

Research Impact

2016/17 Health and Care Research Wales
Annual Report

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Underpinning everything we do is our commitment to improving the health, wellbeing and prosperity of the people in Wales.

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Foreword

Health and Care Research Wales has enjoyed another very successful year. There have been many excellent achievements, several of which are described in this annual report and emphasise the quality and diversity of our work.

Following the launch of the five-year Health and Care Research Wales Strategic Plan in 2015, it has been a pleasure to witness the start of its implementation. A key example of this is the progress made in ensuring public involvement and engagement is central to what we do. The Health and Care Research Wales Public Involvement Delivery Board has now established itself and Wales has played a key role in the development of UK-wide Standards for Public Involvement that will be published later this year. HealthWise Wales, our flagship health and social care research initiative, is closer to realising its full potential, as we continue our work to increase recruitment levels and improve public awareness.

Underpinning everything we do is our commitment to improving the health, wellbeing and prosperity of the people in Wales. We have worked hard to increase the impact our research has and to ensure that knowledge is used to develop more effective services. Strategic plans to deliver research impact have been finalised by all our Centres, Units, Clinical Trials Units and Infrastructure Support Groups and are now being implemented. We have also championed research and development as a key driver to the delivery of high quality services by ensuring its inclusion in NHS organisations' medium term plans and the NHS Wales condition-specific delivery plans.

An excellent example of major progress in the last year has been the culmination of considerable work to ensure research is integral to Social Care Wales. A strong, collaborative model of working means social care research will address key service questions and ensure available knowledge is used to inform improvement work. The Wales School for Social Care Research, which enjoyed a highly successful launch on Valentine's Day, is now working closely with Social Care Wales to develop and deliver a social care research strategy for Wales.

Another major achievement this year has been the completion of the next steps in the transformation of the support and delivery service. The commitment of staff to delivering the changes required to make the service ever more efficient and effective have been clear to see. Recruitment into studies has increased, and changes to our national activity based funding policy are encouraging a focus on the support and delivery of high quality research. This is increasing opportunities for the population of Wales to participate in studies that will make a real difference.

Finally, I would like to take this opportunity to thank the Health and Care Research Wales community for their hard work during 2016-17 and look forward to continued progress in future years.



Professor Jon Bisson
Director, Health and Care Research Wales

Introduction


Health and Care Research Wales is a national organisation made up of a research infrastructure and funding schemes. We are funded and overseen by Welsh Government through its Research and Development (R&D) Division. We support and increase capacity in R&D, run a range of responsive funding schemes and manage resources to promote, support and deliver research. We support translational research with a particular focus on applied and public health research. This includes research into the prevention, detection and diagnosis of disease; the development and evaluation of interventions; the provision of health and social care

services; and the implementation of research findings into practice.

We also support the development of strong partnerships with key individuals and organisations in the United Kingdom and internationally, for example through our membership of the Board of the Office for Strategic Coordination of Health Research. The people of Wales are central to our infrastructure, with programmes that aim to lead to major gains in health and wellbeing, effectiveness of services and wealth generation. A key objective is to ensure Welsh Government-funded research in health and social care is aligned to Welsh Government policy

and has real impact.

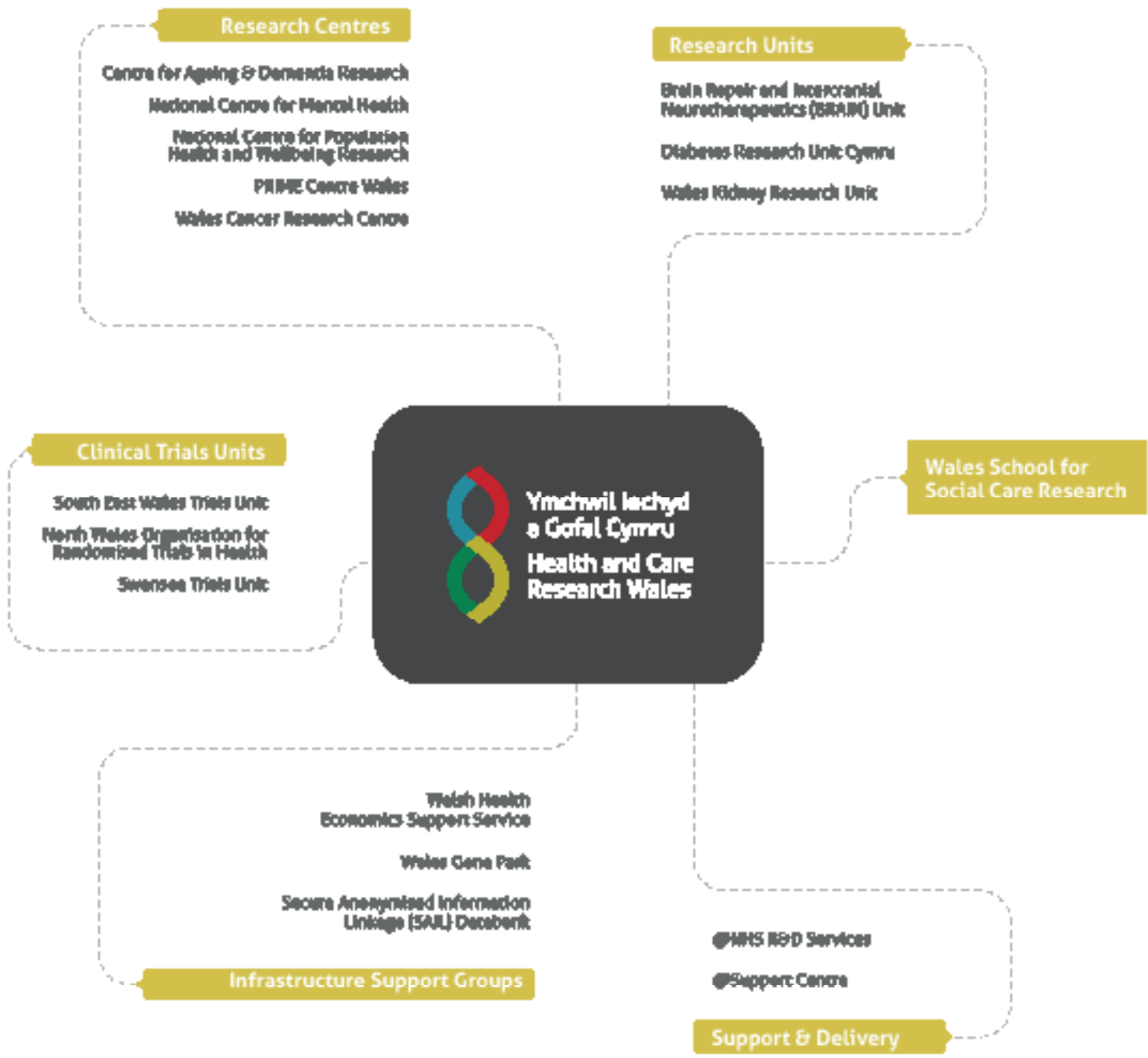
The Health and Care Research Wales Strategic Plan 2015-2020 is underpinned by a robust performance management framework and indicators that cover public benefit, research awareness, research and economic impact. Performance is monitored and managed by Welsh Government with input from public involvement, NHS and Social Care R&D Delivery Boards that feed in to the Health and Care Research Wales Board.



