholders, to link NHS data and rapidly deliver value to patients, healthcare professionals, and the wider NHS – as the Scottish Government has done with the Innovative Healthcare Delivery Programme.

2.4 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 agenda for research in an area, through to the research staff, students and the administrative and technical 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 (radiologists, pathologists and lab technicians) who are needed to screen for eligibility in any given trial.

Issues in the research workforce often overlap with those seen in the infrastructure space due to the intertwined nature of the workforce and the equipment and resources that they need to undertake research.

There is a shortfall in the medical basic research workforce

In 2012, Halligan & Bright estimated the research staff shortfall in Wales[130]. They calculated the FTE researchers in each nation of the UK and compared it to each nation's percentage of the UK population. They found that Wales had 4.3% of the UK's research population, representing a deficit of -0.5%. This is even more pronounced in medical research. In the HESA categorisations of "clinical medicine" and "biosciences" had deficits of -1.3% and -0.6% respectively.

Written to stimulate discussion following the establishment of the Ser Cymru programme, the paper was trying to analyse why Wales was less successful at attracting competitive basic research funding than other parts of the UK.

The Welsh Government recognises this workforce shortfall and in *Science For Wales 2017*[131] stated that "this shortfall has resulted in Wales, with some excellent, indeed, world-leading academics, still not winning the proportionate share of competitively-awarded research funding that it should."

In the 2014 REF assessment, 77% of Welsh university research was awarded three or four stars[132] (denoting it as internationally excellent or world leading) and the only UK nation to perform better in the exercise was Scotland. However, Wales performs poorly in the attraction of competitive research funding (as discussed in the funding chapter). This supports the Welsh Government's statement that, while the quality of research isn't being affected by workforce issues, Welsh researchers are not able to effectively compete with their UK counterparts for funding.

Two questions that exist regarding Welsh workforce levels are; why Welsh research institutions are not able to attract and retain research staff, and how to best address the research workforce shortfall.

While there was recognition of a number of issues with regards to the attraction and retention of the research workforce, our interviewees noted that the issues are not universal. There was recognition that many of Wales' most established and best performing research groups have sufficient research teams.

> "In the areas that we have established groups, then we do attract people and we do retain people. I think the funding we give out to our centres and units is attractive to people and helps with that, as well as some of our other schemes." [Government Representatives]

It was also acknowledged that many issues in this area are not unique to Wales.

> "I don't think it's worse than in England, I think in terms of the university structures I think it's very similar and I think the issues are the same across the board" [Research Director]

Despite this, our interviewees highlighted a variety of issues with attracting and retaining research staff.

In clinical research, Health and Care Research Wales highlighted staffing as one of its Strategic Aims in the Strategic Framework for its Support & Delivery Service 2017-2022[133].

> *"*We will attract and deploy appropriately skilled, qualified and experienced staff in a consistent way across Health and Care Research Wales*."*

In 2016, HCRW's Support and Delivery Service was reconfigured to take on a 'hub and spoke approach' to delivering coordinated services nationally and locally. The integration of research delivery staff by funding the NHS using one, rather than two funding models is now in place - with all research delivery staff previously employed through a nationally funded research workforce embedded into local NHS organisations.

In support of this, each NHS organisation has created a HCRW R&D service which is responsible for the strategic planning of funding received from the Welsh Government's R&D Division.

One reason for these changes is to address geographic disparities that exist in the offering of clinical research. Responses to the Cancer Patient Experience Survey show that a significantly higher proportion of patients in Cardiff, than in the rest of Wales, are being offered opportunities to take part in research (more details on these issues can be found on page 52).

There is a need to attract and develop more research leaders

Our interviewees highlighted issues around research leadership across basic and clinical research.

> "Retention isn't the problem. The attraction is. Getting the very best people to come in Wales is tricky." [Research Director]

> "Although I think we do have very talented people, we could do with more mobility and more people coming in from outside." [Academic Researcher]

> "The people that are leading are doing a really good job, but there are not enough leaders, and that, tailored with the stretch in the clinical service, means lots of pressure is put on a few people to deliver, rather than having a broader leadership. I think there needs to be investment into these early career researchers coming

through, that they're fast-tracked into leadership roles for research to be sustainable." [Research Support Manager]

While the basic research environment does have a few research leaders, there is concern about a lack of incoming leaders from abroad and the rest of the UK in these fields. Such incoming leaders are crucial to building a thriving environment bringing new techniques, new research areas and attracting talented early- and mid-career researchers to a recruitment area.

This incoming research talent can attract new research funding from research councils and other external funding sources, as well as create links with other research institutions and provide access to equipment and opportunities for Welsh researchers to gain wider experience.

This lack of incoming talent can be attributed to a range of factors. One of these mentioned by our interviewees is a lack of opportunities for new researchers to move into Wales. This was partly attributed by some interviewees to a lack of movement in fellowship and lectureship positions in Wales' universities.

> "Within a university, we can create fixed-term fellowships, but there's only so many open-ended lectureship contracts to go around, and so we do lose people. There's a massive bottleneck at that stage of the fellowship and lectureship position and that's a real problem." [Academic Researcher]

This may be a more pronounced problem within the Welsh medical research environment due to the smaller number of Universities Is than other UK nations. With many of the few fellowships in the large research universities being occupied by the same researchers, with relatively little movement, it limits the number of opportunities for researchers to come to Wales.

Another issue raised concerns when positions do become available, Welsh universities are not financially able to compete with the financial and infrastructure offers that exist elsewhere to attract world leading researchers.

> "Trying to put a package together, which is more than the professors' salary, is really difficult. If we want to be serious about attracting people, they've got to have a package, which makes them think they could build a team or bring a team here." [Clinical Academic]

> "I think the problem is, there are not enough research positions that make it attractive enough to come in. So, again, that goes back to funding." [Academic Researcher]

This is not a problem that is unique to Welsh universities. Much of the funding income, and therefore financial power and infrastructure, is concentrated in a few institutions and so competing with these institutions is becoming increasingly difficult for smaller universities. One reason that Welsh universities might struggle to compete with other UK or international institutions is that they cannot offer access to the same equipment as others.

Additionally, one interviewee suggested that the low level of QR funding in Wales may discourage researchers from choosing to work and establish research teams.

> "At the moment there is very little incentive for anybody who's doing preclinical research to come here because of the apparent lack of support for preclinical research." [Academic Researcher]

If the discussions in the basic medical research environment in Wales reflect a feeling of negativity about Welsh Government support, researchers outside of Wales that are aware of this via networks may be put off from considering Wales as a future destination for their work.

There are also concerns about the development routes for clinical research leaders. To create new leaders within the welsh clinical research environment, support and incentive is needed to bring consultants and other health professionals into research.

Health and Care Research Wales currently funds a series of clinical time schemes to enable health professionals to engage in research[134]. These schemes provide opportunities for individuals from both clinical and academic backgrounds to engage in clinical research or to lead their own research projects. This includes Clinical Research Time Awards (CRTAs), which offer NHS staff the opportunity to apply for 'protected time' to engage in research activity.

These awards are seen as valuable by our interviewees who suggest that there may be a need to extend the programme.

> "(The clinical research time awards) give them bought out time for a year so you can have a day a week for example for a year to develop your research ideas and maybe do some piloting, but there's not many of them" [Research Director]

In 2016, only seven awards were given to researchers and it would be valuable to extend such programmes to provide more clinicians to have time engage in research. This would allow for wider access to research. Given that developing better, kinder treatments and improving patient care relies on research, it's vital that more patients are provided with the opportunity to be involved.

The Wales Deanery also offers training through the Wales Clinical Academic Track (WCAT) fellowship programme with training as well as protected time (0.2 WTE) for clinical practices in the training years. However, the Deanery is to be subsumed in 2018 within the new Health Education and Improvement Wales (HEIW). It is unclear at this stage whether this training scheme is to continue following the transfer of functions on 1st October 2018.

HCRW contributions to the NIHR also allow researchers to apply for NIHR clinical fellowships and the NIHR Clinician Scientist Awards[135]. These programmes buy out a fellow's salary and research costs.

Funding for clinical research from the HCRW has recently increased and there are good fellowships and awards available for clinicians to engage in research. However, awards such as the Clinical Research Time Awards are only able to grant a few places. HCRW should look at extending these to allow for more clinicians to benefit.

The limited number of clinical time awards limits the ability of doctors and health professionals in their early-career from becoming involved in clinical research. In an NHS workforce that is stretched, without such opportunities for funded time, many health professionals are not able to engage in research.

It is crucial that Wales is able to retain talented early and mid-career researchers

With issues existing around the attraction of researchers from outside Wales, it is crucial that Welsh research institutions can retain early- and mid-career researchers.

Our interviewees note that while there are initiatives to develop researchers from PhD onwards, they are not sufficient enough to retain the number required to achieve a critical mass of researchers in the Welsh medical research environment. Such critical mass is an important part of attracting world leading researchers to an area.

> "There are some very good initiatives that are taking place which are trying to develop people through the career pathways to support them into their PhDs and fellowships, But they probably almost certainly not as broad as maybe they should be in terms of being able to get the right numbers of people and the support structures in place to get those opportunities" [Research Director]
>
> "But for those who have come through the system here in Wales, at the moment it's remarkably difficult to retain them. In the School of Medicine, we've seen a lot of our best talent leave to go to companies, leave to move to different schools within the university, leave academia altogether." [Academic Researcher]
>
> "I would like to see more support for building capacity particularly in terms of younger leaders, the people coming in at lecturer and perhaps senior lecturer level, to build that capacity and thereby create a vibrant research environment, which can then attract the big stars." [Academic Researcher]

While it is expected that a significant number of those who begin working in medical research will leave at some point in their career, there are several factors that may cause barriers in the academic pathway.

