

# Health and Care Research Wales Annual Report 2017-18



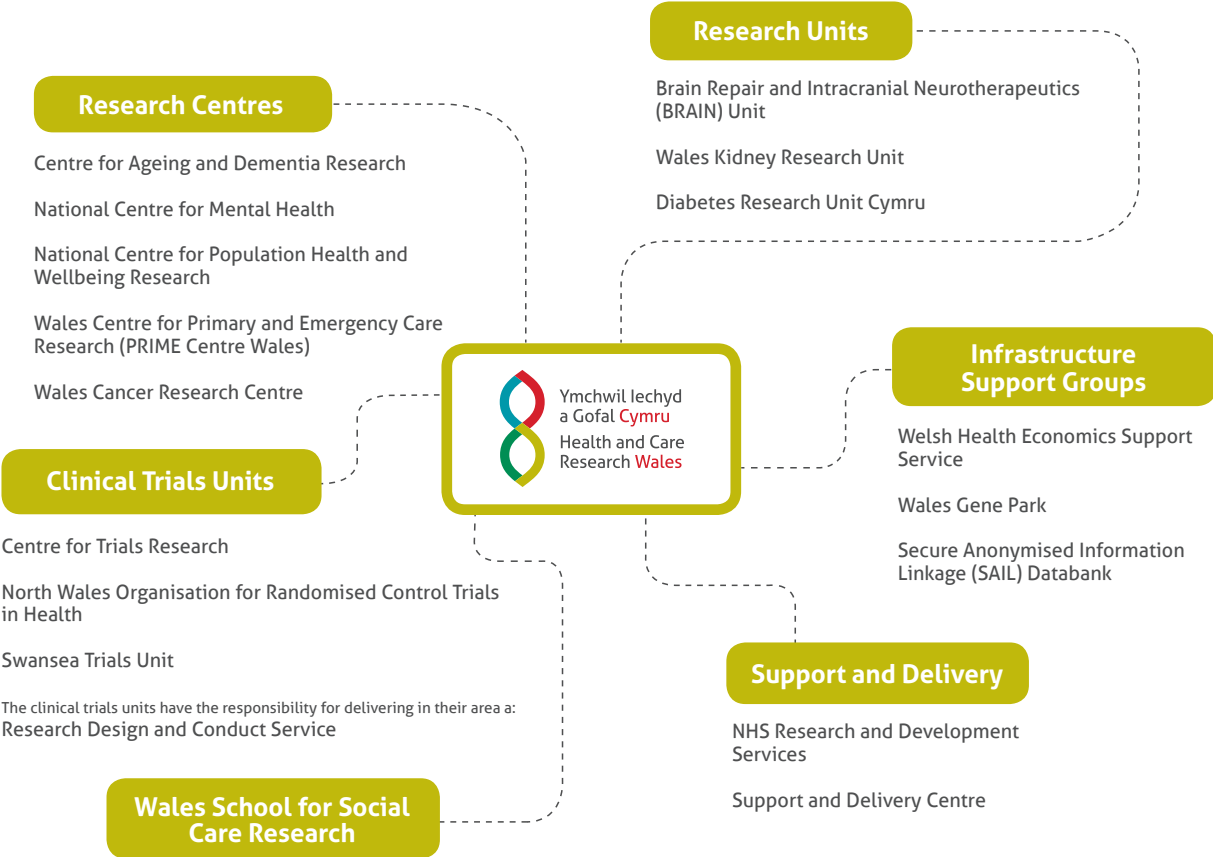
Mae'r ddogfen hon hefyd ar gael yn Gymraeg





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# Research Infrastructure Map



# Foreword

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**Wales is a nation looking to the future on every front.**

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Dr Frank Atherton  
Chief Medical Officer  
for Wales

I'm very pleased to endorse the publication of the Health and Care Research Wales Annual Report for 2017-18. It was a special year as we marked the third anniversary of the launch of Health and Care Research Wales and it has been truly exciting to see its ambitions become reality. Wales is a nation looking to the future on every front. You only have to look at the Wellbeing of Future Generations Act or Prosperity for All, the Welsh Government's national strategy, to see the vision and values we have as a nation.

The fact that research features so prominently in both Prosperity for All and A Healthier Wales - the new national plan for health and social care - speaks both to how vital research is to our futures and to the Welsh Government's recognition of the efforts made by our research community.

There is no doubt that the launch of Health and Care Research Wales in 2015 has been central to the increasing profile of health and social care research in Wales. Putting research evidence at the heart of health and care decision making has never been so important, and I am delighted to see the health and care research community stepping up to the challenge of producing research that matters – research that informs and improves our decision making, improves the health and wellbeing of the population, and helps future-proof our health and care services both for now and for generations to come.

# Introduction

We are Wales' national organisation for health and social care research, funded by the Welsh Government. Our 2017-18 annual report shows the strides we've taken towards our vision of Wales as a country internationally recognised for its excellent health and social care research, since our launch in 2015.

## For the people of Wales, with the people of Wales

The direct involvement of the people of Wales in all that we do and fund ensures that the research we support brings benefits for the health, wellbeing and prosperity of people in Wales and beyond. We strengthened this in 2017-18, contributing to the development of new UK-wide Standards for Public Involvement in Research. Our Public Involvement Delivery Board will play a major role in our application of the Standards to further improve and broaden involvement across Health and Care Research Wales programmes and initiatives.

HealthWise Wales, our flagship initiative to better understand health and wellbeing needs in Wales, has a growing role in increasing public engagement and involvement with all our research. That complements our success in raising the profile of research, with major growth in our social media activity and following, website visitors and media coverage of our researchers, research and infrastructure. Our standing in the Research and Development (R&D) world has also risen, with 2018 seeing Wales host both the UK's health research conference, the NHS R&D Forum, and an international meeting of health funders, the Ensuring Value in Research Forum.

## Investing in people and resources

Core to our work is the research development infrastructure. This year's report demonstrates the diversity of the research groups we support, with the impact of their work highlighted in our Spotlight section. This includes work from the Wales Cancer Research Centre, the Secure Anonymised Information Linkeage Databank, the North Wales Organisation for Randomised Trials in Health and the Diabetes Research Unit Cymru, but it is gratifying that we could have chosen any of our infrastructure groups to show the value of our ongoing investment.

At the frontline of research, the Support and Delivery Service is critical to delivering high quality research that addresses people's needs across a range of care settings. In 2017-18 we saw more studies open than ever before, with initiatives to speed up research study approvals and set-up. At both a practical and a strategic level, we continue to collaborate and align with partners within the Welsh Government, across the UK and beyond, with greater alignment of research with innovation and improvement a key future focus. All of this helps build a Wales that is a go-to location for global research programmes, international researchers and commercial research.

This year has also seen a step change in social care research with the launch of the Social Care Research and Development Strategy for Wales 2018-2023. It is great to see the Wales School for Social Care Research collaborating effectively with researchers, social care providers and Social Care Wales. Their combined efforts are building the social care research capacity Wales needs to advance evidence-based care provision for the future.

## Funding important, quality research

The potential impact and real-world utility of our 2017-18 funding outcomes is clear from the project titles alone and here we report on the awards made through our competitive grant schemes. In doing so we'd like to acknowledge the efforts of our All Wales Prioritisation Panels and Research Funding Boards. They ensure the work we fund meets public, practice and policy needs while building capacity and maintaining quality.

2017-18 was also the year we said goodbye to our Director, Professor Jonathan Bisson. Jon was instrumental in the creation and the launch of Health and Care Research Wales, which has built strongly on the foundations laid by previous Directors and our predecessor organisations, Wales Office of Research and Development for Health and Social Care (WORD) and the National Institute for Social Care and Health Research (NISCHR).