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.

Strategic aims

- 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.



Funding high quality research

Health and Care Research Wales develops high quality research through research centres and units, clinical trials units, and support groups.

Our centres and units cover a diverse range of research, including mental health, primary and unscheduled care, population health and wellbeing, cancer, ageing and dementia, neurodegenerative diseases, diabetes, kidney and social care. Their aim is to increase the number of high quality research studies carried out in Wales, build research capacity and work with NHS and social care partners to ensure research findings are translated into meaningful benefits for patients. They also increase income into Wales by securing external grant funding and publish

their work in high quality scientific journals. A comprehensive list of our funded groups can be found in the infrastructure map (*page 7*).

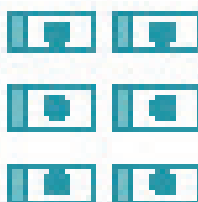
The infrastructure support groups provide expertise in data linkage, genetics and genomics and health economics. Our clinical trials units provide expertise in clinical trials and other well-designed studies. This is vital in ensuring they are not only of high quality but also conducted in a timely manner and meet regulatory and governance requirements.



Trials and Research
in Clinical Open
Health and Care
Research Wales

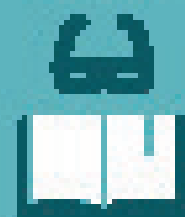
Clinical Research
Infrastructure 2015-17

Number of Open
Trials (copies listed)



14,318

Number of research
publications

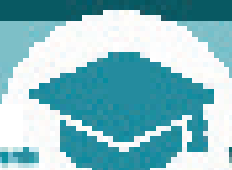


1,597

Number of grants awarded

#

373



Value of grants awarded

£

95m

Number of
trials funded

160

Number of
trials funded

433

Spotlight

Work from two of our centres and two of our units is described over the following pages to provide examples of the high quality research and to demonstrate its positive impact on people and services.

PRIME Centre Wales carries out research into primary and emergency care. These are essential areas for research as over 90% of all patient contacts occur here. A strong academic base, with primary and emergency care providers working together, is vital.

PRIME has supported new collaborations that have helped develop new and valuable research across health and social care. PRIME funding has enabled researchers to develop successful grant applications across universities and research units. PRIME has also been successful in winning significant research funding from National Institute for Health Research (NIHR) programmes, for which Health and Care Research Wales is a funding partner.

While PRIME projects vary in focus, all aim to support effective care and management of patients in primary care. They also aim to develop early and mid-career researchers into positions of research leadership.

Case Study

Study title: *Primary care management of lower urinary tract symptoms in men: development and validation of a diagnostic and decision making aid (The PriMUS Study)*

Funder: National Institute for Health Research (NIHR) Health Technology Assessment (HTA)

Amount: £1,555,527

PRIME researchers are working with colleagues at the South East Wales Trials Unit on this study which aims to develop a clinical decision aid to diagnose the cause of lower urinary tract symptoms in men and make recommendations.

Symptoms affect more than 10% of older men and is a common reason for them to visit their GP. While GPs follow established procedures when considering signs of more serious conditions like cancer, there are no easily available assessment tools to identify other more common causes of lower urinary tract symptoms. It means patients are increasingly referred to hospital based urology specialists for tests and diagnosis (referral rates have trebled in recent years).

If proven effective, the use of the clinical decision aid has the potential to give men with symptoms early access to treatment plans. The decision aid could also reduce waiting times before assessment and diagnosis, reduce the burden on secondary care and allow for earlier referral of men with more complex problems to specialist urology services.



PRIME Centre Wales is going from strength to strength. Health and Care Research Wales' funding is hugely valuable and vital for primary and emergency care research. Over 90% of patient encounters happen in this sector, but to date only 7% of research patients are recruited from this sector, so we absolutely need to build capacity and power for research in this sector to build the evidence base for safe, good quality healthcare.