One of the major issues that may be causing researchers to leave medical research in Wales early is a lack of progression routes for early- to mid-career researchers. This can lead to researchers either deciding to leave Wales to find new opportunities or leaving research for another career.

Another major issue, discussed previously, is a lack of long term fellowships and lectureship positions. Not only can this prevent the attraction of research leaders coming to Wales, it can also lead to talented researchers moving away from Wales to seek opportunities at larger research institutions.

Again, issues with infrastructure may cause researchers to leave Wales, especially those in the middle of their career. A researcher who is looking to advance to a leader in their field, may need to leave to learn and take advantage of new techniques and equipment that

might not be available in their institution. Such issues highlight the importance of identifying and supporting areas of excellence within the medical research environment, as well as collaboration and pooling of equipment between Welsh research institutions. This will allow developing researchers in these fields of excellence to undertake innovative and world-leading research, and therefore encourage the most talented researchers to continue their careers in Wales.

Another pressure on developing researchers is increasing job instability in higher research positions:

> "People are getting more and more senior in their careers and still being on very short-term contracts and only funded from external funding" [Research Director]

A reduction in job security for mid- and late-career researchers will inevitably lead to some research leaders leaving for other institutions to gain greater job security through lectureships and fellowships.

The fact that many roles are solely funded from external funding is symptomatic of the low level of QR funding. The real-terms decrease in this stream over a period of time means that universities are less able to offer long-term contracts to researchers as they have less stable funding for medical research. It is crucial that the Welsh Government enact the recommendations of both the *Reid Review* and the *Diamond Review* around QR funding as soon as possible to enable the support of a thriving research workforce and the attraction, retention and development of future medical research leaders (as discussed in the Funding chapter)

This small number of long-term positions means that Wales relies on a small number of research leaders. This affects the resilience of the medical research environment in Wales, where the loss of a small number of individuals from medical research can have major knock-on effects for the quality of research and the strategic leadership.

The small number of leaders also limits the scope of the strategic thinking for research. Widening the opportunities for the attraction and development of leaders is crucial for the future of medical research, helping to identify strategic priorities and improve the development of an infrastructure to support research excellence.

> "The coordination of research for cancer in Wales has been then too focused on single individuals that have an awful lot of power both within the research environment but also within key universities, and I think that's really detrimental for research development in Wales." [Research Director]

The Sêr Cymru programme is helping to address issues in the capacity of the research workforce

The Ser Cymru[136] programme is the Welsh Government's attempt to address the issues surrounding the research workforce. As previously discussed in the Funding chapter, Sêr Cymru[137] aims to build strengths in areas of existing excellence through increasing research capacity in Welsh universities, helping them to win more competitively-awarded funding[138].

So far, the Welsh Government, the EU and the Welsh Higher Education sector have invested more than £100 million into the initiative. As of 2017, the first phase of the initiative has

brought in approximately £67.1 million in additional research council grant income to Wales through the research groups it has funded[139]. This represents a significant return on the investment made already and these groups are like to continue to attract this additional funding to the Welsh research environment. More information about the aims of the initiative can be found in box 4.

As of 2017, the scheme had attracted over 190 research fellows and PhD students through three specific recruitment strands aimed to address issues in the research workforce:

- Rising Star fellowships: aims to award fellowships for the very best 'rising stars' of academic research. The aim was to fund 12 fellowships via this strand and it has so far recruited seven.
- 'Welsh' Fellowships: three-year fellowships for stellar candidates, to be recruited from anywhere in the world to come to work in Wales. This strand aimed to recruit 30 individuals and has, as of 2017, recruited 11 research chairs and their teams.
- Recapturing Research Talent: for talented researchers returning to work following a career break or who have left the scientific world. The strand set a target of recruiting 12 fellows and has so far recruited 4.

The Sêr Cymru programme was valued by our interviewees who recognised its impact in increasing the talent pool:

> "Sêr Cymru has attracted in several major international researchers from outside Wales into Wales by offering relatively big money to set up their labs in Wales. It is bringing some very strong minds into research in Wales." [Government Representative]

> "I think certainly, schemes like Ser Cymru are very helpful in (attracting new talent)." [Academic Researcher]

> "We have government initiatives such as the Ser Cymru initiative which has government support and funding to bring in key research leaders to Wales, particularly in strategically important areas. We need to make sure we fund the strategy effectively and use that funding effectively in order to bring those individuals to Wales." [Research Director]

Sêr Cymru has brought a significant grant income and many research staff into the welsh medical research environment. The programme has also supported the appointments of 161 Post-doctoral researchers and 159 PhD/EngD students[140].

The Sêr Cymru programme has been successful in catalysing an influx of research staff and addressing some of the issues laid out in Halligan & Bright's stimulus paper. In January 2018, the Cabinet Secretary for Economy and Transport agreed to undertake a full evaluation of the Ser Cymru programme[141]. It is crucial that the Welsh Government publishes this review as soon as possible and regularly evaluates its schemes aimed at increasing research workforce capacity. The Welsh Government should also look at ways that they can capitalise on the increase in research workforce to improve the attraction of medical research funding from competitive sources.

Pressures on the NHS are affecting the delivery of clinical research

The increasing strain on the NHS in Wales, and in other parts of the UK, is also having an impact on clinical research. As NHS staff are becoming more stretched in their clinical work, they are less able to commit time to supporting clinical research. This strain was mentioned by several our interviewees.

> "within the NHS in Wales, staff recruitment is difficult and that has an impact in terms of clinicians being overworked and therefore creates difficulty with clinical research." [Research Director]

> "I think we should invest more in retaining our multi-disciplinary workforce - radiologists, pathologists and anybody who has anything to do with clinical trials. So we can all maintain the good work that we're doing now." [Senior Research Nurse]

> "research isn't just done by a clinician. It's supported by pathology, radiology and ophthalmology etc. We need all of those support services in place. If they're stretched and they haven't got the capacity to do research, then actually research can falter." [Research Support Manager]

With the increased specificity of the indications for new treatments, a greater amount of screening is needed to find eligible patients. This draws on the work of a range of diagnostic staff including radiologists, endoscopists, pathologists and clinical geneticists. Current pressures on these areas means that they are less able to give time to the screening of patients for clinical trials. This severely affects that capacity for NHS Wales to support clinical trials.

It is therefore crucial that the Welsh Government works with NHS Wales to support the diagnostic workforce. The recruitment and retention of a multi-disciplinary workforce will be key to ensuring clinical trials are well-supported. Cancer Research UK published a position paper[142] highlighting issues around the diagnostic work force in wales. It is important that Welsh Government and Health Education and Improvement Wales (HEIW) and other stakeholders act to address the issues in this workforce.

This issue is not only affecting the diagnostic staff involved in research, but also research nurses. Research nurses play a crucial role in the delivery of clinical trials. They provide and deliver high quality patient care as well as dealing with data collection, follow-ups, patient groups and industry. They also play a key role in bringing together the multi-disciplinary teams that deliver research.

Our interviewees stated that research nurse numbers are falling, with knock on effects for patient recruitment.

> "we used to have dedicated research nurses with dedicated time, who could really get to grips with putting patients into trials. Trials are of course more complicated now. It takes more time to talk to patients." [Clinical Academic]

> “there's been a nurse recruitment problem for a few years now, out of research, so within research it's even harder because it's more specialist.” [Senior Research Nurse]
>
> “Outside the WCRC, the wider clinical research infrastructure struggles partly because of lack of dedicated research nursing time.” [Research Director]

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> “there's been a nurse recruitment problem for a few years now, out of research, so within research it's even harder because it's more specialist.” [Senior Research Nurse]
>
> “Outside the WCRC, the wider clinical research infrastructure struggles partly because of lack of dedicated research nursing time.” [Research Director]

Our interviewees note one potential contributing factor to this reduction in capacity in some clinical areas. For example, some say that research nurses that were formerly focused solely on supporting cancer trials are now being used as generic research nurses to cover a wide range of clinical areas.

> “In the last three years, Welsh government has restructured parts of Health and Care Research Wales. And I'm sure this will be similar in England, where that workforce has become more generic” [Research Support Manager]
>
> “delivery staff – at the moment is very limiting. There is no dedicated cancer research workforce – if you’re a renal nurse you’re doing cancer and non-cancer studies.” [Research Director]

Reductions in the number of research nurses and the reduction in specialised nurse support in clinical areas could negatively impact on the ability of Wales to open and run clinical trials, especially in clinical areas where the support is much more specialised, such as cancer. Without their crucial work in bringing together multi-disciplinary teams, as well as looking after patients, it would make it increasingly difficult for health professionals to engage in research. This would have a large impact on the ability of the NHS Wales and other organisations to open clinical trials.

RECOMMENDATIONS

- The Welsh Government should publish the ongoing evaluation of Sêr Cymru by 2020 and regularly evaluate schemes aiming to increase research workforce capacity in Wales. This evaluation should include recommendations for Welsh research institutions to capitalise on the increased research workforce from Sêr Cymru and to increase the proportion of competitive medical research funding they attract.

- Welsh Government, HEIW and HCRW 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. This should include HCRW extending its Clinical Research Time Awards.