Our next Director, due to be appointed in 2018-19, will be able to draw on this year's light touch review of our operations and activities in shaping our strategic direction and future investments. In the interim we're pushing forward with new funding calls for our Research Funding Scheme, Social Care Fellowships, Research for Patient and Public Benefit and Clinical Research Time Awards. There will also be new calls for senior research leaders and specialty leads, and continued access to key National Institute for Health Research (NIHR) programmes for our researchers.

We will also follow through on our commitment to an open call for new infrastructure awards early in 2019, and continue working to establish seamless 'One Wales' research services for sponsors, researchers and the public. You can expect to see new research prioritisation exercises and dissemination activity as we work to further raise the profile and uptake of the work we fund. It'll be a busy year for all!

The benefits of health and care research are profound and its importance cannot be underestimated, whether that be in preventing ill health, enhancing wellbeing, reducing inequalities, developing better treatments or shaping services. We are acutely aware of the challenges and opportunities posed by Brexit as we work to ensure not just a safe passage for health and care research in Wales but a climate that supports increasing success and prosperity for Wales.



Carys Thomas      Michael Bowdery  
 Joint Interim Directors, Health and Care Research Wales

# Strategic aims

**Our vision is for Wales to be internationally recognised for its excellent health and social care research that has a positive impact on the health, wellbeing and prosperity of the people in Wales.**



1

To ensure public involvement and engagement is central to what we do and visible in all elements of it.

2

To ensure our work is aligned to Welsh Government policy and has real impact.

3

To fully integrate our infrastructure and programmes across health and social care.

4

To invest in areas in which Wales excels and is unique.

5

To increase capacity in health and social care research in Wales.

6

To develop systems that ensure excellent delivery and maximise the use of resources.

# Involving the public 2017-18

**We believe that the people of Wales are central to ensuring the relevance and quality of the research we fund on their behalf. That's why we aim to involve and engage the public in all that we do.**

That starts at the top with the strategic input of our Public Involvement Delivery Board, set up in 2015. Made up of a majority of public members, and with a public chairperson, its role is to ensure the continual improvement and embedding of partnership working with the public across our own and our funded work.

The Board has been instrumental in growing public involvement and in developing the UK-wide Standards for Public Involvement in Research. Launched in March 2018, these aim to improve the quality and consistency of public involvement in research.

A result of our close collaboration with England's National Institute for Health Research (NIHR) and others on shared interests, our role in establishing these Standards has ensured that Wales' voice and field-leading experience contributed to their development. It also saw the Wales School for Social Care Research and CADR (the Centre for Ageing and Dementia Research) become one of the ten lead pilot sites in the UK testing the Standards.

We think the Standards are vital to further progressing public involvement, a longstanding strength of our grant schemes and infrastructure. Our next steps will be focused on developing use of the Standards to capture good practice in Wales and assessing progress on our expectations that all our fundees involve and engage the public as a core part of their work, building a culture of dialogue and partnership working with the public.

## Reviewing Wales' involvement network

Since 2006, the Involving People Network has been the bedrock of public involvement in Wales. With around 250 public volunteers across the country, the Network has enabled our Public Involvement and Engagement Team to link researchers with members of the public to develop better research.

We're now looking to expand on the Network's success by developing it into a more inclusive and diverse public involvement community. Based on consultation with Network members and a review of our services supporting involvement, this new development aims to provide a platform for many more people to get involved in research in Wales.

## Involving People Network 2017 - 18







Doeth am Iechyd  
Cymru  
HealthWise  
Wales

**HealthWise Wales is Wales' national project to better understand and improve our health and care. It aims to collect detailed health and lifestyle data from as many people in Wales as possible to inform new treatments, health policy and NHS and social care services long into the future.**

With more than 25,000 people across Wales already registered we also anticipate a growing role for the initiative in public engagement with

all our research. Its national role and reach provides a superb platform for engaging the people of Wales with the nature, shaping and conduct of health and care research. That broad engagement is going to be key to our ambition to foster a larger, more diverse community of the public involved in research.

Core to the project's aims is prioritising research questions and the creation of research ideas in partnership with the public. As we look to the future,

the broadening role of HealthWise Wales as the touchpoint for public engagement with research, will be a major focus.

It is the largest research study of its kind in Europe, collecting the information needed to better prevent and treat long term health conditions such as heart disease, diabetes and dementia.

## Case study

# The impact of public involvement

By involving more people in the design and delivery of research, the relevance of studies to people's needs, the quality of participants' experience and the clarity of trial information can be greatly improved.

The Centre for Trials Research, one of our funded trials units, completed a feasibility study in June 2017 trialling an innovative way of diagnosing bowel cancer; the second most common cause of cancer death in the UK.

Some abnormalities or cancerous cells in the colon are hard to detect and can be missed by standard colonoscopies, which play a large role in the diagnosis of bowel cancer and monitoring after treatment.

The CONSCOP study looked at whether spraying a bright blue dye throughout the large bowel during a colonoscopy would help to spot small growths that lie flat to the skin, known as serrated

polyps: by finding these hard-to-detect growths, more could potentially be removed, helping to improve survival rates.

Jeff Horton was diagnosed with bowel cancer in 2010 and the standard colonoscopy procedure was an important part of his diagnosis and follow up checks.

Jeff got involved in the CONSCOP study and felt his personal experience made a big difference to how the study was carried out.

"I felt I made a difference with this particular project from a lay perspective," said Jeff. "The new method, using a dye during a colonoscopy, took slightly longer than the standard procedure and I thought it was important that members of the public knew that. So, the information sheet that was sent out to patients was amended to take that into account."

"When looking over the evidence of how long it took, it was around an extra 12 to 15 minutes," said Georgina Gardner, the CONSCOP study trial manager. "That extra time could be the decider about whether a patient takes part in a trial or not. So, there were things like that the clinician hadn't thought of, and us as a trial team, about the effect that would have on the patient.

"We can be so focused on the clinical outcomes of the trial and how well we want it to work that it might not always be suitable for the patient."

The results of this feasibility study are now being analysed to help inform further studies into potential changes in practice for the detection and diagnosis of bowel cancer.

# Driving high quality research

## **Our centres, units and other infrastructure are where research into better care and treatments is developed.**

They concentrate world class people and resources to support high quality research that will benefit the health, wellbeing and prosperity of people in Wales.

Tasked with increasing Wales' high quality research output through external grant funding, our research centres and units cover a range of key health areas from mental health to kidney disease. Expected to publish high impact research and build research capacity in their field, they work with NHS and social care partners to ensure that their research addresses real-world needs and challenges.

Supporting them and the wider research community are our infrastructure support groups and clinical trials units. Data linkage, genetics and genomics and health economics infrastructure support groups provide on-demand expertise and specialist resources for researchers across health areas, while our clinical trials units provide clinical trial and study design expertise, ensuring efficient, safe delivery of studies generating high quality data.

## **Prolific output**

Since our launch in April 2015, the combined infrastructure has led on 532 successful grant awards, won over £139m research funding, and created more than 580 skilled jobs for Wales. That return on the £28.4m direct funding awarded, and 182 directly funded posts, demonstrates how our funding has leveraged success, driving research outputs of over 2,300 new research articles and 49,000 new tissue samples - with more than 15,200 tissue samples issued in support of translational research projects in Wales and beyond.