Professor Adrian Edwards,
Director, PRIME Centre Wales



Case Study

Study title: CARer-ADministration of as-needed sub-cutaneous medication for breakthrough symptoms in home-based dying patients: a UK study (CARIAD)

Funder: National Institute for Health Research (NIHR) Health Technology Assessment (HTA)

Amount: £490,856

PRIME researchers specialising in general practice and palliative medicine are working with colleagues from the Wales Cancer Research Centre to investigate how families of dying patients can be supported to care for their relatives at home in the last weeks or days of life. The team is testing a model of care from Australia in which relatives are trained to safely administer medication by injection, in order to alleviate symptoms such as pain, agitation, nausea and noisy breathing. Usually, these injections are administered by a district nurse. The time taken to request the call out and the following wait can be distressing for patients and their carers as the symptoms can worsen by the time the nurse arrives. The study aims to find out if this new model of care is effective in empowering carers and minimising the distress of patients who want to be cared for and die at home.

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This project aims to empower carers to extend their role in looking after someone dying at home. Our collaborations across Wales and across disciplines are key to knowing whether this practice is acceptable and feasible in the UK. This project forms the basis of Dr Marlise Poolman’s PhD, and provides her with a rapid career trajectory as a clinical academic.

Professor Clare Wilkinson,
Study leader, Bangor University

CADR was set up to integrate world-class research taking place in Wales on ageing and dementia, and to develop areas of expertise from biological, through psychosocial and environmental to social policy. It has the specific aim of improving the lives of older people through the integration of research policy and practice.

CADR has reported great success in placing ageing research at the heart of the research agenda. It has worked collaboratively to support significant grant capture for Wales, including grants from the research councils and major charitable funders.

Case Study

Study title: *Dementia Research Institute, Cardiff University*

Funder: Medical Research Council, Alzheimer's Society & Alzheimer's Research UK

Amount: £13m

CADR is bringing together biological, social and arts based inquiry into ageing and gerontology. The Dementia Research Institute will seek to understand the causes of Alzheimer's disease as well as Parkinson's disease and Huntington's disease. This research is helping develop new therapies designed to delay disease progression, reduce dementia risk and enhance quality of life in individuals with dementia.

CADR will continue to work closely with the Institute, examining the relative contributions of biological, social, and environmental factors that contribute to dementia.

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CADR is shaping a new breed of interdisciplinary researchers with new visions for future scientific challenges. Furthermore, by bringing our interdisciplinary scientific community together with stakeholders and users of research, we make great impact.

Professor Vanessa Burholt, Director, CADR

Case Study

Study title: *Challenging Human Environments and Research Impact for a Sustainable and Healthy Digital Economy (CHERISH-DE)*

Funder: Engineering and Physical Sciences Research Council (EPSRC)

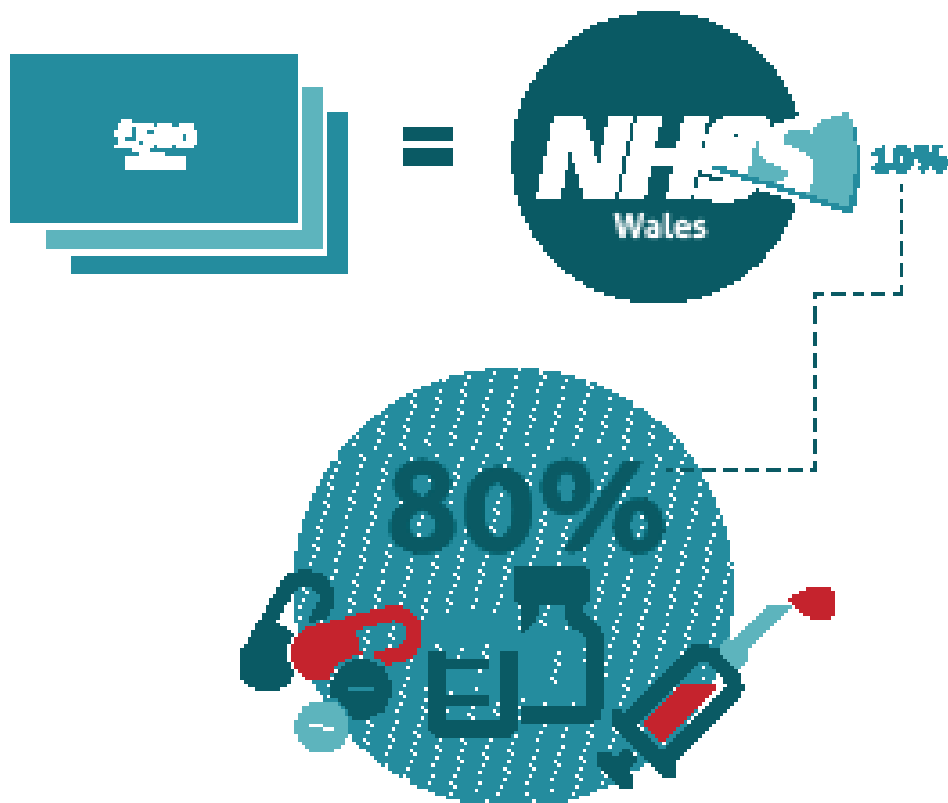
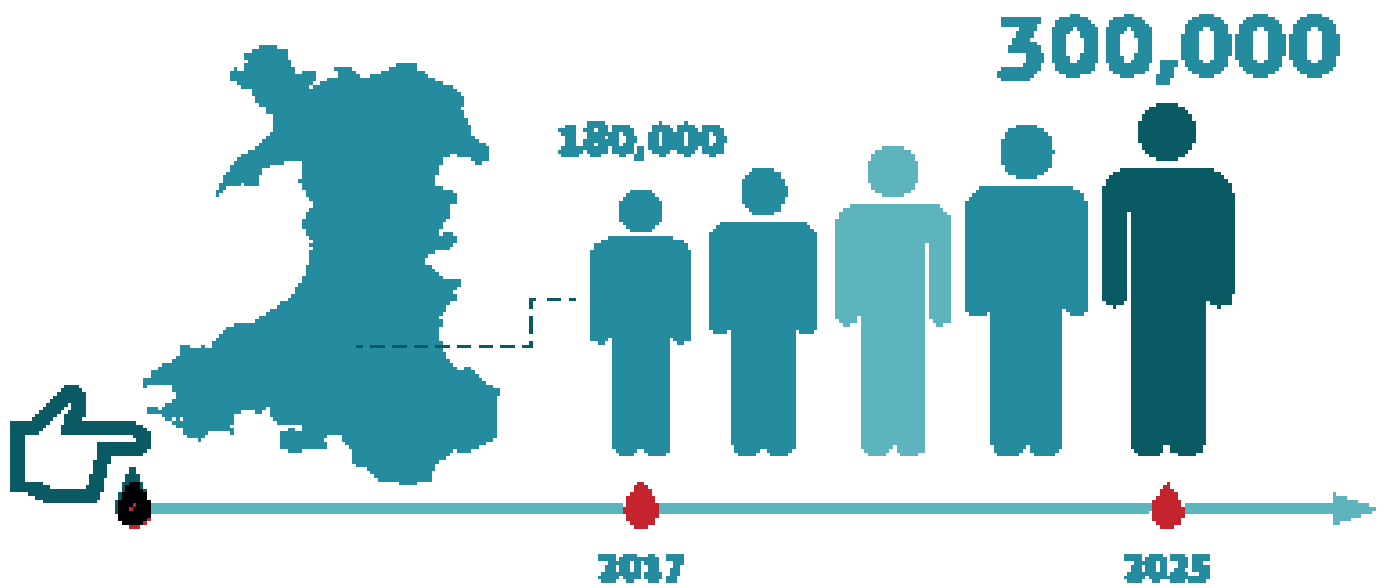
Amount: £3,091,610 (total funding £8m)