Box 4 – Ser Cymru

Ser Cymru I

The first phase of the initiative committed up to £50m to attract researchers and to support the development of national research networks in three 'grand challenge' areas: life sciences and health; low carbon, energy and environment; and advanced engineering and materials. This phase has attracted four research chairs to Wales and supports 26 research fellows with post-PhD research experience. This phase of the Sêr Cymru programme is due to end in 2018.

Ser Cymru II

Ser Cymru II, the second phase of the programme, was launched in 2015. It is a £56 million programme, led by the Welsh Government, the European Union (EU) and the Welsh Higher Education sector.

This second phase was designed to address the following issues:

- That Wales produces high quality, efficient and impactful research that makes a positive economic development contribution to the Welsh economy.
- That Wales has lagged behind the other UK regions in terms of its population share of competitive research council funding. While Wales has 5% of the UK's population, research funding secured from Research Councils in total has been around 3.5% of the UK share, largely due to the inability to secure sufficient funds from the largest research funding councils.
- That Wales currently has too few research scientists in STEMM subjects to be able to make up this shortfall in research income.
- That an additional 600 STEMM research scientists are needed for Wales to address the identified shortfall.

To help address this, the Welsh Government aimed to use Ser Cymru II to support around 150 posts to work in Welsh Universities.

£17 million of this funding has been raised to attract up to 90 new research Fellows to work with the best researchers in Wales. This has been funded by the Welsh Government, the Welsh Higher Education sector and the European Union, through the Horizon 2020 programme.

In addition to this stream, the Welsh Government and the Higher Education sector has provided a further £16 million, with the ERDF providing £23 million to support three additional strands to recruit fellowships from both within the UK and internationally.

2.5 PATIENT ACCESS TO CLINICAL TRIALS

The ability for 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, so it's vital that more patients take part in research. Clinical trials often represent the best standard of care; therefore, it is important that patients have access to clinical trial opportunities. For these reasons, it's imperative to highlight issues around patient access to clinical 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. 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. 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 in specific hospitals. The increasing specificity of trials mean that they are now often run across many sites. The reporting of these trials onto public databases often do not specify where the trials are currently open across these sites, making it difficult to create an accurate picture of clinical trial participation in Wales specifically.

The Cancer Patient Experience Survey provides an insight into how the NHS Wales 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.

Wales' population size, centralised NHS and University excellence means that clinical trial recruitment is often successful

We know that there are a number of clinical trials available to patients in Wales, particularly in the South East. HCRW's research portfolio for July 2018 contains 649 pieces of clinical research that were ongoing at that time[143].

We also know that there are examples of success in Welsh hospitals attracting patients to trials, such as the MRC STAMPEDE trial (more information can be found in Box 5[144][145]).

These studies serve to demonstrate that in Wales, especially Cardiff and Swansea, there is a solid infrastructure for the recruitment of research patients. However, there are concerns that the numbers of patients that are being recruited for research are beginning to fall:

> "the rates of recruitments, patients into clinical trials, having been really very good in showing a continual upward trajectory, has now fallen." [Clinical Academic]

Box 5 – MRC STAMPEDE trial recruitment in Wales

STAMPEDE aims to provide evidence as to what is the best way of treating men with newly diagnosed advanced prostate cancer. This multi-arm study aims to see if the way in which prostate cancer is currently managed can be improved.

The trial, funded by Cancer Research UK, was opened in 2005 and is open to patients across the UK and Switzerland. It has now grown to include 127 sites and has recruited over 10,500 patients up to August 2018.

Of these 127 sites, the Velindre Hospital in Cardiff has recruited the most patients for any single site, recruiting 396 patients to date. The Singleton Hospital in Swansea has also recruited 213 patients in this time, with 10 patients coming from Bronglais General Hospital in Aberystwyth.

One potential reason for this fall has resulted from recent advancements in the specificity of understanding and treatment of cancer and other diseases. This increased specificity of indications for new trials means that a great deal more screening is required before a patient can take part in research, and this has an impact on recruitment.

> "If you were to look at performance targets of patient recruitment, there's less patients going into trials, because we've got personalised medicine, and the days of big numbers in randomised controlled trials has stopped" [Research Support Manager]
>
> "clinical trials now are looking at specific type of disease and patients, there's a smaller eligible group… So then you don't account for people who don't want to do it, or are not fit enough to do it... So recruitment is much more difficult for clinical trials now than what they were." [Research Nurse]
>
> "There is a lack of large trials where everyone has the same treatment. Now there are stratified treatments, so the complexity gone up, but the patient numbers have gone down so the workload is the same. We didn't foresee that change, we need to be more innovative in terms of how we address those issues." [Research Director]

This issue is not unique to Wales, with this increased specificity leading to a reduction in patient recruitment across the UK and internationally. There are, however, a number other issues that may be also impacting the ability of patients to access clinical trials.

The advertisement 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 NHS to carry out clinical research[146].

However, in the 2016 Welsh Cancer Patient Experience Survey (CPES)[147], only 23.1% of respondents stated that someone had discussed whether they would like to take part in research. This is a lower than the figure in England, where 27.4%[148] of patients who

responded to the 2016 survey had research discussed with them, a figure that rose to 29.5% in England's 2017 survey. However, Wales' figure was higher than both Scotland and Northern Ireland (all of the figures can be seen in Table 3 below).

The number of Welsh patients who reported having research discussed with them in the 2016 survey was lower than the CPES in 2013[149], where 29% of interviewees stated that research had been discussed with them. This fall is also seen in England (the only other country to have run a survey in 2013) where the figure was 32%[150]. This suggests that the issues that led to this fall may not be unique to Wales.

Nation	% of interviewees who had research discussed with them	
	2013	2015/6
Wales	29%	23.1%
England	32%	27.4%
Scotland[151]	N/A	22%
Northern Ireland[152]	N/A	18%

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

These figures suggest that while Wales is performing relatively well compared to other nations in offering research to patients, there is still a significant amount that can be done to improve patient access to research.

There are several possible attributing factors to this low figure. One significant factor may be pressures on the NHS. A total of 19,088 new cases of cancer were diagnosed and registered amongst the resident population of Wales in 2015. This is a 10% increase of 1,699 more cases in 2015 compared with ten years previously[153].

Oncologists are seeing an increasing number of patients, putting pressure on their time for consultations. This means that they might increasingly not have enough time to discuss research with their patients.

In addition, 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 interviewees raised issue around the systems in place to advertise clinical trials to clinicians.

> "not everybody knows that a trial is coming along or open, so they can't recruit the patients. More could be done to promote this rather than just relying on word of mouth, we need more education sessions to raise awareness of this" [Research Director]
>
> "for consultants, we don't think currently that the central database for clinical trials is robust enough. If somebody says, "Yes, I want to get involved (in research)", there isn't then an easy way for them to share what is out there with the patient." [Charity Representative]

If consultants are unaware of what research opportunities, they will not be able to offer them to their patients. It is important that the Welsh Government, NHS Wales, HCRW and HEIW assess any possible tool or infrastructure improvement that could support consultants in offering research opportunities to their patients. Research in England has shown that in NHS Trusts that conduct more clinical research provide better care and have better patient outcomes than those that conduct less clinical research[154].

There are a number of trials databases that effectively advertise the clinical trials available to patients. Examples of this are Cancer Research UK's clinical trial database[155] and the NIHR UK Clinical Trials gateway[156]. 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.

However, there is concern amongst clinicians that these databases are often not optimised to their needs. The increasing complexity of the indications needed for clinical trials means that clinicians often need to access more information than is available on these public databases quickly. The ability to search for trials by molecular marker and to have access to contact information for the lead researchers of trials would allow clinicians to find research opportunities for their patients in a less labour-intensive way.

Currently, clinicians might not feel able to offer trials to patients without further time invested into the trials available, such as time to find the contact details for trial leads, which may not be possible with increasing pressures on their time.

There is a need for collaborative working to create solutions that enable more patients to be offered clinical trials.

There are examples of new databases that are being developed, that are aimed at clinical audiences. One proposed solution that is being developed for cancer specifically by the ECMC network. The Experimental Cancer Trial Finder (EC Finder) is a tool that is being created to allow clinicians in the ECMC network to search and identify relevant clinical trial options from across the network using a number of patient-specific attributes. (more information on this project can be found in Box 6).

However, the multiplication of databases for different audiences is not the only possible solution for these issues across the Welsh clinical research environment. Further collaboration between clinical research stakeholders could create solutions through adapting existing resources and processes to clinical need. This could be through the enabling of new access to more detailed information through creating health professional specific logins or expanding the search options for clinical benefit.

Bodies such as NHS Wales, HCRW and the Welsh Government, working closely with patients, clinical stakeholders and the owners of clinical trials databases could help to find solutions to allow health professionals to more easily discuss research with their patients.

Box 6 – EC Trial Finder

The ECMC network leads identified that a lack of UK-wide visibility of open trials was one of the main hurdles for efficient patient referral. Currently clinicians have access to trial data within their local portfolio management system but do not have visibility of all early phase trials across the ECMC network. Additionally, the existing publicly available trial databases are not optimal for the needs of the clinicians (e.g. molecular stratification search, availability of contact details and timely updates).

The EC Trial Finder project, launched in March 2017 by the ECMC Programme Office, in collaboration with CRUK's IT department, will allow clinical staff in the network to search relevant trials according to specific trial criteria, such as cancer type, recruitment status, molecular profile, treatment type, age; and the search result will include contact details of recruiting site.