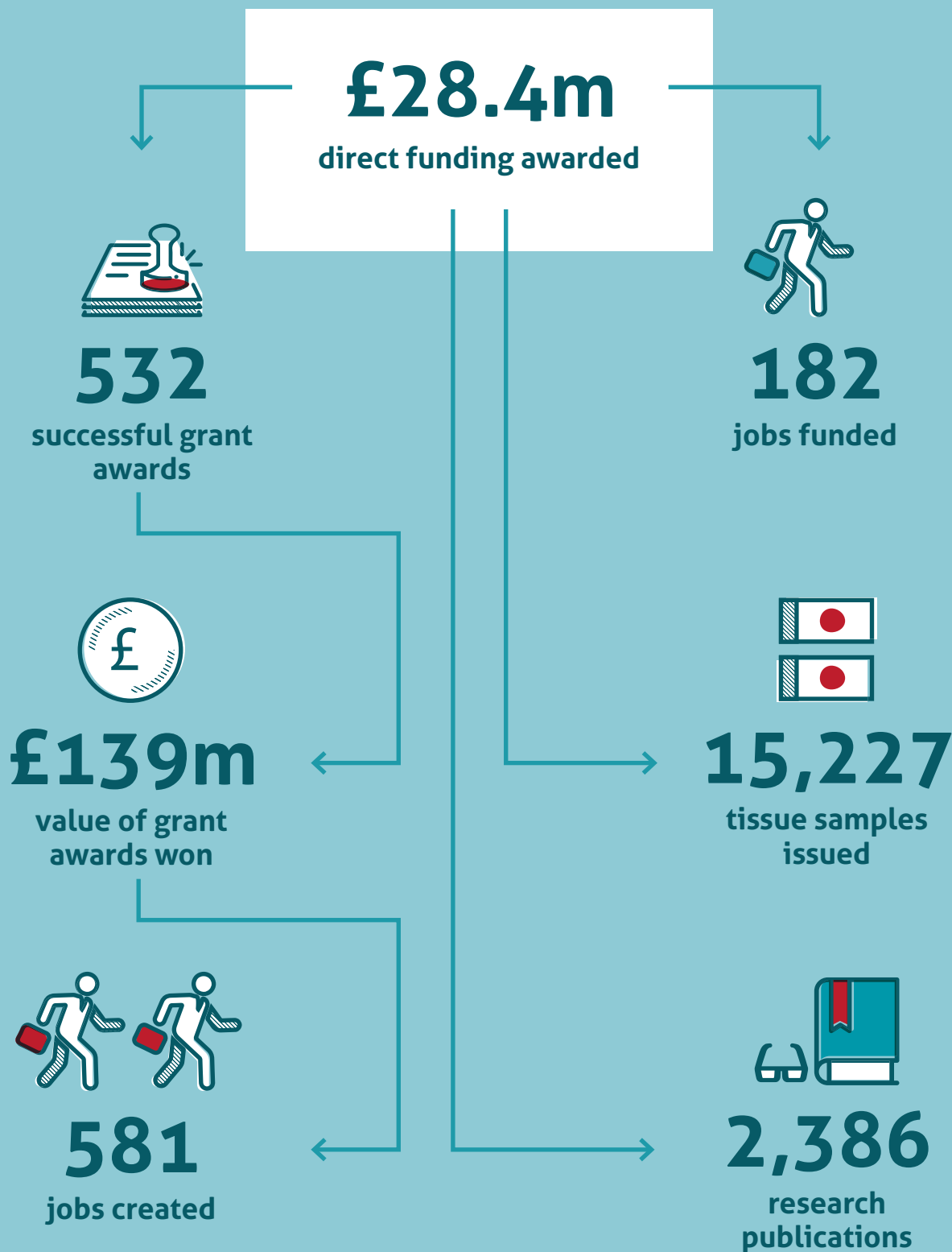
## **Looking forward**

Our research infrastructure provides the continuity and structured support critical to tackling the big questions that often require many years work to result in new treatments or benefits to society.

Our infrastructure strategy takes the long view, built on regular external, expert input. This year an international panel of experts appraised all our funded groups, finding the research quality, and return on our investment, to be excellent.

Their review was the basis for extension funding awards for all groups, and a £19m commitment from the Welsh Government to support further research over 2018-2020. Testament to the progress made, that funding will allow our infrastructure to build on their achievements so far and realise the full impact of their work. We will work closely with them to ensure that we fully capture the development and impact of the excellent work that they do.

# Clinical Research Infrastructure 2015-18



# Spotlight

The following pages highlight some of the stand-out examples of research from across our infrastructure, and its impact on people and services.

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**This is a very exciting time. Without this collaboration, this complex new treatment would not be available to patients in Wales. We are proud to have come together to deliver this study with TC BioPharm which we hope will improve future anti-cancer treatments.**

**Dr Rob Jones, Wales Cancer Research Centre**

**co-lead for early phase trials, on the ImmuniCell@**

**Immunotherapy trial.**

## Wales Cancer Research Centre

**The Wales Cancer Research Centre (WCRC) is dedicated to improving the lives of cancer patients and their families, in Wales and beyond, through better screening, treatments and care. They're tackling a deadly disease that affects us all, with one in two of us having cancer over our lifetimes and around 120,000 people in Wales currently living with the disease - a figure set to almost double in the next 15 years.**

### Improving clinical decision-making

The Wales Cancer Research Centre has designed new genetic tests to better diagnose cancer, help patients decide on their best treatment options and help them and their clinicians to better understand the likelihood of controlling or curing their cancer.

Professor Duncan Baird's (Cardiff University) group is focused on better understanding the role of telomeres, protective caps at the end of chromosomes, in cancer. The team has developed a test of telomere length to calculate the outlook, and likely response to treatment, for patients with the most common blood cancer in adults, Chronic Lymphocytic Leukaemia (CLL).

Telomeres protect the ends of the chromosome each time a cell divides, much like the plastic caps of shoelaces. Each time a cell divides, these caps are shortened until they no longer work and cell division stops. In cancers like CLL, the telomeres can become unstable, removing a natural block to the uncontrolled growth of cells and allowing cancerous mutations and

changes to develop. Dr Baird's group has developed the highest resolution measure of telomere length available, allowing them to define the length at which telomeres contribute to damage to chromosomes and development of cancer.

The team's University spin-out company 'TeloNostiX', is now working to bring the benefits of this new technology to patients. TeloNostiX is creating new jobs for Wales, having established a testing facility and won a contract for inclusion of telomere measurement in a major pharmaceutical company's ongoing clinical trial for cancer patients.

### Collaborating to deliver new treatments in Wales

The Centre is working to give new treatment options to late-stage cancer patients, partnering with Cardiff and Vale University Health Board's Clinical Research Facility and Velindre Cancer Centre's Clinical Research Treatment Unit to deliver a trial of the ImmuniCell® Immunotherapy.

Immunotherapies harness the body's immune defences to fight cancer, in much the same way as your body might fight a cold. Offered to those with melanoma, kidney cancer, and some lung cancers, the trial treatment aims to tackle solid tumours, by priming the body's white blood cells to destroy cancer cells.

The three partners aim to build on this first-time collaboration to increase the number of early phase studies - the earliest tests of a new treatment - taking place in Wales, giving more patients more treatment options closer to home, and accelerating the fight against cancer.



## Diabetes Research Unit Cymru

Diabetes and related conditions are a leading cause of ill-health and early death across the UK, damaging lives and costing the NHS.

The Diabetes Research Unit Cymru (DRU Cymru) is the focus for research tackling this disease and has harnessed its clinical, public involvement and laboratory strengths to win funding to slow the development of type 1 diabetes in the young.

### Slowing type 1 diabetes

Around 3,000 people are diagnosed with newly developed type 1 diabetes each year in the UK. Over half of them are young people and children under the age of 18.