The CHERISH-DE Centre at Swansea University is looking at how people's lives might be improved through digital technologies. CADR is working with CHERISH-DE in three main ways:

- Charles Musselwhite, Associate Professor of Gerontology at Swansea University, is working with Welsh Government's transport division to help prioritise research areas relevant to an ageing population and its transport and mobility issues.
- Investigating how technology could bring the mental and physical health benefits of the outdoors to those who are permanently or temporarily housebound.
- Through a project exploring the use of technology to capture people's stories about their connections to places to support the regeneration of former industrial areas of Wales.

Diabetic kidney disease

The need for research



Nearly half a million people in Wales suffer from kidney disease, and more than 1 in 10 people admitted to hospital suffer a sudden loss of kidney function as part of their illness. Those with kidney damage stay, on average, twice as long in hospital and have double the risk of dying during their admission. At the Unit, researchers across Wales work together with clinicians and patients to understand and improve the identification, prevention, treatment and social context of kidney disease.

Infections: Identifying the cause

Infections are a common problem for people with kidney disease. The usual way to identify the cause is to take samples and try to grow the offending bug from them. This often leads to less than optimal antibiotic treatment, which contributes both to poor outcomes for patients with infections and also to antibiotic resistance, a major global problem for healthcare.

To help with this, WKRU investigator Dr Eberl has developed the concept of immune fingerprinting, with support from NIHR, Health and Care Research Wales, Medical Research Council, Kidney Research UK and the European Commission. This means using our growing understanding of the unique immune fingerprint that different bugs leave at the site of infection to

identify them and direct treatment without delay. Working with Dr Eberl, industrial partner Mologic have been able to develop a new diagnostic test prototype for kidney patients receiving peritoneal dialysis, which is now in widespread testing across the UK. Dr Eberl continues to uncover combinations of immune biomarkers in both peritoneal dialysis and haemodialysis, as well as in individuals with urinary tract infections which may cause harm to the kidney. He is working in partnership with Siemens Healthcare on their Immulite platform.