This should enable the clinician to quickly determine whether there are clinical trials in the ECMC Network that their patients may be eligible for and to provide the necessary information to allow the clinician to confirm potential trial eligibility and slot availability directly with the individuals who are managing the clinical trial.

The project is currently in a pilot phase and is expected to go live to a selected user testing group within the ECMC network in November 2018. If successful, this will potentially be made available for larger user group outside of the ECMC Network.

Patient awareness of research

Because of the low figures in the Cancer Patient Experience Survey for the discussion of research with patients, it is important that, in addition to increasing clinician awareness of research, steps are taken to increase the awareness of research amongst the Welsh public.

Even if patients do not have research discussed with them, it is important that they are able to look for and find potential research opportunities that might be available to them. This can take the shape of publicly-searchable trials databases, initiatives to engage the public in research (such as HealthWise Wales), and public awareness campaigns.

There are several places where patients in Wales can seek research opportunities, should they be interested. HCRW maintains a research directory which is updated monthly and contains information about eligible non-commercial and industry-funded health and social care research studies, Pathway to Portfolio studies, biobanks, and research data registries available[157]. This categorises trials by disease area and contains a small amount of information about the trial itself. This resource, however, is not clearly visible on the HCRW website and would be difficult for patients to access. Additionally, NIHR provides the UK Clinical Trials Gateway for information about clinical trials across the UK, searchable by condition and location[158].

In specific disease areas, charities and other organisations may house databases for that area such as the Cancer Research UK clinical trials database[159]. While this information is available for patients who seek out research, many might not be aware that such

opportunities exist and what medical research might entail. Thus, there is a need to raise the awareness of clinical trials and medical research to empower more patients to engage in research where possible.

HealthWise Wales (HWW)[160], as previously in the infrastructure chapter (page 30), is a good example of a large-scale project to engage many people in Wales with research over the long term. The project is aiming to recruit 100,000 people to register in the first five years. Such projects not only sign up members of the public directly to research, but also raise awareness of medical research in the public. This means that when these individuals use the NHS in the future, they are more aware of the possibility of medical research involvement, and potentially, will actively seek research opportunities when not discussed with a clinician.

While initiatives such as HWW have helped to increase awareness of research in subsections of the population, more is needed to raise wider awareness in the public. Public Awareness campaigns and targeted use of social media and other outlets could offer new avenues to reach members of the public about the benefits of taking part in research. NHS Wales, HCRW and research active healthcare sites should be looking for ways to expand the reach of their information about clinical trials.

There is significant variation in the advertising and availability of trials across Wales

In addition to the awareness of trials amongst patients and clinicians, concerns are also raised about the geographical variation that exists in the offering of trials to patients.

> "patients in Wales having access to research that should be as a given. We shouldn't be a postcode lottery in terms of research. Whether you're living in North or West Wales you should be able to access research" [Research Support Manager]

> "We've lost research nurses, and now there's probably no Wales Cancer Bank activity. Well, there is none in North Wales, West Wales, or Swansea. It's heading towards being virtually Cardiff only." [Clinical Academic]

There are concerns that, due to the concentration of research centres in Cardiff, patients in other parts of Wales are not receiving the same opportunities to take part in research. This is demonstrated by the results of the last Cancer Patient Experience Survey (see Table 4). For the question regarding having research discussed with the patient, there was significant variation between the Cardiff Health Boards and those in the rest of Wales.

Only two of the Health Boards/Trusts were above the Welsh average level of 23.1%, Cardiff and Vale HB and the Velindre Health Trust. Both are in the Cardiff area and champion figures significantly above the average – 38% and 30% respectively. This highlights the scale of the variation, the number of patients having research discussed with them in Cardiff & Vale HB is double the level in the Hywel Dda HB. This suggests patients in Cardiff are twice as likely to be offered participation in research than those in Carmarthenshire, Ceredigion and Pembrokeshire.

Health Board/Trust	% of interviewees who had research discussed with them	
	2013	2016
Abertawe Bro Morgannwg University	26%	22%
Aneurin Bevan University Health Board	25%	22%
Betsi Cadwaladr University Health Board	25%	22%
Cardiff & Vale University Health Board	35%	38%
Cwm Taf University Health Board	18%	22%
Hywel Dda University Health Board	24%	19%
Powys Teaching Health Board	N/A	20%
Velindre NHS Trust	38%	30%
Wales average	**29%**	**23.1%**

Table 4: Percentage of Cancer Patient Experience Survey interviewees who had research discussed with them by Welsh Health Board/Trust.

There are some of the possible reasons for this variation. The core of these is the ability of hospitals in different areas of Wales to run clinical trials. As noted in the quote above, without research nurses in health boards, hospitals are unable to offer clinical trials to patients in their area. This has two possible consequential effects.

Firstly, health professionals may not suggest research participation to patients who are elderly or have co-morbidities if travel to Cardiff is required. Secondly, if research is not happening in a Health Professional's hospital or area, they are less likely to be aware of a particular study, and therefore less likely to offer it to a patient.

There have been steps taken by the Welsh Government and HCRW to address this regional variation. As discussed in the workforce chapter, the Welsh Government has established NHS R&D departments in each Health Board or Trust in a 2015 restructure of research funding and structures[161] as part of a support and delivery service.

This service was then reconfigured in 2016 to follow a hub and spoke model (More detail can be found on page 42). In the model[162], research services are delivered at a local level by R&D teams in each Health Board or Trust, where R&D managers/coordinators facilitate the sponsoring and/or hosting of studies in each area. At a national level, NHS research delivery staff provide oversight to create a nationally coordinated service to support research delivery in health and social care, facilitating the spread of studies across Wales[163].

Given that these changes were brought in after the latest Cancer Patient Experience Survey, it is difficult to understand what impact they might have had. It will be interesting to see

what impact that these changes might have had and will have in any future survey. It is important that HCRW and Welsh Government continue to support moves to expand the number of research studies available to patients across Wales.

There are concerns about barriers which slow down the approval of clinical trials

Another important set of barriers to patient access to research are those that prevent trials being set up in Wales. Delays in approvals and permissions processes can affect the number of trials that are opened, with companies sometimes opting for other nations where trials can be opened more quickly.

Our interviewees noted issues that exist in the Welsh system of permissions and approvals. The first of these is what some involved in research think is an excessive system of approvals.

The Welsh permissions system was set up by the National Institute for Social Care and Health Research in 2011[164] and is now coordinated by HCRW. Any application for permission to conduct a research project requires review from both the national Permissions Coordinating Unit as well as a local governance review by the NHS R&D unit[165] in each NHS organisation where the trial is set to be run. This means that those who are setting up trials must duplicate work for each NHS organisation.

> "We do have a problem with how quick the trial could be processed through. There is a system that trials have got to go through different ethical committees and there seems to be a lot of bureaucracy and a lot of steps involved that prolong the process." [Research Nurse]

> "I think in terms of the way the R&D structures are set up, we frequently have to duplicate an awful lot of work across organisations, not so much for ethical support but local review by R&D structures and hurdles that you have to get over, it should be once for Wales." [Research Director]

Duplication of work takes up significant time for both principal investigators and support staff. This affect their ability to engage with other pieces of research and could impact on a consultant's interest in opening a research trial. Time spent on applications for permissions to multiple organisations for consultants is weighed up against other commitments. If this amount of work is too burdensome, this could deter some health professionals from pursuing opportunities in research, affecting the numbers of trials that are opened.

One other potential drawback of this system is the time that it might take for multiple teams to assess permissions applications. This has been addressed by the governance guidance from HCRW who require all NHS R&D departments to give decisions within 40 days.

> "we're not there yet, and probably have a system that still relies on too many different people getting permission for multi-centre trials in particular, so I think there's more work to be done on streamlining, but that is going on at the moment and that is moving forward positively." [Government Representative]

It is important that the Welsh Government, HCRW and other stakeholders assess ways to reduce the burden of permissions on potential clinical researchers. This could have a hugely positive impact on research in Wales. A streamlined permissions system within a centralised health system would be a major selling point for research in Wales to bring in trials from industry and subsequently, additional funding to Wales.

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

Some effort is being made to address key issues in the approvals system is 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 within the UK.

> "I think UK overall, what we should be aiming for is to have a unique selling point of a very efficient, slick way of a) saying whether we can take part in a study, b) getting the approvals done and c) delivering it." [Government Representative]

Such harmonisation would be incredibly valuable for patients. Quick approval of research in Wales, for trials that are being led in other UK nations, would allow for a greater number of trials to be offered to patients in Wales. Researchers who set up trials in one UK nation may not open up their trials to 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.

The Welsh Government and HCRW are heavily engaged in this process. In April 2018, HCRW's approval merged with the HRA to form HRA and Health and Care Research Wales (HCRW) Approval and applies to all project-based research taking place in the NHS in England and Wales.

> "I think having the common approvals and permissions system that's being worked on at the moment with the HRA work is very important to us. So we're part of a formations working group on that, and my sincere hope is that we do come up with a once for the UK system that really is seamless between the four nations, and I think that would help the UK environment a lot." [Government Representative]

This process is intended to remove the need for each NHS organisation in England and Wales to assess the legal compliance of research projects. This reduces the administrative time for the organisations to focus purely on their capacity and capability to deliver a study[166]. This will reduce the amount of administrative work on researchers and the support staff in local hospitals in gaining approval for any given trial to open in their area. If this harmonisation can be extended to all four of the UK nations, it could allow the UK to further establish itself as a world leader in clinical trials. This would bring more trials to the UK, and to patients across Wales.