Type 1 diabetes sees the body's own immune defences attacking the insulin-producing cells of the pancreas, leading to uncontrolled blood sugar levels, causing ill health and if unchecked, coma and death. The 'Ustekinumab in adolescents with recent-onset type 1 diabetes' (USTEKID) study is looking at how well a new monoclonal antibody (ustekinumab) can block immune cells from attacking the pancreas in young people who have recently developed type 1 diabetes.

The study team want to know whether interrupting destruction of the insulin producing cells at the time of diagnosis could improve the long-term management of these patients' diabetes. DRU Cymru made Wales' first successful bid to the National Institute for Health Research-run Efficacy and Mechanism Evaluation (NIHR EME) programme, to secure five years' funding for this study.

### Patient and public involvement

Making research relevant and of benefit to those with diabetes is core to DRU Cymru's work, and the design of USTEKID was no exception with two members of the Unit's Public Reference Panel on the trial steering group, and a programme of engagement informing the study's development.

The unit's public engagement team organised a focus group of young people and their parents to look at how the study would be run, and to discuss it with Professor Colin Dayan, the chief investigator. That feedback was used to design the final study and to produce a video explaining the research.

Young people of a similar age to those to be recruited into the study were also involved in reviewing the trial information before this went to the ethics committee for approval, attended by a parent from the Unit's Public Reference Panel.

### Quality samples and reliable data

The DRU Cymru laboratory also had critical input into the study design, ensuring sample collection was feasible at all sites across the UK and

would yield reliable, high quality data. They advised on sample collection, storage and testing processes plus effective distribution of sampling kits and temperature controlled transport of collected samples from across the UK. Over the four and a half years of the trial, the laboratory team will perform quick initial tests to determine whether someone is eligible for the trial, and also carry out the 'batched' testing of samples to understand the effect of treatments.

### Part of a UK-wide effort

With support from the Swansea Trials Unit, the USTEKID study is also part of the Type 1 Diabetes UK Immunotherapy Consortium (T1D UK). Funded by Diabetes UK and the Juvenile Diabetes Research Foundation (JDRF) since 2015, this network of 15 research sites strategically distributed across the UK, including Cardiff and Swansea, is focused on advancing a wide range of immunotherapy research in type 1 diabetes.



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For this trial, we need volunteers aged 12-18 years. The engagement team advised us that a 3-4 minute 'clickable' online film would help teenagers and their families see and understand what the study involves better than a traditional written information sheet - so we made the first video patient information sheet. DRU Cymru advised us on a film-maker and the engagement team and families with type 1 diabetes guided us on style and content with a great result.

Professor Colin Dayan, Chief Investigator



## North Wales Organisation for Randomised Trials in Health

**Delivering high quality research in Wales and beyond is the focus of the North Wales Organisation for Randomised Trials in Health (NWORTH).**

**A UK Clinical Research Centre registered Clinical Trials Unit in Bangor, NWORTH supports the design and delivery of a wide range of studies, with more than one in three outline grant applications made with NWORTH winning funding, thanks to its responsive, flexible and tailored service.**

### Reducing MRI scan anxiety

Lying in the tight confines of an MRI scanner commonly induces anxiety in patients before and during their scan. This can cause them to move, reducing image quality or even preventing the scan from being completed, requiring more time in the scanner, causing more distress and increasing NHS time and financial costs.

NWORTH worked with radiographer Jena Tugwell-Allsup from Betsi Cadwaladr University Health Board to compare the use of a video demonstration or a telephone conversation to reduce patient anxiety before a scan.

The trial found that both approaches significantly reduced pre-MRI anxiety in patients attending for a head or upper body scan, and that the standard appointment letter didn't give enough information for most patients. Providing strong evidence for change, the study was shortlisted for an NHS Wales Award in 2017 in the 'Promoting Clinical Research and Application to Practice' category.

### Cognitive rehabilitation in early stage dementia

Memory loss in dementia can impact on activities, relationships and enjoyment for those affected. Early action to help them and their carers to manage early stage dementia can reduce the impact on everyday life, and slow the progression of disability. Cognitive rehabilitation is one approach that focuses on realistic and achievable goals in everyday activities affected by changes in memory and the mind.

In the 'Goal-oriented Cognitive Rehabilitation in Early-stage Alzheimer's and Related Dementias' (GREAT) trial, NWORTH worked with Professor Linda Clare to see whether this therapy could improve the experience of those with early-stage dementia, their family, friends or carers.

NWORTH provided study design support, designed and carried out statistical analyses, developed and implemented electronic data capture systems and provided quality assurance input for all aspects of the trial, which ran in several locations.

The trial, which recruited over 500 participants, showed that cognitive rehabilitation leads to progress in the ability to perform activities that enable independent living, with the approach now being developed in NHS memory clinics.



**NWORTH has an increasingly broad portfolio with success across a range of clinical areas from respiratory health in neonates, early diagnosis and knowledge of cancer, palliative care, evaluating contract reform and role-substitution in dentistry and parenting interventions to tackle inequalities in childhood. We hope to continue to help research teams be successful in getting grants to make a meaningful difference to the people of Wales and beyond.**

Professor Paul Brocklehurst, Director, NWORTH





## Secure Anonymised Information Linkage Databank

Since 2007, the Health Informatics Group at Swansea University has been custodian of the Secure Anonymised Information Linkage (SAIL) Databank, a safe haven for billions of anonymised person-based records about the population of Wales for use in research.

Internationally recognised as world-leading for its innovation in data de-identification, security and linkage technology, SAIL allows researchers to identify influences on health and wellbeing at population scale, helping shape care and policy.

### Fuel Poverty Data Linkage Project

The Welsh Government's 'Warm Homes Nest' scheme, part of its Warm Homes Programme, was part of its strategy to reduce fuel poverty in Wales, allowing households to apply for money to improve the energy efficiency of their homes.

To explore the impact of the scheme on health outcomes, SAIL collaborated with the Welsh Government's Energy Policy and Knowledge and Analytical Services. Linking health records, Warm Homes Programme data and other datasets, the study found positive impacts of the scheme on recipients' general health and hospital admission rates.

These results directly informed the Welsh Government's debate and consultation on the successor scheme, providing key evidence for continuing funding through that scheme and extending eligibility to low income people with respiratory and circulatory conditions.

The value of the project and of SAIL in informing effective policy decisions, is underscored by the award of further project funding for 2018-21.



Findings from the study have directly supported decisions on policy including the targeting and eligibility of our energy efficiency and fuel poverty programme. In particular, they have informed our decision to extend eligibility for free home energy efficiency improvement measures to low income homes where people suffer with respiratory or circulatory health conditions. We are currently piloting this through our Warm Homes Nest scheme.

The positive findings have also assisted us in engaging with health partners by demonstrating clear benefits to the health of recipients and reduced use of our National Health Service. It is an excellent example of the potential for data linking to improve the delivery of public services.

Welsh Government Energy Efficiency official



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For me research is about changing things for the better; innovating and improving. I've been involved in studies aiming to develop new treatments, better manage chronic conditions, improve people's quality of life and optimise patient care and NHS services. All those experiences have shown me the value of a supportive network of peers in moving research opportunities and our professional practice forward.

Zoe Boulton, Senior Nurse, Research Education and Training,

Cardiff and Vale University Health Board

# Supporting and delivering research

**Our Support and Delivery Service is making Wales a place where health and social care research is quicker and easier to set up and better supported.**

**In 2017-18 we delivered an increased number of studies across Wales (501 studies, an increase of 7%).**

Our Support and Delivery Service provides researchers working on commercial and non-commercial studies with a range of support and services throughout the research pathway. Delays can often occur when studies are being set up, which is why we're working hard with our English colleagues. By aligning study approval processes across England and Wales, this now means that just one application is needed to set up extra sites across either nation. Our local NHS organisations are responsible for ensuring their capacity and capability to deliver the study.