Diabetic kidney disease

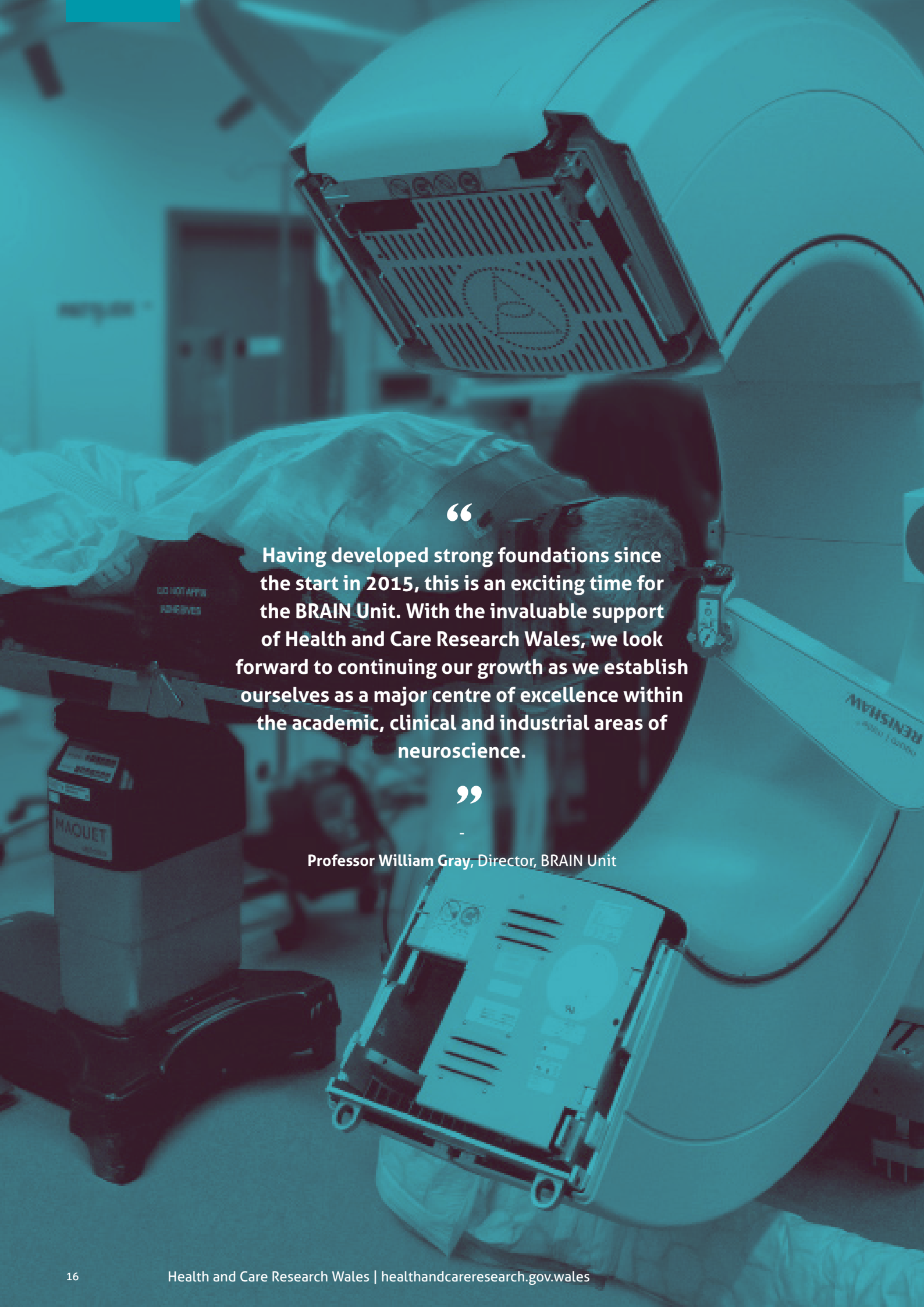
Diabetic kidney disease is one of the most common and most serious complications of diabetes (*see diagram, page 16*). It brings great risk of premature death and disability, and requires life-sustaining but expensive and burdensome treatment in the form of dialysis or kidney transplantation. Led by Dr Bowen and Professor Fraser, WKRU researchers have worked in partnership with South Wales-based companies BBI Group, Gwent Electronics Ltd, GX Design and UCB Pharma. These collaborations have pioneered novel methods to detect microRNAs (recently discovered molecular regulators present throughout the body) in urine as a new way of identifying and monitoring people with diabetic and other kidney diseases. This research, funded by a number of research bodies including Health and Care Research Wales, has recently led to the group filing an international patent application for a urinary microRNA-based diagnostic test for diabetic kidney disease.

Patients: At the centre of research planning and delivery

Patients from across the country have the opportunity to develop a greater insight into how research can impact on a whole range of diagnostic, monitoring and management techniques along with major improvements in replacement therapies. They are also key partners in the WKRU research agenda – not just by participating in the studies but also by determining the agenda and taking part in the planning of research studies.

“ At five years of age in 1960, I had the traumatic experience of losing my father to undiagnosed and thus untreated renal disease when he was just 37 years old. Now 62 years of age, my own experience of renal failure shows a stark contrast and I am able to describe a story of successful treatment and survival. It is both an honour and privilege to be associated with the Wales Kidney Research Unit. Initiatives to improve and increase patient involvement and participation in research, an approach adopted by the Unit from the outset, are beneficial to patients and researchers alike. Involvement and participation helps patients develop an insight into the relevance and application of the work and this can improve compliance in terms of treatment. Without patient involvement, research can appear very remote.

Janet Williams, Kidney patient & WKRU board member



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Having developed strong foundations since the start in 2015, this is an exciting time for the BRAIN Unit. With the invaluable support of Health and Care Research Wales, we look forward to continuing our growth as we establish ourselves as a major centre of excellence within the academic, clinical and industrial areas of neuroscience.

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Professor William Gray, Director, BRAIN Unit

BRAIN carries out research to develop new therapies for brain diseases. The Unit brings together academic experts, clinicians, patients, and colleagues in NHS Wales and industry to benefit people with diseases such as epilepsy, Huntington’s disease, Parkinson’s disease and multiple sclerosis.

Building strong relationships

The Unit’s success in establishing strong partnerships enables the team to fulfil an unmet need for pioneering therapies in Wales, while translating research from the laboratory to the patient’s bedside effectively and safely.

A charitable donation from the Oakgrove Foundation, with technical support from the technology company Renishaw, is providing a neuro-robot to assist with operations at the University Hospital of Wales. This is already benefiting people affected by neuro-conditions.

In March 2016, the Unit’s Professor William Gray performed the first ever robot-assisted epilepsy procedure in Wales with patient Denise Casey, who was diagnosed with epilepsy when she was 31 and suffered up to six fits every day for the past 20 years.

With the robotic arm, it took Professor Gray 55 minutes to accurately identify and operate on the epileptogenic zone in a procedure that would normally take four hours. Denise has not suffered any seizures since her two procedures.

A successful collaboration with the NHS has also resulted in the launch of a clinical Neuroscience Research Unit facility specialising in the development, testing and delivery of novel therapies. Key research includes the Ionis Pharmaceuticals trial to deliver a gene-silencing drug in Huntington’s disease, developing novel tests for assessing cognitive and motor function, and expanding nursing capacity to provide more intensive support to patients.

Public involvement

Embedded in the Unit’s work is a strong public involvement structure established through the BRAIN Involve network, and partnership with the Wales Neurological Alliance, whose members sit on BRAIN’s Executive Board.