However, there are, concerns about how the merging of approvals processes might negatively impact the positive aspects of the Welsh system, such as the time guidelines that exist for approvals to be granted or rejected.

> "the HRA has just changed the process to remove R&D offices approval but they do still have to give a letter of support. As part of that change, this has removed their clocks to complete the approval… there's some anxiety that this is going to see us slide backwards because there is going to be no clocks even though there is less work for the R&D to do." [Research Director]

The HCRW needs to engage with those involved with clinical research to reassure them that this new process will not negatively impact their research. If this harmonisation of approvals is achieved, it could truly benefit patients. It is important that the Welsh Government and HCRW work closely with their UK counterparts to ensure that this harmonisation provides as much benefit to patients as possible.

RECOMMENDATIONS

- NHS Wales, HCRW and the Welsh Government should work with clinicians and patients to optimise the tools and infrastructure that support clinicians to quickly find suitable research opportunities for their patients.
- HCRW should continue to support measures to expand the number of research studies available to patients across Wales, evaluating the effectiveness of the hub and spoke model. They should assess the processes and infrastructure of NHS Trusts and Boards where the percentage of patients who reported a discussion about research is very low. This assessment should include involvement of patients in these areas to discover issues and possible solutions before targeting additional resources to these bodies.
- The Welsh Government should continue to work closely with other UK nations to ensure that permission streamlining work of HRA is realised and operates smoothly.

3. CONCLUSION AND RECOMMENDATIONS

Cancer Research UK has undertaken this research to assess the strengths of the medical research environment in Wales and to outline potential opportunities for policy action to further the success of medical research. The findings highlight the importance of a long-term coordinated investment in medical research.

There is a need for greater coordination of the medical research environment for the Welsh Government's policies. The policy oversight of research is currently split between two Welsh Government departments and the oversight of research is undergoing significant change with the introduction of TERCW, RIW and the ongoing strategy review process at HCRW. There are concerns regarding a lack of coordinated strategic planning for the long-term future of medical research.

There is increasing pressure on the funding of basic research in Welsh universities. QR funding, crucial for the research infrastructure and workforce, has been flat for several years. This is affecting researchers' ability to compete on a UK and international level for funding. The interviews demonstrate a desire for greater support for basic research. The Diamond and *Reid Review*s set out recommendations for how the Welsh Government should address this.

Across all types of medical research, infrastructure, both in terms of support workforce and equipment access, has a strong foundation. However, our interviewees expressed concern about the Welsh Government's long-term support for world-leading infrastructure projects.

Developing new research leaders is highlighted as a serious area of concern in the medical research workforce across the research pathway. The Sêr Cymru programme has been successful in attracting researchers to Wales but this needs to be built on. Furthermore, Welsh Government should look to protect such schemes from the potential loss of funding when the UK exits the EU.

The research workforce is also affected by external pressures on NHS Wales. This is also negatively impacting the recruitment of patients to take part in clinical trials. Wales has the potential to excel in clinical research due to its size – both in population and geography – and the centralised structure of its health system. There is ongoing work to develop tools that improve efficiency in the sourcing of clinical trials, which the Welsh Government should use to place Wales at the forefront of clinical research.

Wales is home to a great deal of world-leading medical research. However, improvements in the medical research environment would allow Wales to become a more competitive destination for research at a UK and international level. There is need for more support and coordination to maximise the effectiveness of the talent and ensure the sustainability of medical research in Wales.

LEADERSHIP & COLLABORATION

- The Welsh Government should put in place mechanisms to ensure better coordination and planning for the medical research environment. Any mechanism should link the work of all of the bodies that influence medical research in Wales – including HCRW, TERCW and HEIW - to ensure the Welsh Government's medical research priorities and targets are achieved.
- The Welsh Government should implement the recommendations in the Reid and Diamond Reviews.
- The Wales Cancer Research Strategy being developed under the Cancer Implementation Group should be completed as a priority. The strategy should set out clear roles for the key actors in the ecosystem, the ecosystem's interdependencies and how they can be optimised to leverage the most impact. The strategy should include:
  a. A set of key strengths and priorities for cancer research in Wales.
  b. An all-Wales infrastructure plan to maximise access to the most advanced equipment for researchers across Wales and ensure a sustainable funding approach.
  c. A plan to harness the strengths of Wales in big data, such as SAIL and HealthWise Wales, which provide an opportunity to carry out population level research in Wales.

FUNDING

- The Welsh Government should increase QR funding to Welsh Universities in 2019/20, to enable researchers to compete for funding at the UK-level in the long-term.
- The Welsh Government and Wales' 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 other sources – to mitigate against this loss and ensure the Sêr Cymru programme's continuation.
- The Welsh Government and HCRW should review the portfolio of funding available to clinical researchers in Wales, considering all funding streams from Welsh bodies, the NIHR and other funders such as Cancer Research UK. The clinical research community should be consulted to ensure no gaps exist.

INFRASTRUCTURE

- The Welsh Government should work with universities to identify opportunities to expand infrastructure access, either through existing funding mechanisms or a new specific fund.
- The Welsh Government should assess the possibility of working with HDRUK and other stakeholders, to link NHS data and rapidly deliver value to patients, healthcare professionals, and the wider NHS – as the Scottish Government has done with the Innovative Healthcare Delivery Programme.

WORKFORCE

- The Welsh Government should publish the ongoing evaluation of Sêr Cymru by 2020 and regularly evaluate schemes aiming to increase research workforce capacity in Wales. This evaluation should include recommendations for Welsh research institutions to capitalise on the increased research workforce from Sêr Cymru and to increase the proportion of competitive medical research funding they attract.

- Welsh Government, HEIW and HCRW 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. This should include HCRW extending its Clinical Research Time Awards.

PATIENT ACCESS TO CLINICAL TRIALS

- NHS Wales, HCRW and the Welsh Government should work with clinicians and patients to optimise the tools and infrastructure that support clinicians to quickly find suitable research opportunities for their patients.
- HCRW should continue to support measures to expand the number of research studies available to patients across Wales, evaluating the effectiveness of the hub and spoke model. They should assess the processes and infrastructure of NHS Trusts and Boards where the percentage of patients who reported a discussion about research is very low. This assessment should include involvement of patients locally to discover issues and possible solutions before targeting additional resources to these bodies.
- The Welsh Government should continue to work closely with other UK nations to ensure that permission streamlining work of HRA is realised and operates smoothly

4. APPENDIX – DETAILED MEDICAL RESEARCH LANDSCAPE IN WALES

Role of the Chief Scientific Adviser

The role of the Chief Scientific Adviser is to provide independent scientific advice to the First Minister and lead the development of the Welsh Government's science policy.

The Chief Scientific Adviser is supported by the Science Advisory Council for Wales (SACW). The SACW helps shape, review and monitor science policy in Wales, reporting directly to the Chief Scientific Adviser rather than to ministers.[167]

Role of the Chief Scientific Adviser (Health)

The role of the Chief Scientific Adviser (Health) is to provide the Welsh Government and ministers with advice relating to health science.

The Chief Scientific Adviser (Health) acts as the professional lead for Genomics, Imaging, Pathology and Healthcare Science, and for Healthcare Scientists in NHS Wales

Welsh Government ministerial responsibilities

Responsibilities of the Cabinet Secretary for Economy, Infrastructure and Transport:

- Science: development of science policy, including day to day liaison with the Chief Scientific Adviser for Wales and the National Science Academy;
- Life Sciences;
- Research and Innovation: research and development, knowledge transfer and commercialisation; maximising research and innovation incomes; and Research Centres of Excellence;
- Development, retention and attraction of higher level research students for Wales.

Responsibilities of the Cabinet Secretary for Health and Social Services:

- Research and development in health and social care;
- Medical workforce training and development with the exception of years 1-5 of University Education for Doctors.

Welsh Government senior official responsibilities

Remit of the Chief Scientific Adviser[168]:

- to promote science, technology, engineering and mathematics, known as the STEM subjects;
- lead the scientific effort within the Welsh Government;
- review scientific advice provided to the Welsh Government;
- engage with the wider scientific community;

- bring together businesses, the Welsh Government and universities for their mutual benefit and to expand our economy;
- work with the Chief Scientific Adviser (CSA) and Departmental Chief Scientific Advisers in the UK Government;
- act as Head of Profession for science and technology staff in Wales and particularly in the Welsh Government.

Remit of the Chief Scientific Adviser for Health[169]:

- providing Welsh government and ministers with advice relating to health science;
- professional lead for Healthcare Scientists in NHS Wales.

Remit of the Chief Medical Officer for Wales:

- leads public health policy and programmes, with the aim of improving health and reducing health inequalities;
- leads the clinical contribution in Wales to improving the quality of healthcare and patient outcomes;
- leads the medical profession in Wales, having key roles in medical regulation, education and training, standards and performance;
- maintains appropriate UK and international links, working with other UK Chief Medical Officers, government departments and organisations.

The aims, roles and infrastructure of Health and Care Research Wales

To achieve its vision be internationally recognised for our excellent health and social care research, HCRW aims to[170]:

- ensure public involvement and engagement is central to what we do and visible in all elements of it;
- ensure our work is aligned to Welsh Government policy and has real impact;
- fully integrate our infrastructure and programmes across health and social care;
- invest in areas in which Wales excels and is unique;
- increase capacity in health and social care research in Wales;
- develop systems that ensure excellent delivery and maximise the use of resources.