Further coordination and efficiency has been supported through a common R&D finance policy implemented across all NHS organisations, and through improvements to our research directory and information management – giving better visibility and management of health and social care research activities across Wales.

Our direct support for research teams has also grown, with the launch of a national online guide to research processes for research staff, guiding them to the people and information they need to deliver their research, and the sharing of new guidance on mental capacity in research and consent.

## Primary care

During 2017-18, 118 GP practices in Wales were actively involved in research through our Primary Care Research Incentive Scheme (PiCRIS), which was launched in 2012 to

provide a platform to engage General Practices and provide mentorship to grow research. These PiCRIS registered practices recruited 1,004 participants to take part in studies.

We value this performance and our strong relationship with primary care providers, yet we feel there's more we could do here to realise the full research potential. That's why we completed a major review of primary care study delivery, which has given us the basis for plans to strengthen primary care study set up and delivery services going forward.

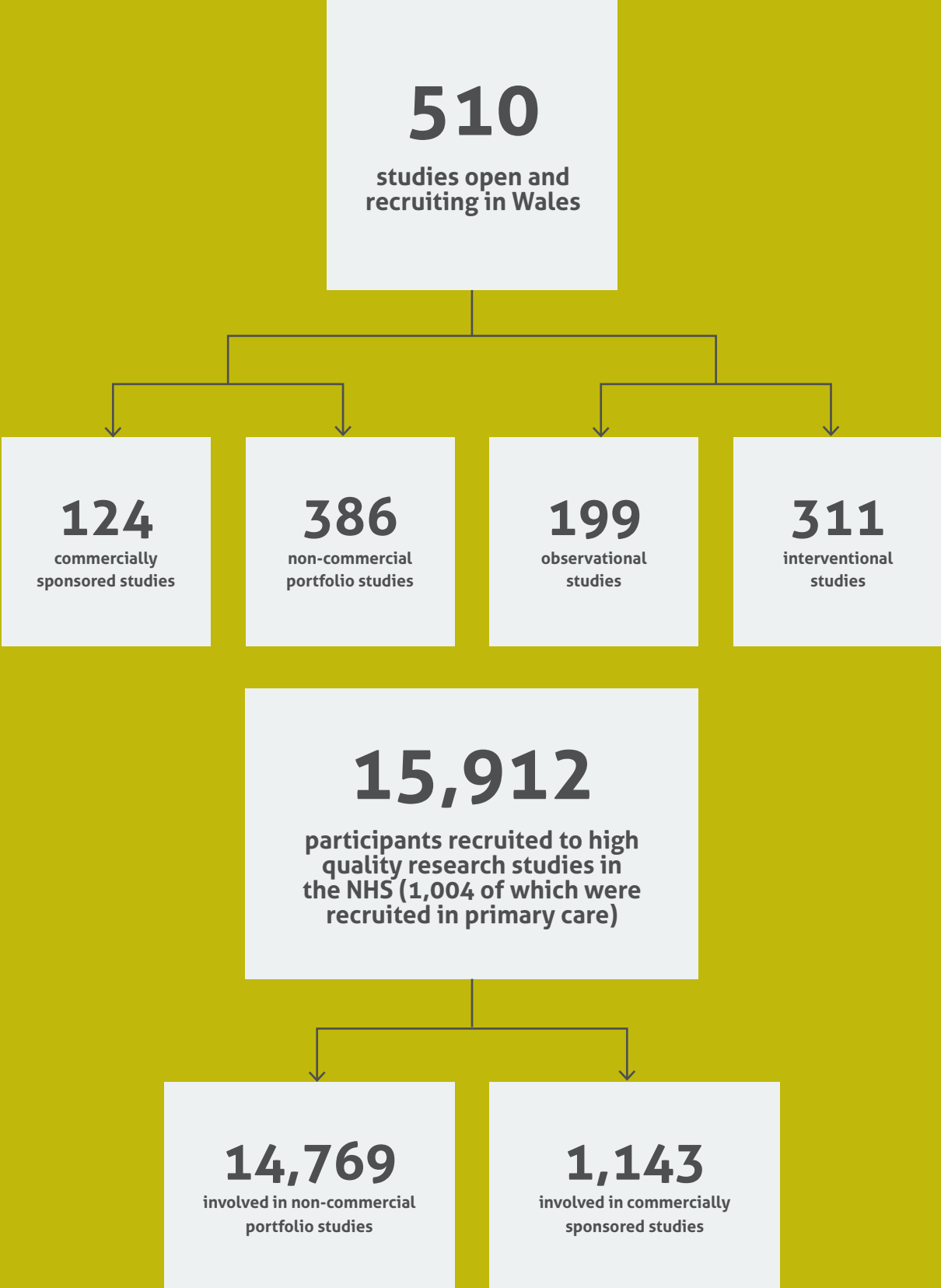
## Commercial research

Wales was part of a new UK-wide approach to commercial research piloted in 2017-18, with a selection of studies opened to all NHS organisations to express interest in delivery. Positive feedback has cleared the way for further development, accelerating the matching of studies and sites, and the progress of new treatments into the clinic.

That same collaborative approach and global outlook saw us joining UK colleagues on a trade mission to the East and West coasts of the USA. The mission established new relationships on what Wales can offer global companies.

# Support & Delivery

## 2017-18





**96%**

of research studies received NHS permission within 40 calendar days (portfolio and commercial studies)



**1,336**

delegates trained via the Health and Care Research Wales training programme



**77,840**

website sessions on the Health and Care Research Wales website



**317**

applications reviewed by Research Ethics Committees in Wales, as part of the UK service



**99%**

of full NHS research ethics applications received a final decision within 40 calendar days



**118**

GP practices involved in the Primary Care Research Incentive Scheme (PiCRIS)



**77%**

of commercial studies recruited their first patient within 30 days of go-live date \*



**£243,133**

of Excess Treatment Costs provided to cover additional clinical services or treatments for patients involved in high quality research studies\*\*

\* Where studies have a target of one participant or more per month  
\*\* These are elements of care that are being analysed within a research study that are not currently part of standard care

# Case studies

## Supporting primary care research

Primary care research has traditionally been focused on general practice where the majority of research activity has taken place. However, we are now seeing more involvement in other areas of primary care - dentistry, optometry and pharmacy - providing patients with increased access to research in these settings. The following studies, both open in Cwm Taf University Health Board, are excellent examples of how high quality primary care research is being delivered in the community.

**Title: Smoking Treatment Optimisation in Pharmacies Study (STOP)**

**Funder: National Institute for Health Research**

Collaboration between Health and Care Research Wales (Cwm Taf University Health Board Research & Development Office and Support and Delivery Centre), Public Health Wales and the study team in Queen Mary University of London resulted in 12 community pharmacies engaging with the STOP study. Cwm Taf University Health Board provided pharmacies with research nurse time to support the opening of the study which aims to assess the effectiveness and cost-effectiveness of the STOP intervention on recruitment, retention and quit rates of smokers on the NHS stop smoking programme.

**Title: Genetics of Thyroid Hormone Study (Genthyr)**

**Funder: Amdipharm Mercury Company Ltd**

Hypothyroidism (underactive thyroid gland) is often treated with T4 thyroid hormone replacement, which can lead to patients feeling low or depressed more often than the general population. Genthyr aims to explain this finding by focusing on genetic makeup. Primary care pharmacists have been actively involved with designing and running this study with collaboration between secondary care and primary care service providers within Cwm Taf University Health Board.