The BRAIN Involve network provides a strong patient voice by bringing together people who are, or have been, directly affected by neurological diseases. The initiative offers a range of opportunities to get involved in research and training, but also focuses on disseminating research to the wider community.

BRAIN Involve members Peter and Christine Roberts used their personal understanding of epilepsy to deliver a talk on the importance of research into neurological conditions.

Moving forward

Setting up this strong infrastructure has enabled BRAIN to secure funding to collaborate with industry and undertake the first study in Wales assessing the impact of neural transplantation in people with Huntington’s disease. Patient input from the outset will help support and develop the study to understand possible treatments for this currently incurable and devastating condition. By setting up this work, BRAIN will be in a strong position to lead the way for future stem cell studies, novel therapy generation, and become a centre of excellence for refining treatments and delivering therapies to help treat these debilitating diseases.

“ **My original motivation for getting involved with BRAIN Involve was actually my mother’s experience of Parkinson’s disease. In the later stages of her life, my mother suffered greatly with Parkinson’s disease – the last three years of her life were hell. This is one of the many reasons why the Unit’s research is so vitally important. If there is anything at all I can do to support or progress Cardiff University’s treatments in Parkinson’s disease or epilepsy – I will do so!** ”

.....
Peter Roberts, BRAIN Involve member

Working collaboratively to open opportunities

Health and Care Research Wales continues to work with partners to create funding opportunities for Wales-based researchers in areas of public and patient need.



In 2016-17, we worked with Cancer Research UK to renew funding support for the Experimental Cancer Medicine Centre (ECMC) based at Cardiff University. The Centre was awarded a further five years funding that will see it receive over £1.5m from Cancer Research UK and Welsh Government to continue its research into the development of better treatments for cancer patients in the UK.

Cardiff ECMC is part of a network of 18 hubs across the UK where promising cancer treatments – including small molecule drugs, surgery, immunotherapy and vaccines – are safely tested for the first time in patients.

The Centre's vision is to be internationally recognised for its contribution to the control and cure of cancer through outstanding research and the development of safe and effective new treatments. Having a centre in Cardiff ensures that people in Wales with cancer have opportunities to take part in cutting-edge research, testing new ways of detecting and monitoring cancer and its response to treatment.

2016-17 also saw the strengthening of our partnership with the Economic and Social Research Council (ESRC)

and through its Cardiff University-based Doctoral Training Programme, we co-funded two new social care PhD Studentships. Aelwyn Williams will conduct research into supportive communities for people with dementia, while Lucy Sheehan will investigate variations between local authorities in the number of children entering care. This brings the number of active studentships co-funded through the scheme to four.

Along with other UK Clinical Research Collaboration (UKCRC) partners, we continue to fund DECIPHER – one of five UKCRC Public Health Research Centres of Excellence. We co-fund prevention research within the Scar Free Foundation's Children's Burns Research Centre, and, in partnership with the Medical Research Council (MRC), support the training and public engagement work of the MRC Centre for Neuropsychiatric Genetics and Genomics. We have also agreed to continue supporting Welsh involvement in Health Data Research UK, formerly the Farr Institute.

We are one of the funders driving the new UK Prevention Research Partnership (UKPRP). The UKPRP is a research initiative designed to generate new knowledge and sustainable and cost-effective ways of improving population health and

reducing health inequalities. It is an alliance of research councils, charities and UK health departments who are pooling resources to fund 'whole system', multi-disciplinary approaches to tackling the challenges presented by the prevalence of chronic disease.

We continue to participate in a range of NIHR funding programmes with other government health departments. These create full access for researchers based in Wales to the Health Technology Assessment, Health Services and Delivery Research, Public Health Research and Efficacy and Mechanism Evaluation programmes. In 2016-17, 29 applications were submitted to these schemes by lead applicants from Wales, seven of which were successful. Also, 94 applications were submitted that had co-applicants from Wales (including those which were led from Wales), of which 17 were successful. Leading researchers in Wales are working together to increase the number of high quality and successful applications to UK-wide research programmes, facilitated by collaborations developed through Health and Care Research Wales.

Funding impactful research

In 2016-17, Health and Care Research Wales ran funding calls for Health Research Grants, Research for Patient and Public Benefit projects and Social Care Research Fellowships. As a result, ten new awards were made with a combined value of £2.44m.

The Social Care Research Fellowship call included a Welsh Government theme focused on looked after children, people with dementia, and care and support at home.

The three successful applications were:

- **Social exclusion and use of care services in Wales: experiences of people with cognitive impairment and dementia**
- Catherine MacLeod,
Bangor University
- **The economics of third sector provision of support services for informal carers of people living with dementia in Wales**
- Carys Jones,
Bangor University
- **Talking Changes: Developing best practice in co-producing wellbeing outcomes with looked after children in Wales**
- Jennifer Lyttleton-Smith,
Cardiff University

While applicants always have to demonstrate the need for their research and the likely public and

patient benefit, themed calls are a way of aligning funded projects with Welsh Government policy priorities. Themes have therefore become a standard feature of our calls, giving applicants the choice of applying into the theme or the general call. The 2016-17 Health Research Grant and Research for Patient and Public Benefit (RfPPB) calls incorporated a theme brief highlighting i) health inequalities; and ii) the movement of care and services from hospitals to communities.

To increase the impact of our funded research, all applications for project grants are reviewed by the All Wales Prioritisation Panel (AWPP). The AWPP consists of health and social care service professionals, public members and policy officials. Its role is to assess the importance of the research question. Only applications considered to be of importance to public, practice and policy progress to the scientific review stage, which consists of external, independent peer review and Scientific Funding Board assessment.

Projects funded in 2016-17 span a range of topics, with those led by Gareth Collier and Sarah Rodgers emerging through the themed call.