HCRW provides infrastructure to support and increase capacity in research and development (see Figure 3). This includes:

- *Research Centres:* Wales has five Research Centres with an all-Wales remit, to support multi-disciplinary health and social care research teams. The Centres are: ageing and dementia; mental health; cancer; primary and emergency care; population health and wellbeing.
- *Research Units:* Similar to the Centres, Research Units support health and social care research teams to address areas of public need. However, Units have a remit to focus on more specific areas of research, such as certain points on the translational spectrum and/or areas of emerging strength in Wales. The Research Units are: brain

repair; kidney; and diabetes. (The remits of Research Centres and Units can be found in Box 7[171])

- *Infrastructure Support Groups:* Infrastructure Support Groups offer specialist support to researchers within the Health and Care Research Wales infrastructure. They do this by developing work packages and activities that are both tailored and responsive to the support requirements of other Health and Care Research Wales organisations. Researchers can access support in the areas of genetics/genomics, health economics and data linkage techniques.[172]
- *Clinical Trials Units:* Clinical Trials Units offer expertise in specialist trial design, conduct and analysis to researchers in Wales and beyond. They facilitate trial conduct and ensure that regulatory and governance requirements are met. Through Health and Care Research Wales, the Welsh Government invests in three Clinical Trials Units: Centre for Trials Research at Cardiff University; North Wales Organisation for Randomised Trials in Health; Swansea Trials Unit.

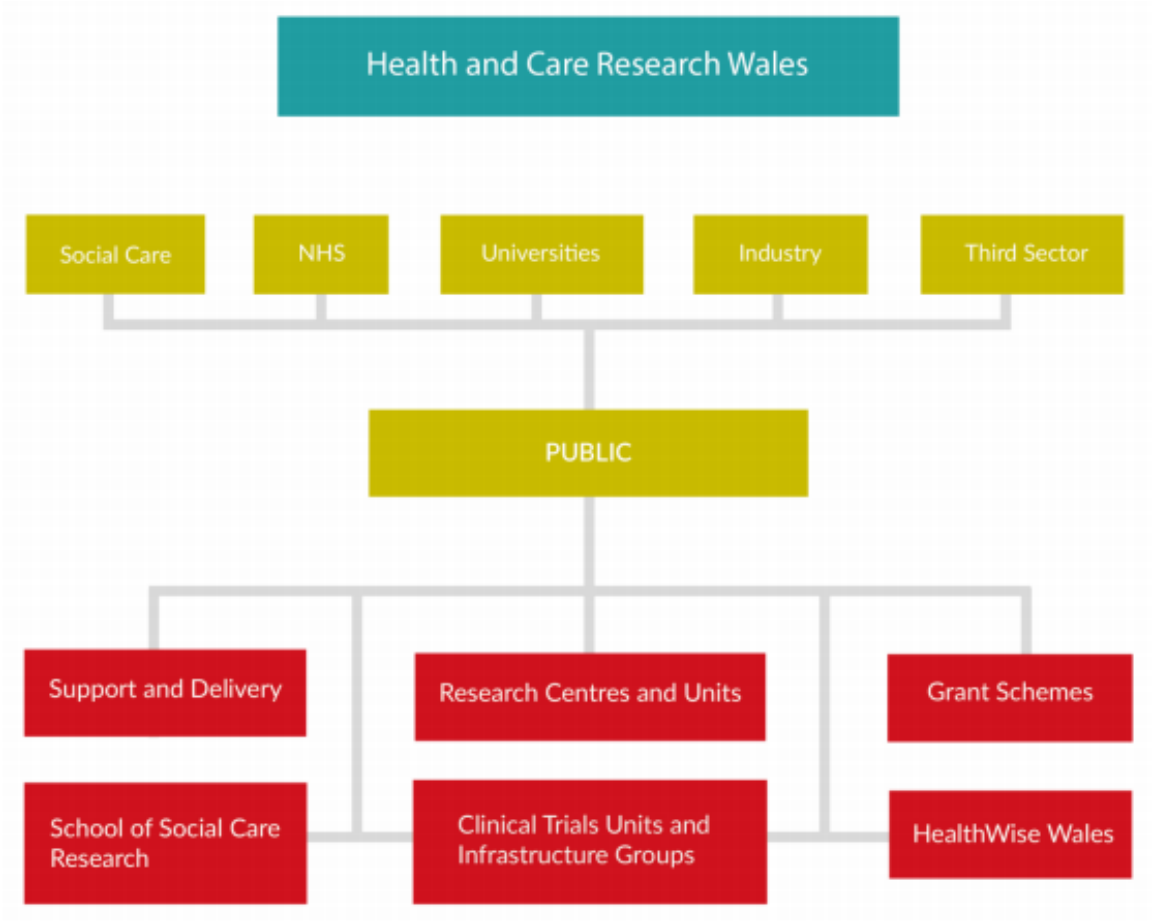

Figure 3: Map of the stakeholders of the HCRW and the infrastructure for which it has oversight

Box 7 – Remits of Research Centres and Research Units

The remit of each Centre, within its area of expertise, is to:

- be a 'pillar of research excellence';
- drive research development and delivery across the translational spectrum;
- generate grant funding;
- build capacity and capability;
- foster collaboration across sectors;
- engage with and involve the public in research; and
- facilitate translation of research.

Within their area of research, Research Units will:

- drive research development and delivery;
- generate grant funding;
- build capacity and capability;
- foster collaboration across sectors;
- engage with and involve the public in research;
- facilitate translation of research.

5. REFERENCES

[1] Cancer Research UK. Cancer incidence for all cancers combined 2015. https://bit.ly/2xumDV5 Accessed September 2018.
[2] Welsh Government consultation on the foundation of Tertiary Education and Research Commission Wales. https://bit.ly/2Jttamt. Accessed October 2018
[3] Welsh Government (2018) Reid Review. https://bit.ly/2CmXcrA. Accessed October 2018
[4] Welsh Government (2016) Review of higher education funding and student finance arrangements: final report. https://bit.ly/2CD2K1X. Accessed October 2018
[5] Welsh Government (2011) Science for Wales. https://bit.ly/2J42lWS. Accessed October 2018
[6] MRC recipients of research funding (2018) https://bit.ly/2Ae2Zyi. Accessed October 2018
[7] HEFCW (2012) HEFCW's Funding Allocations 2012/13. https://bit.ly/2CDwRqm. Accessed October 2018
[8] National Assembly for Wales, External Affairs and Additional Legislation Committee (2018) Wales' future relationship with Europe, Part one: a view from Wales. https://bit.ly/2Ae3pES. Accessed October 2018
[9] Technopolis Group (2017) The role of EU funding in UK research and innovation. https://bit.ly/2xWG9Z8. Accessed October 2018
[10] Welsh Government (2011) Science for Wales. https://bit.ly/2J42lWS. Accessed October 2018
[11] Health and Care Research Wales (2018) Local Support & Delivery Funding Allocations 2012/13 - 2017/18. https://bit.ly/2Cnh3qD. Accessed October 2018
[12] Welsh Government (2017) Science for Wales 2017. https://bit.ly/2NoszZx. Accessed October 2018
[13] Quality Health (2013) Wales Cancer Patient Experience Survey 2013: National Report. https://bit.ly/2yIpCsA. Accessed October 2018.
[14] Welsh Government (2017) Wales Cancer Patient Experience Survey 2016: National Report. https://bit.ly/2P5uKRR. Accessed October 2018.
[15] Welsh Government (2017) Wales Cancer Patient Experience Survey 2016: National and Board Reports. https://bit.ly/2PEaHqu. Accessed October 2018.
[16] Cancer Research UK. Cancer incidence for all cancers combined 2015. https://bit.ly/2xumDV5 Accessed September 2018.
[17] Smittenaar CR, Petersen KA, Stewart K, Moitt N (2016) Cancer incidence and mortality projections in the UK until 2035. https://bit.ly/2QmPMJ6. Accessed November 2018
[18] Wales Cancer Partnership figures. Source: NCRI partnership
[19] Cancer Research UK (2011) Cancer Building the Ideal Environment for Medical Research: Cancer Research UK's analysis of the components required to conduct world-class research across the UK. https://bit.ly/2DcD79s. Accessed September 2018
[20] UK Government (2017) Life Sciences Industrial Strategy – A report to the Government from the life sciences sector. https://bit.ly/2yWHuTY (Accessed September 2018)
[21] Welsh Government (2016) Taking Wales Forward 2016-2021. https://bit.ly/2L4ZoZw. Accessed November 2018
[22] Welsh Government (2017) Prosperity for All: the national strategy. https://bit.ly/2KTXXxF. Accessed November 2018
[23] Welsh Government (2018) A Healthier Wales: our plan for Health and Social Care. https://bit.ly/2sTpjs2. Accessed November 2018
[24] Welsh Government (2017) Science. https://bit.ly/2zzkDL4. Accessed November 2018
[25] Welsh Government (2017) Science for Wales 2017. https://bit.ly/2NoszZx. Accessed October 2018
[26] Welsh Government (2016) Towards 2030: A framework for building a world-class post-compulsory education system for Wales. https://bit.ly/2PPWMRT. Accessed November 2018.
[27] Welsh Government (2016) The Review of Higher Education Funding and Student Finance Arrangements in Wales. https://bit.ly/2OrvEDN. Accessed November 2018.
[28] Welsh Government (2017) Review of government funded research and innovation in Wales begins. https://bit.ly/2SPTXyL. Accessed November 2018.
[29] Welsh Government (2018) Reid Review. https://bit.ly/2CmXcrA. Accessed October 2018
[30] Welsh Government (2016) Cancer Delivery Plan for Wales 2016-2020. https://bit.ly/2QpiSro. Accessed November 2018.