## Working with industry

In November 2017 our respiratory specialty lead, Professor Keir Lewis, and senior industry manager met with Glaxo Smith Kline (GSK) to discuss a Chronic Obstructive Pulmonary Disease (COPD) study to be run in the UK and Europe. The study, Intrepid, was assessing the effectiveness of TRELEGY ELLIPTA relative to non-ELLIPTA Multiple Inhaler Triple Therapies (MITT) for COPD within the usual clinical practice setting.

GSK had not placed a respiratory study in Wales for around ten years, and wanted to understand how we could ensure that the study would set up in good time and would run to time and target. Professor Lewis was able to confirm the study was feasible and the relevant populations were present across Wales. We were able to offer GSK the use of the one-cost one-contract service to set the study up swiftly and we worked closely with Professor Lewis to ensure several suitable Principal Investigators (PIs) were identified. Our senior industry manager provided additional oversight of set up activities in all three sites that were selected to run the study; Prince Philip Hospital (PI Prof Keir Lewis), Neville Hall Hospital (PI Dr Patrick Floodpage) and Clarence Medical Centre (PI Dr Simon Dobson).

GSK have said that they would use the service again and that the oversight provided by our specialty lead, senior industry manager and contracts officer was extremely beneficial and enhanced the planning and set up of the study in all three sites. As a result of the success of the project we are exploring the option of forming a strategic partnership with GSK.



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GSK has a long track record of working with NHS sites in Wales with numerous active studies running across primary and secondary care. GSK has always been impressed with the level of expertise and commitment demonstrated by staff working in NHS Wales and are excited about building on these collaborative relationships in the future.

Robyn Miles, Government Relations Manager, GSK

# Moving social care research forward

**Evidence-based social care is needed now more than ever to ensure effective, sustainable care in Wales' communities. That's why we've collaborated across the sector and supported our Wales School for Social Care Research as the focus for research capacity building efforts in Wales.**

We continue to drive forward social care research and development in Wales with our partner organisations, in particular Social Care Wales, a new national leadership body for the social care sector.

With them, and our Wales School for Social Care Research, we have formed a joint Social Care Research & Development Strategic Coordination Group. This group is the single point of coordination and oversight for Welsh Government-funded social care research.

Chaired by Professor Fiona Verity, it has set national priority areas for funding, leading to themed grant calls on specific areas including social prescribing (NHS referrals to non-clinical support) and predictive research (simulating the costs of different care).

## **Social care strategy**

These strengthening collaborations, and the growth of the Wales School for Social Care Research, underwrite progress towards the vision of the Social Care Research and Development Strategy for Wales 2018-2023: 'For Wales to be internationally renowned for its excellent social care

research that supports the people of Wales by informing and improving social care policy and practice'.

Over the next five years, social care research and development will focus on:

- Home care
- Children in care
- Dementia

The strategy was produced collaboratively with experts, people working in care, those using care services, the third sector and members of the public.

## **Wales School for Social Care Research**

Launched in February 2017, our Wales School for Social Care Research is based at Swansea University. It is led by Professor Fiona Verity and provides the focus and leadership needed to build a structured, strong social care research programme for Wales.

Through its varied research projects, the School's work is changing practice and policy for improving the care of older people and those living with dementia.

Working with the Centre for Ageing and Dementia Research (CADR), the School is focusing on one of its key priorities, to build research capacity in social care, by helping to develop a network of 'research ready' care homes. Enabling Research in Care Homes (ENRICH) Cymru is providing opportunities for new and innovative research studies to take place, which aim to improve the lives of people

living in and working in care homes.

Under the leadership of Nick Andrews, the School's Developing Evidence Enriched Practice (DEEP) initiative has produced some standout achievements during 2017-18, including the rollout of 'rights-based' dementia care training for care home staff across West Wales.

The School is also leading the way for public involvement in social care research in the UK. Together with CADR, it has been selected as one of ten sites that will pilot and review the new National Standards for Public Involvement in Research. The joint site is the only one selected in Wales and the only social care site involved in the testing across the UK.

To ensure social care research continues to move forward and research activity increases, it is vital to attract and support new talent. In 2017, the School started funding Social Care PhD Studentships, receiving a strong response to its call for applications. An increase in investment has provided more opportunities to apply for funding. Social Care PhD Studentships are also available through a match-funding arrangement with the Economic and Social Research Council Doctoral Training Partnership.





# Supporting exceptional people and their ideas

**Our funding calls support researchers answering vital questions while building Wales' capacity for health and social care research.**

Since 2015, Health and Care Research Wales has awarded 61 personal or project grants, totalling over £9m. This includes:



7

Health or Social Care Fellowships



7

Health or Social Care PhD Studentships



12

Health or Social Care Research Funding Scheme Grants



15

Research for Patient and Public Benefit (RfPPB) awards



20

Clinical Research Time Awards (CRTAs)

In 2017-18, 20 new awards were made, with a combined lifetime value of £3.5m across funding schemes including Social Care Grants, Research for Patient and Public Benefit (RfPPB) projects, Health Studentships, Health Fellowships, and Clinical Research Time Awards (CRTAs).

We've worked hard to develop our tracking of outputs and outcomes of our awards, to better understand their effect and the impacts of the resulting research. Quarterly and end of project

reports, plus submissions to the online Researchfish database, annually and for five years beyond the end of funding, collect measures including publications and public involvement and engagement activity, giving us the long view on research impact.

We're now working to streamline and boost how we support sharing of findings and impact with the public and others, for greater uptake of our funded work.



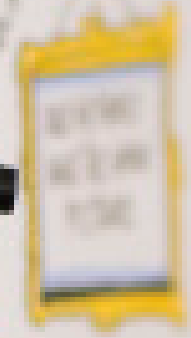
DO NO HARM  
WILL, HARM + HURT  
SOME OF WILL  
RESEARCH

DO NO HARM  
WILL, HARM + HURT  
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ALL PEOPLE  
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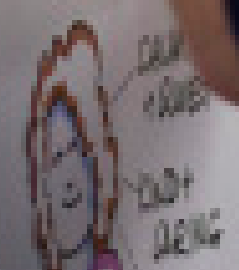
DO NO HARM



RESEARCH

YOU CAN'T RESEARCH  
DON'T RISK THE

RESEARCH



# Funded projects 2017-18



## Health Fellowships

Giving people the support needed to become independent researchers, and to undertake high quality research projects benefiting patients, public, service users and/or carers in Wales.

- **David Gillespie**, Cardiff University: Development of an intervention to Optimise use of pre-exposure prophylaxis (PrEP) to prevent HIV-acquisition in at-risk individuals living in Wales [DO-PrEP].
- **Ashrafunnessa Khanom**, Swansea University: INFORM: Improving care for people who Frequently call 999: co-production of guidance through an Observational study using Routine linked data and Mixed methods.
- **Sara Long**, Cardiff University: Integration of health and wellbeing into the school curriculum: a mixed methods investigation of preparations for Wales-wide school reform and its impact on health and wellbeing.
- **Stephanie Smits**, Cardiff University: Understanding experience, completion and outcomes of colorectal cancer screening among participants with multi-morbidity.



## Health PhD Studentships

Giving talented people their first stepping stone into research, addressing the health and care needs of service users, carers and the wider population, or the organisation and delivery of efficient and effective services in Wales.

There were four successful applications, including two under the theme of 'Co-production':

- **Ian Jones**, Cardiff University: Making the invisible visible: Using lived experiences of severe mental illness around childbirth to co-produce tools for individualised pregnancy planning (Themed call).
- **Rhiannon Phillips**, Cardiff University: Starting a family when you have inflammatory arthritis: can a co-production approach to creating pre-conception health improve the sustainability of NHS services? (Themed call).
- **Sharon Williams**, Swansea University: Co-producing an intervention to improve care for children with Autism Spectrum Disorders: A cross-disciplinary mixed-methods study.
- **Tom Wilkinson**, Swansea University: Identifying host and bacterial biomarkers to predict sepsis.