Funded projects

Research Funding Scheme: Health Grants

- *Children's and adolescents' experience of emergency departments and the Child and Adolescent Mental Health Services (CAMHS) Crisis Liaison Team service provision following presentation for self-harm: Systematic review and qualitative study*
- Rhiannon Evans, Cardiff University
- *The role of patient bone marrow microenvironment in relapsing acute myeloid leukaemia after stem cell transplantation: A study to pre-empt early relapse*
- Joanna Zabkiewicz, Cardiff University
- *Safe in my own home? Investigating the impact of community home modification services on hospital utilisation for fall injuries: A controlled longitudinal study using data linkage*
- Sarah Rodgers, Swansea University

Research for Public and Patient Benefit Wales

- *Trial designs for Delivery of Novel Therapies for Neurodegeneration (TRIDENT)*
- Anne Rosser, Cardiff and Vale University Health Board
- *Feasibility and Acceptability of a new Clinical Pathway for the Identification of Non-Responders to Glaucoma Eye Drops (the TRIAGE study)*
- James Morgan, Cardiff and Vale University Health Board
- *PLUS study – Pharmacy referral for Lung Cancer Symptoms: A feasibility study to assess the role of pharmacists in lung cancer diagnosis compared to current pathways*
- Gareth Collier, Hywel Dda University Health Board
- *Diagnostic accuracy of a clinical prediction tool (BuRN-Tool) to identify maltreatment associated with burns in children*
- Alison Kemp, Cardiff and Vale University Health Board

Funding scheme: Research for Public and Patient Benefit Wales (RfPPB)

Case Study

Developing a clinical prediction tool (BuRN-Tool) to identify maltreatment associated with burns in children

– Alison Kemp

In 2012, the Centre for Children's Burns Research was established with joint funding between Health and Care Research Wales and the Scar Free Foundation. The collaboration between Cardiff, Bristol and Bath Universities and the University of the West of England includes a burns prevention theme.

A Burns and Scalds Assessment Template (BaSAT) has been established by Alison Kemp and her team, providing a standardised assessment for all children who have sustained a burn and go to the emergency department. BaSAT now underpins assessment in a number of emergency departments.

In addition to BaSAT, the team has developed and validated a Clinical Prediction Tool to help clinicians identify maltreatment in these children. The BuRN-Tool (Burns Risk assessment for Neglect or abuse Tool) provides a simple numerical score from seven indicators of maltreatment. If a threshold score is reached there is an increased likelihood of maltreatment and the healthcare professional is prompted to follow local child safeguarding procedures.

The new RfPPB-funded study will evaluate whether the BuRN-Tool improves the recognition of children who require a safeguarding action from children's social care in five regional emergency departments.

If effective, the BuRN-Tool has the potential for widespread introduction across the NHS. Child abuse and neglect are 'Adverse Childhood Experiences' (ACEs) and strongly associated with future violence, victimisation and lifelong adverse health and poor opportunities. There can be benefits however if ACEs are recognised and acted on early.

“ Every year 40-50,000 children attend hospital for the treatment and assessment of burns. Through a series of funded projects, Health and Care Research Wales has enabled us to understand the epidemiology of childhood burns and to recognise that one in ten cases arise from physical abuse or neglect. It can be challenging for busy emergency department staff to recognise these children but they must be identified so that children and their families can receive the right support from health and social care to prevent future injuries and neglect.

Alison Kemp

In 2016-17, 21 directly funded Health and Care Research Wales projects were completed. Grant holders are required to track and record outputs, including the impact of their projects, for five years post award. Results from one of the studies completed in 2016-17 demonstrates the impact the study will have on patients and NHS services.

Case Study

Development and Evaluation of Advanced Algorithms for Fully Automated Intensity Modulated Radiotherapy Treatment Planning

– Philip Wheeler

Half of all patients cured of cancer receive radical radiotherapy as part of their treatment. Intensity Modulated Radiotherapy Treatment (IMRT) is an advanced form of radiotherapy which reduces acute and long term treatment side effects and leads to improved quality of life. Whilst IMRT is safe and effective, it is also more complex and requires additional resources compared to standard treatments. As a result, it is not available to all patients who would benefit.

“ Funding from Health and Care Research Wales alongside strong support from Velindre NHS Trust has empowered clinical staff to develop and evaluate innovative solutions which will deliver vital improvements to radiotherapy service efficiency.

Philip Wheeler

IMRT treatments require precise planning on patient CT scans before delivery. This process represents a significant additional cost and is a major barrier to a more widespread implementation of IMRT. The aim of the Health and Care Research Wales-funded project was to develop and evaluate innovative computer

algorithms, within the treatment planning system RayStation, which automates the planning process. The hypothesis was that automated planning would deliver significant improvements in service efficiency without compromising treatment quality.

This was tested through a study comparing the automated algorithms against current clinical techniques for the cancer sites of prostate and head and neck. The study was designed to compare: i) staff and computer resource requirements per treatment plan generation; and ii) treatment quality through a review by clinical oncologists.

Results showed that automated planning had efficiency savings of more than 90% and 79% for staff and computer resource requirements respectively. Furthermore, upon review 100% of automated plans were of clinically acceptable quality with 92% equivalent or better than current manual techniques.

The conclusion was automated planning results in high quality treatment plans in less time than conventional manual techniques. While plan generation is only one part of a complex radiotherapy pathway,

implementation of automated planning will improve service efficiency, which will in turn increase patient access to IMRT.

“ An outstanding piece of research that will bring immense benefits to patients and save NHS Wales money and staff time. At present, not all patients who need IMRT can access it. Now more patients will benefit from this important treatment.

