

BENCH TO BEDSIDE

BUILDING A COLLABORATIVE MEDICAL RESEARCH ENVIRONMENT IN WALES

EXECUTIVE SUMMARY



CANCER
RESEARCH
UK

EXECUTIVE SUMMARY

Around 19,000 people are diagnosed with cancer every year in Wales¹. 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 Reid³ and Diamond⁴ 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 nations⁵ 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 2012/13⁷. 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 politicians⁸ are concerned about the impact of leaving the EU on research funding. Wales is the biggest recipient of EU structural funds of any UK nation⁹ and EU funds have been crucial to the Sêr Cymru¹⁰ 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 years¹¹. However, interviewees raised concerns about National Institute for Health Research (NIHR) funding access. 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 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.

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 funding¹² to Wales between 2011 and 2017.

There are, however, worries about the impact of leaving the European Union on the research workforce. It is crucial that the UK and EU 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 and 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. However, interviewees reported that it is becoming harder to recruit patients to trials in 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 2013¹³ and 2016¹⁴.

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 CPES¹⁵ 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.

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/2J42IWS>. 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/2J42IWS>. 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 2017.