### Social Care Research Grants

Supporting high-quality research projects with clear relevance to social care service users, carers, and/or the organisation and delivery of effective social care services.

There were two successful applications, including one under the theme of 'Social Prescribing':

- **Ceri Jones**, Cardiff University: Time Credits as a Social Prescription: The Co-production of a Conceptual Framework, Programme Evaluation and Social Return on Investment (Themed call).
- **Martin Elliott**, Cardiff University: Child Welfare Inequalities in Wales: Practice and Prevention.



### Research for Patient and Public Benefit

Funding research which is related to the day-to-day practice of the health service, with clearly defined patient and public benefits.

There were five successful applications to the NHS-focused call, including two under the theme of 'Co-production':

- **Anwen Cope**, Cardiff and Vale University Health Board: Developing a decision aid to support shared decision making regarding risk-based recall intervals in general dental practice (Themed call).
- **Gareth Roberts**, Cardiff and Vale University Health Board: Which factors determine treatment choices in patients with advanced kidney failure: Co-productive study with patients and key stakeholders (Themed call).
- **Jeremy Hall**, Abertawe Bro Morgannwg University Health Board: Treating Anxiety to Prevent Relapse in Schizophrenia (TAPERS) - a feasibility trial.
- **Dean Harris**, Abertawe Bro Morgannwg University Health Board: Patient acceptability and clinical effectiveness of combined Raman/FIT testing for colorectal cancer diagnosis in primary care.
- **Grayham Maclean**, Welsh Ambulance Services NHS Trust: ARRIVE: Ambulance paramedics Responding to urgent patient Requests In general practice for home Visits - Evaluation development.

### Clinical Research Time Awards

Carving out time for top-performing NHS staff to engage in research activity:

- **Ceri Battle**, Abertawe Bro Morgannwg University Health Board
- **Sarah Bent**, Betsi Cadwaladr University Health Board
- **Lim Jones**, Public Health Wales
- **Sarah J Jones**, Public Health Wales
- **Marlise Poolman**, Betsi Cadwaladr University Health Board

## Case study

### Developing talent in social care research

One of our key aims is to expand capacity and expertise. Awarding post-doctoral fellowships to talented researchers is a key element of our approach.

Dr Rhiannon Evans completed her Health and Care Research Wales Fellowship in 2017 and is currently a Senior Lecturer in Social Science and Health based at DECIPHer (Centre for the Development and Evaluation of Complex Interventions for Public Health Improvements), a UK Clinical Research Centre (UKCRC) Public Health Research Centre of Excellence.

Rhiannon is also an affiliated Senior Lecturer at CASCADE (Children's Social Care Research and Development Centre). The fellowship project 'self-harm, suicide ideation and suicidal behaviours in looked-after children and young people: Incidence, prevalence and prevention', focused on suicide in children and young people in care. Rhiannon identified

there had been a lack of research on whether children and young people who have been in care were at an increased risk of suicide or self-harm. There was also limited research exploring existing management and prevention strategies used within care settings to deal with any potential risk.

A systematic review and meta-analyses of the prevalence of suicide-related outcomes in children and young people with experience of care compared with non-care populations was conducted. Semi-structured interviews and focus groups with a sample of foster carers and residential carers took place across Wales.

The results of the meta-analyses confirmed that suicide attempts are more than three times as likely in children and young people placed in care compared to non-care populations and that targeted interventions to prevent or reduce suicide attempts in this population may be required. The

qualitative data explored the symbolic meanings carers ascribe to self-harm amongst the children and young people they care for.

As a result of the project, Rhiannon was awarded further funding from a Health and Care Research Wales grant scheme to explore the experiences of children and young people who present to emergency departments with self-harm. The study began in October 2017 and has a specific focus on the experience of children and young people in care, and their carers.



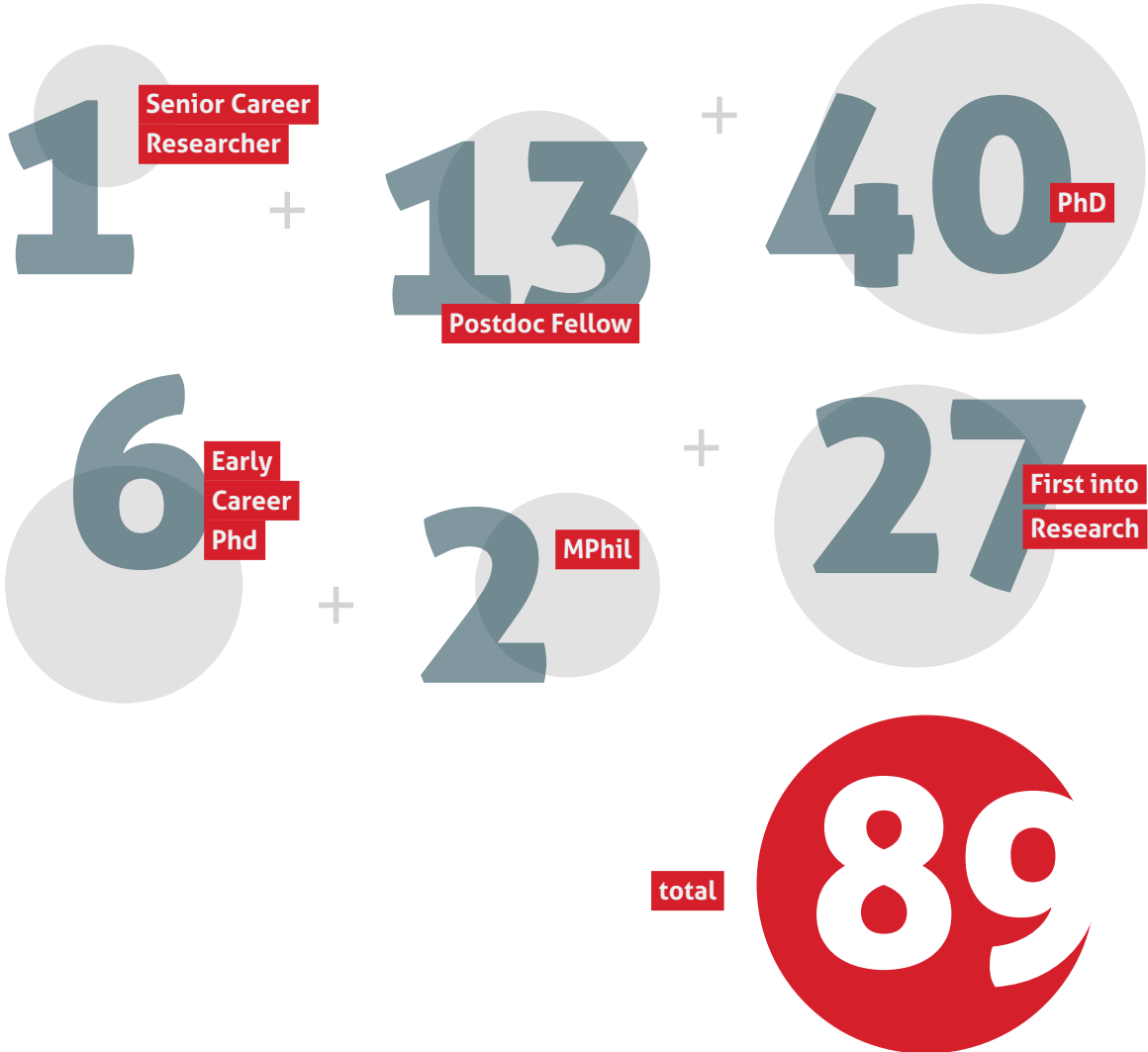
# Spotlight

## Developing non-medical talent in NHS Wales: The Research Capacity Building Collaboration (RCBC) Wales

The Research Capacity Building Collaboration (RCBC) Wales has been funded by Health and Care Research Wales (or its predecessor organisations) since 2005. It aims to increase the number of research active nursing, midwifery, pharmacy and allied health professional staff,

and support development of clinical academic career paths for these groups through fellowship awards. These range from First into Research to postdoctoral study awards, with 89 fellowships awarded to date across Wales in a range of professions.