[31] Garau M, Mordoh A, Sussex J. (2011) Exploring the Interdependency between Public and charitable medical Research. https://bit.ly/2NBJYsT. Accessed November 2018.
[32] Shah K et al. (2014) Exploring the Interdependencies of Research Funders in the UK. https://bit.ly/2DnC9qj. Accessed November 2018.
[33] UKRI Strategic Prospectus (2018) https://bit.ly/2Il1z6O. Accessed October 2018.
[34] UK Government (2018) Research and innovation funding allocation: 2017-2021. https://bit.ly/2OEMaS3. Accessed November 2018.
[35] UKRI (2018) Strategic Prospectus: Building the UKRI Strategy. https://bit.ly/2Il1z6O. Accessed October 2018.
[36] Welsh Government (2017) Science for Wales 2017. https://bit.ly/2NoszZx. Accessed October 2018
[37] Welsh Government (2017) Science for Wales 2017. https://bit.ly/2NoszZx. Accessed October 2018
[38] Welsh Government (2017) New commission with responsibility for higher and further education in Wales to be created. https://bit.ly/2MRVL5T. Accessed November 2018.
[39] Welsh Government (2017) Prosperity for All: the national strategy. https://bit.ly/2KTXXxF. Accessed September 2018
[40] Welsh Government (2018) A Healthier Wales: our Plan for Health and Social Care. https://bit.ly/2t19EqF. Accessed September 2018
[41] HCRW (2018) Health and Care Research Wales 2020 and beyond. https://bit.ly/2JGUFtT. Accessed November 2018.
[42] UK Government (2018) Research and innovation funding allocation: 2017-2021. https://bit.ly/2OEMaS3. Accessed November 2018.
[43] Welsh Government (2018) Reid Review. https://bit.ly/2CmXcrA. Accessed October 2018
[44] Scottish Government (2018) Innovation and Investment Hubs. https://bit.ly/2Pe2iht. Accessed November 2018.
[45] Welsh Government (2011) Science for Wales. https://bit.ly/2J42lWS. Accessed October 2018
[46] HCRW (2018) Health and Care Research Wales Research Directory. https://bit.ly/2PFbV4Y. Accessed November 2018.
[47] ABPI (2018) ABPI Cymru Wales. https://bit.ly/2D71UtZ. Accessed November 2018.
[48] Universities Wales (2013) The Economic Impact of Higher Education in Wales. https://bit.ly/2F8dPu6. Accessed November 2018.
[49] Welsh Government (2016) Review of higher education funding and student finance arrangements: final report. https://bit.ly/2CD2K1X. Accessed October 2018
[50] MRC recipients of research funding (2018) https://bit.ly/2Ae2Zyi. Accessed October 2018
[51] MRC recipients of research funding (2018) https://bit.ly/2Ae2Zyi. Accessed October 2018
[52] MRC recipients of research funding (2018) https://bit.ly/2Ae2Zyi. Accessed October 2018
[53] MRC recipients of research funding (2018) https://bit.ly/2Ae2Zyi. accessed October 2018
[54] MRC recipients of research funding (2018) https://bit.ly/2Ae2Zyi. Accessed October 2018
[55] Welsh Government (2016) Delivering Science for Wales 2015-16: Annual report on our strategy for science, https://bit.ly/2J16fzK. Accessed October 2018
[56] Welsh Government (2017) Science for Wales 2017. https://bit.ly/2NoszZx. Accessed October 2018
[57] Welsh Government (2017) Science for Wales 2017. https://bit.ly/2NoszZx. Accessed October 2018
[58] Welsh Government (2011) Science for Wales. https://bit.ly/2J42lWS. Accessed October 2018
[59] Russell Group (2010) Staying on top: The challenge of sustaining world-class higher education in the UK. https://bit.ly/2yi2EJq. Accessed October 2018
[60] For case studies on the impact of QR funding see also: Empowering UK universities: how strategic institutional support helps research thrive, Wellcome (2018) https://bit.ly/2KNqL6V. Accessed November 2018.
[61] Wellcome (2018) Empowering UK universities: how strategic institutional support helps research thrive. https://bit.ly/2KNqL6V. Accessed October 2018
[62] UK Government (2016) Autumn Statement 2016. https://bit.ly/2f4veU6. Accessed October 2018.
[63] UK Government (2017) Autumn Budget 2017. https://bit.ly/2jdAdnN. Accessed November 2019.
[64] Welsh Government (2016) Review of higher education funding and student finance arrangements: final report. https://bit.ly/2CD2K1X. Accessed October 2018
[65] Welsh Government (2018) Reid review. https://bit.ly/2CmXcrA. Accessed October 2018
[66] HEFCW (2017) Funding for higher education in 2017/18. https://bit.ly/2EoUaWA. Accessed October 2018.
[67] HEFCW (2017) Funding for higher education in 2017/18. https://bit.ly/2EoUaWA. Accessed October 2018
[68] HEFCW (2017) Funding for higher education in 2017/18. https://bit.ly/2EoUaWA. Accessed October 2018
[69] HEFCW. The QR Funding Formula. https://bit.ly/2P0lhv9. Accessed October 2018.

[70] HEFCW (2012) Funding Allocations 2012/13. https://bit.ly/2CDwRqm. Accessed October 2018
[71] HEFCW (2013) Funding Allocations 2013/14. https://bit.ly/2NLh5KU. Accessed October 2018
[72] HEFCW (2014) Funding Allocations 2014/15. https://bit.ly/2P4pNIW. Accessed October 2018
[73] HEFCW (2015) Funding Allocations 2015/16. https://bit.ly/2PbDje5. Accessed October 2018
[74] HEFCW (2016) Funding Allocations 2016/17. https://bit.ly/2Ah2Km9. Accessed October 2018
[75] HEFCW (2017) Funding Allocations 2017/18. https://bit.ly/2GU362y. Accessed October 2018
[76] Welsh Government (2017) Science for Wales 2017. https://bit.ly/2NoszZx. Accessed October 2018
[77] HEFCW (2012) Funding Allocations 2012/13. https://bit.ly/2CDwRqm. Accessed October 2018
[78] Scottish Funding Council (2017) Outcome Agreement Funding for Universities – Final Allocations for AY 2017-18. https://bit.ly/2yVeZDT. Accessed November 2018.
[79] Scottish Funding Council [Archive] Earlier funding decisions. https://bit.ly/2ySPuD0. Accessed November 2018.
[80] HEFCW (2017) Funding Allocations 2017/18. https://bit.ly/2GU362y. Accessed October 2018
[81] HEFCW (2012) Funding Allocations 2012/13. https://bit.ly/2CDwRqm. Accessed October 2018
[82] Welsh Government (2015) Growing research in Wales. https://bit.ly/2EsbMkk. Accessed October 2018
[83] Welsh Government (2017) Science for Wales 2017. https://bit.ly/2NoszZx. Accessed October 2018
[84] HEFCW (2018) Strategic development funding. https://bit.ly/2PAe8ic. Accessed November 2018
[85] HEFCW (2017) Funding Allocations 2017/18. https://bit.ly/2GU362y. Accessed October 2018
[86] HEFCW (2018) Funding Allocations 2018/19. https://bit.ly/2pTbM2G. Accessed October 2018
[87] Welsh Government (2016) The Review of Higher Education Funding and Student Finance Arrangements in Wales. https://bit.ly/2QZmfVR. Accessed October 2018
[88] HCRW (2018) Support and Delivery Funding and Activity Based Funding formula 2017/18 – overview. https://bit.ly/2PDvzhH. Accessed October 2018
[89] HCRW (2018) NHS R&D / Local Support & Delivery Funding Allocations 2012/13 - 2017/18. https://bit.ly/2Cnh3qD. Accessed October 2018.
[90] HCRW (2018) NHS R&D / Local Support & Delivery Funding Allocations 2012/13 - 2017/18. https://bit.ly/2Cnh3qD. Accessed October 2018.
[91] HCRW (2018) Local Support and Delivery Funding 2018/19. https://bit.ly/2CSnDX2. Accessed October 2018
[92] HCRW (2018) Partner Funding Schemes. https://bit.ly/2REv8nY. Accessed November 2018
[93] HCRW (2018) Our Funding Schemes. https://bit.ly/2sK9Uc7. Accessed November 2018
[94] UKRI (2018) Horizon 2020 underwrite guarantee update. https://bit.ly/2PRPOJg. Accessed October 2018.
[95] UK Government (2018) UK Position Paper on the Ninth EU Framework Programme for Research and Innovation (FP9). https://bit.ly/2PDxK53. Accessed October 2018.
[96] Welsh Government (2017) Science for Wales 2017. https://bit.ly/2NoszZx. Accessed October 2018
[97] Technopolis Group (2017) The role of EU funding in UK research and innovation. https://bit.ly/2xWG9Z8. Accessed October 2018
[98] Technopolis Group (2017) The role of EU funding in UK research and innovation. https://bit.ly/2xWG9Z8. Accessed October 2018
[99] Welsh Assembly External Affairs and Additional Legislation Committee (2018) How is the Welsh Government preparing for Brexit? https://bit.ly/2NMMQTN. Accessed October 2018
[100] Welsh Government (2018) Welsh Government Response to Recommendations from the External Affairs and Additional Legislation Committee Report: How is the Welsh Government preparing for Brexit? https://bit.ly/2QZqHnx. Accessed October 2018
[101] Life Sciences Hub (2018) https://lshubwales.com/ Accessed October 2018
[102] UK Government (2017) Record boost to R&D and new transport fund to help build economy fit for the future. https://bit.ly/2zZht3r. Accessed October 2018
[103] ONS (2018) Gross domestic expenditure on research and development, UK: 2016. https://bit.ly/2EzQL1E. Accessed October 2018
[104] Welsh Government (2018) *Reid review*. https://bit.ly/2CmXcrA. Accessed October 2018
[105] AMRC (2017) Medical Research Charities: Investing in research. https://bit.ly/2pZieoQ. Accessed October 2018
[106] Source: AMRC grants database
[107] Source: AMRC grants database
[108] Wales Cancer Partnership figures. Source: NCRI partnership
[109] HRCS Online. UK Health Research Analysis 2014. https://bit.ly/2ylBJg2. Accessed October 2018
[110] HEFCW (2010) Recurrent Grant 2010/11. https://bit.ly/2NQyBh6. Accessed October 2018
[111] Source: AMRC grants database