## Fellowships awarded:





The collaboration comprises six university nursing and allied health departments/schools in Wales; Universities of South Wales, Swansea, Cardiff, Cardiff Metropolitan, Glyndwr and Bangor. They work together to provide a shared infrastructure and support for the fellowships, several of which have received match funding from Tenovus.

All RCBC Wales Fellows join the Community of Scholars, which provides mentorship and master classes in research methods and research leadership throughout the year, including engaging with and influencing policy.

Highly valued by fellows, the Community of Scholars is an integral part of the scheme, which provides a stepping-stone to a future career in research, and is providing the focus for a growing community of research active professionals.

## Professions awarded:



Nursing



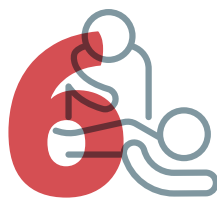
Physiotherapy



Dietetics



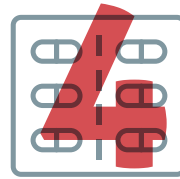
Podiatry



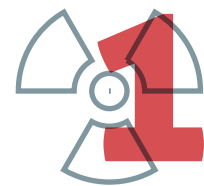
Occupational Therapy



Midwifery



Pharmacy



Radiography



Biomedical Scientist



Paramedic



Physiology



Speech & Language Therapy

# Working collaboratively

**We continue to work with partners to increase the value of health-related research and to create funding opportunities for Wales-based researchers.**



**While agreeing a consensus statement and set of principles does not in itself add value to research, we see it as a precursor to action at both individual and collective levels. In some cases we know what kind of action is needed and the challenge is a practical one. In other cases matters are less obvious. Either way, the Forum allows the exchange of ideas and the sharing of good practice among organisations who have a real will to effect change.**

Michael Bowdery,  
Head of Programmes and Joint Interim  
Director, Health and Care Research Wales

## **Ensuring Value in Research - an international effort**

We are proud to be a member of the Ensuring Value in Research (EViR) Funders Collaboration and Development Forum. Co-convened by the National Institute for Health Research (NIHR, England), the Patient Centered Outcomes Research Institute (PCORI, USA), and The Netherlands Organisation for Health Research and Development (ZonMw), the Forum brings together research funders, and others, in a dedicated, collaborative, international effort to advance research funding practice, reduce waste and increase the value we get from the research we fund. The work of the Forum gained considerable momentum in 2017-18, with meetings in The Hague and Washington DC leading to the agreement of a consensus statement, a set of guiding principles, a Lancet article and the creation of the EViR website.

In May 2018 we hosted a two-day Forum meeting in Cardiff, the first non-convening organisation to be afforded the privilege. 2018-19 should see the continuing international expansion of the Forum and the further development of its work programme. In time it intends to publish work on the principles and their effective implementation.

## **Creating funding opportunities**

In keeping with our long term strategy, we work with partners to create funding opportunities for Wales-based researchers.

In 2017-18, the launch of the UK Prevention Research Partnership (UKPRP) resulted in a strong network bid from Wales with possible Welsh involvement in other networks and developing consortia.

We continued to work with a range of funding partners, including the Medical Research Council (MRC), Economic and Social Research Council (ESRC), Engineering and Physical Sciences Research Council (EPSRC), British Heart Foundation, Wellcome Trust and UK government health departments, to help establish the MRC-led Health Data Research UK, of which the Wales and Northern Ireland site, directed by Professor Ronan Lyons of Swansea University, is an integral part.

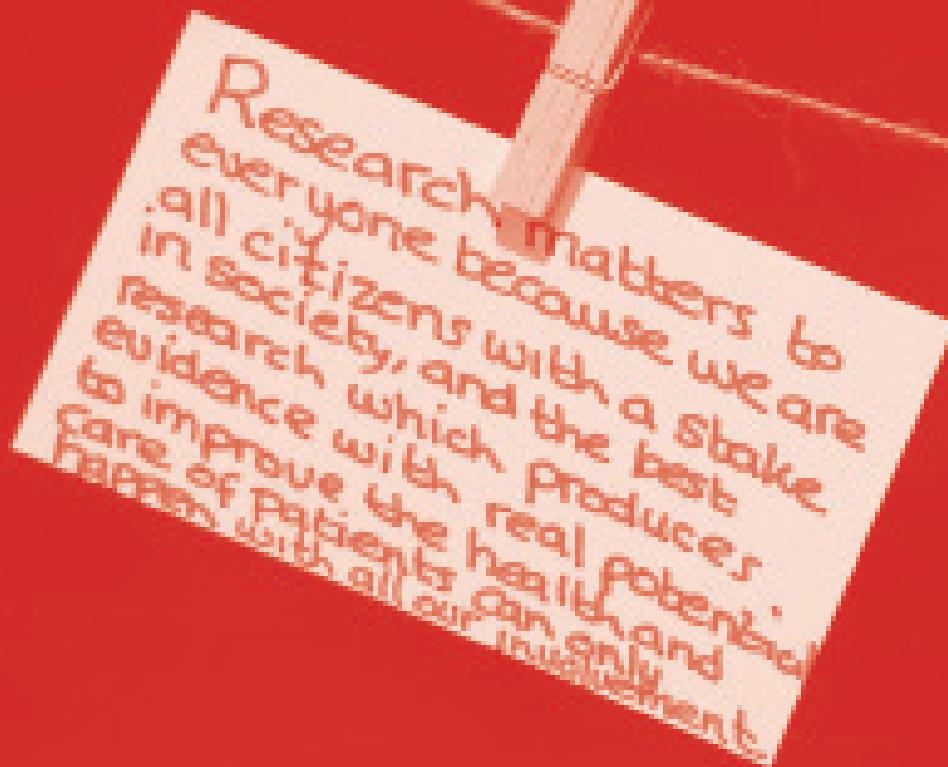
We also continued to invest in the NIHR-run Health Technology Assessment, Health Services and Delivery Research, and Public Health Research programmes, and the NIHR/MRC Efficacy and Mechanism Evaluation programmes.

In 2017-18, 31 applications were submitted to these schemes led by Welsh applicants or institutions, eight of which were successful. 102 applications were submitted that had co-applicants from Wales (including those which were led from Wales), of which 27 were successful.



We would like to thank the Health and Care Research Wales community for their dedication and commitment - amply demonstrated by the achievements and progress described in this report. It's important to recognise that none of this would be possible without the involvement and participation of the people of Wales. As we move forward we will continue to ensure that the work we fund is fit for the future, allowing us to meet the most challenging health and care questions of the coming decades and to deliver new treatments, new care and a healthier, happier nation.

Carys Thomas and Michael Bowdery, Joint Interim Directors,  
Health and Care Research Wales



Research matters to everyone because we are all citizens with a stake in society, and the best research which produces evidence which the real potential to improve the health and care of patients can only happen with all our involvement.

## Today's Research; Tomorrow's Care.

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