[112] Cardiff University (2018) Research Equipment. https://bit.ly/2youfso. Accessed October 2018
[113] GW4 (2018) http://gw4.ac.uk/. Accessed October 2018
[114] HCRW (2005) Strategic Development Fund. https://bit.ly/2CmI25E. Accessed October 2018
[115] HEFCW. Reconfiguration and collaboration. https://bit.ly/2NIXzPn. Accessed October 2018
[116] HEFCW (2007) Review of the merger between Cardiff University and the University of Wales College of Medicine. https://bit.ly/2P5XycX. Accessed October 2018.
[117] HCRW. Research Infrastructure Map. https://bit.ly/2QT6xvh. Accessed October 2018.
[118] Welsh Government (2017) Science for Wales 2017. https://bit.ly/2NoszZx. Accessed October 2018
[119] UKCRC (2017) Registered CTUs. https://bit.ly/2Cpr8n8. Accessed October 2018.
[120] Velindre Cancer Centre. Clinical Trials Unit. https://bit.ly/2Cn13os. Accessed October 2018.
[121] Cardiff University. CUBRIC. https://bit.ly/2RWl8XZ. Accessed October 2018.
[122] HCRW. Research Infrastructure Map. https://bit.ly/2QT6xvh. Accessed October 2018.
[123] Cardiff University (2018) Wales Research and Diagnostic PET Imaging Centre https://bit.ly/2CMARF3. Accessed October 2018
[124] ECMC Network. https://bit.ly/2RYSJRt. Accessed October 2018.
[125] Welsh Government (2017) Science for Wales 2017. https://bit.ly/2NoszZx. Accessed October 2018
[126] Jones KH, Ford DV, Lyons RA (2017) The SAIL Databank: 10 years of spearheading data privacy and research utility, 2007-2017. Swansea University. doi: http://dx.doi.org/10.23889/ sail-databank.1001101
[127] Welsh Government (2017) Science for Wales 2017. https://bit.ly/2NoszZx. Accessed October 2018
[128] Cardiff University. HealthWise Wales. https://bit.ly/2yIIR5j. Accessed October 2018
[129] HealthWise Wales. https://bit.ly/2yGUwla. Accessed September 2018.
[130] Halligan PW, Bright L (2015) The Case for Growing STEMM Research Capacity in Wales. https://bit.ly/2zwQFHH. Accessed November 2018.
[131] Welsh Government (2017) Science for Wales 2017. https://bit.ly/2NoszZx. Accessed October 2018
[132] Universities Wales (2014) Research Excellence Framework 2014.
[133] HCRW (2017) Support & Delivery Service 2017-22. https://bit.ly/2OuOS0l. Accessed November 2018
[134] HCRW (2018) Our Funding Schemes. https://bit.ly/2sK9Uc7. Accessed November 2018
[135] HCRW (2018) Partner Funding Schemes. https://bit.ly/2REv8nY. Accessed November 2018
[136] Technopolis Group (2017) The role of EU funding in UK research and innovation. https://bit.ly/2xWG9Z8. Accessed October 2018
[137] Welsh Government (2015) Growing Research in Wales. https://bit.ly/2EsbMkk. Accessed November 2018
[138] Welsh Government (2017) Science for Wales 2017. https://bit.ly/2NoszZx. Accessed October 2018
[139] Welsh Government (2017) Science for Wales 2017. https://bit.ly/2NoszZx. Accessed October 2018
[140] Welsh Government (2017) Science for Wales 2017. https://bit.ly/2NoszZx. Accessed October 2018
[141] Welsh Government (2018) Ser Cymru Evaluation. https://bit.ly/2zusBoY. Accessed November 2018.
[142] Cancer Research UK (2018) Cancer Research UK position paper: The diagnostic workforce in Wales. https://bit.ly/2PO3EiE. November 2018.
[143] HCRW (2018) Research Directory: July 2018. https://bit.ly/2PFbV4Y. Accessed October 2018.
[144] STAMPEDE (2018) http://www.stampedetrial.org/. Accessed October 2018.
[145] STAMPEDE (2018) STAMPEDE August accrual report. https://bit.ly/2P3Y0Zf. Accessed October 2018
[146] NIHR (2014) National Institute for Health Research Clinical Research Network – Division One, Cancer Speciality, Supporting Information File. London: Department of Health
[147] Welsh Government (2017) Wales Cancer Patient Experience Survey 2016: National Report. https://bit.ly/2P5uKRR. Accessed October 2018.
[148] Quality Health (2016) National Cancer Patient Experience Survey 2016: National Results Summary. https://bit.ly/2PzPi1W Accessed October 2018.
[149] Quality Health (2013) Wales Cancer Patient Experience Survey 2013: National Report. https://bit.ly/2yIpCsA. Accessed October 2018.
[150] NHS England (2013) Cancer Patient Experience Survey 2013: National Report. https://bit.ly/2J7iw5X. Accessed October 2018.
[151] Scottish Government (2016) Scottish Cancer Patient Experience Survey 2015/16: Full report. https://bit.ly/2EuqUgX. Accessed October 2018.
[152] HSC Public Health Agency (2015) Northern Ireland Cancer Patient Experience Survey: 2015 All Trusts Report. https://bit.ly/29bZlcR Accessed October 2018.
[153] Wales Cancer Intelligence and Surveillance Unit (2018) Cancer Incidence in Wales. https://bit.ly/2CPrrZe. Accessed October 2018

[154] Baris A. Ozdemir, Alan Karthikesalingam, Sidhartha Sinha, Jan D. Poloniecki, Robert J. Hinchliffe, Matt M. Thompson, Jonathan D. Gower, Annette Boaz and Peter J. E. Holt. *Research Activity and the Association with Mortality* (2015) https://bit.ly/2DpAvEj. Accessed November 2019
[155] Cancer Research UK (2018) Find a clinical trial. https://www.cancerresearchuk.org/about-cancer/find-a-clinical-trial. Accessed October 2018
[156] UK Clinical Trials Gateway (2018) https://www.ukctg.nihr.ac.uk/ Accessed October 2018
[157] HCRW (2018) Research Studies in Wales. https://bit.ly/2pmeQE2. Accessed October 2018
[158] UK Clinical Trials Gateway (2018) https://www.ukctg.nihr.ac.uk/ Accessed October 2018
[159] Cancer Research UK (2018) Find a clinical trial. https://www.cancerresearchuk.org/about-cancer/find-a-clinical-trial. Accessed October 2018
[160] HealthWise Wales (2018) https://www.healthwisewales.gov.wales/homepage/.
[161] HCRW (2017) Support & Delivery Service 2017-22: Strategic Framework. https://bit.ly/2OuOS0l. Accessed October 2018.
[162] HCRW (2018) Support and Delivery. https://bit.ly/2Ox6zMI. Accessed October 2018.
[163] HCRW (2018) Research Delivery Staff. https://bit.ly/2POC5BR. Accessed October 2018.
[164] National Institute for Social Care and Health Research (2011) Permissions Coordinating Process. https://bit.ly/2QTJkJc. Accessed October 2018.
[165] National Institute for Social Care and Health Research. NHS Wales - R&D Office Functions. https://bit.ly/2yIfKze. Accessed October 2018.
[166] Integrated Research Application System (2018) HRA and HCRW Approval. https://bit.ly/2EqB02h /. Accessed October 2018
[167] Welsh Government (2018) SACW: What we do. [ONLINE] Available at: https://bit.ly/2pljxhD Accessed September 2018
[168] Welsh Government (2018) Chief Scientific Adviser for Wales. https://bit.ly/2xAolDg. Accessed September 2018
[169] Welsh Government (2018) Chief Scientific Adviser (Health). https://bit.ly/2NXJMs8. Accessed September 2018
[170] HCRW (2018) Aims and Objectives. https://bit.ly/2NR7bvz. Accessed November 2018.
[171] HCRW (2018) Research Studies in Wales. https://bit.ly/2pmeQE2. Accessed November 2018.
[172] HCRW (2018) Infrastructure Support Groups. https://bit.ly/2NTiljq. Accessed November 2018.