Sue Campbell,
Public and patient representative

The results of this innovative research project are influencing decisions on the future clinical provision of radiotherapy treatment planning both at a local and national level. The host site, Velindre Cancer Centre, which provides radiotherapy services to 50% of the Welsh population, aims to introduce automated planning by October 2018. The Centre is also in the process of collaborating with Welsh radiotherapy centres with the aim of funding a large scale delivery programme. At a UK level, a multi-centre study is in development which will hopefully lead to wider implementation of automated planning.



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The patients have embraced being part of research trials. They enjoy the chance of being able to change medical practices for the better.

”

Dr Neela Chatakodu, Marches Medical Practice

Supporting and delivering research

Health and Care Research Wales includes a support and delivery service which is provided through a national support centre and Research and Development (R&D) services in all NHS organisations in Wales. The service builds local capacity and capability to support high quality research that benefits patients.

All NHS organisations in Wales are research active. Welsh Ambulance Services NHS Trust demonstrated the largest annual increase in patient recruitment, 155% increase from 2015-16, and the highest recruiting study was PARAMEDIC2 (Pre-hospital Assessment of the Role of Adrenaline: Measuring the Effectiveness of Drug administration In Cardiac arrest) with 687 patients recruited.

In addition to academic or NHS-led studies, we also undertake commercial research studies. The coordination of these types of studies has been improved to provide an enhanced service to industry and access to emerging treatment options for patients.

“ **Working alongside the industry team has been beneficial in the area of site selection and in helping us to resolve issues as they arise at sites.**

.....
Sarah Durston, Senior Manager, Development Operations, Amgen

Health and Care Research Wales aims to set up studies as quickly and efficiently as possible, whilst also ensuring all our research complies with the necessary legal and regulatory requirements and that NHS organisations have the capacity and

capability to deliver it successfully. A new strategic framework for support and delivery was launched in March 2017 with the aim of realising a 'One Wales Seamless Service' for supporting and delivering high quality health and social care research. A programme of work has been developed to improve the research environment in Wales and support researchers and industry. This complements a major UK-wide programme which will increase the consistency of how research is set up and approved across all four nations. Alongside this, a local portfolio management system is being implemented across Wales to support the efficient management of information across the service.

We undertook research in each of the 30 UK clinical specialty areas and appointed new specialty leads to provide clinical leadership for research in each topic area, increase research across Wales and promote links across the UK.

The collaboration with Cancer Research UK (CRUK) to co-fund a network of cancer research nurses continued with great success. These staff are embedded within the support and delivery service. They play a key role in a range of engagement and awareness raising activities, such as, Race for Life, supporting the CRUK stand at the National Eisteddfod and attending open days and public events.

Increasing opportunities for patients to participate in research, and particularly in primary care research, is important and 24 studies taking place in primary care were included in our research portfolio. The number of funded and affiliated practices across Wales involved in the Primary Care Research Incentive Scheme (PiCRIS), now in its fifth year, continues to increase. The aim of PiCRIS is to enable practices to embed research activity within

their daily work and for this activity to become self-sustainable. As part of the scheme, GP practices can access local research support and delivery staff, a centralised training programme, regional PiCRIS mentors and peer support from experienced practices.

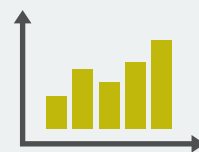
We are also keen to increase opportunities for service users and carers to participate in social care research. Whilst social care research has been informally supported for some time, a new project was launched to fully integrate it into the support and delivery service.

“ **PiCRIS has provided the funding, expertise and motivation to develop the practice to become more involved in research in the future.**

.....
Dr Sue Fish, Borth Surgery

Support & Delivery

2016 - 17



371

high quality research studies open and recruiting in the NHS



15,728

participants recruited to high quality research studies in the NHS (20% increase from 2014/15 baseline)



105

commercially sponsored studies open and recruiting in the NHS



1,289

participants recruited into commercially sponsored studies in the NHS



26%

of studies open in more than one site in Wales



670

NHS research permissions granted for research studies



84%

high quality studies received NHS research permission within 40 calendar days



93%

commercial studies received NHS research permission within 40 calendar days



287

NHS research ethics committee applications, 44 of which were proportionately reviewed



96%

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



97

research contracts reviewed, 59 non-commercial & 38 commercial*



153

commercial feasibility requests sent to potential investigators*



116

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



1,467

delegates trained via the Health and Care Research Wales training programme



70,915

website sessions on the Health and Care Research Wales website



125

information reports provided to stakeholders*

* From the centralised support centre service

Case Study

High recruiting primary research

••••

The Bath Additives for the Treatment of Childhood Eczema (BATHE) study successfully exceeded the original overall study target of 423 patients. Welsh GP practices helped contribute 145 patients to the final total of 483.

BATHE is a Southampton University sponsored study which has three research centres (Southampton, Bristol and Cardiff) coordinating GP practice involvement across the UK. The study aimed to determine whether children with eczema are receiving the best treatment option. It also looked at whether the NHS can save money by cutting down on unnecessary prescriptions for bath emollients, if the findings indicated they had little impact on the treatment of eczema.

The Cardiff centre oversaw the involvement of 39 GP practices across Wales. The practice staff helped identify and contact eligible patients and were supported by research delivery staff who conducted BATHE clinics in GP premises to assist with the informed consent process, recruitment and supported patients' study participation.

This additional support from research delivery staff needed to be coordinated and flexible to ensure that patients were seen within 24 hours of referral from their GP and to accommodate home visits on some occasions.

Case Study

Impact of specialty leads

••••

There were 36 active cardiovascular research studies in 2016-17 and the cardiovascular specialty lead, Dr Zaheer Yousef, has been focusing on ways to develop this activity across Wales.

A Cardiovascular Research Interest Group has been established to bring together clinicians from across Wales. The first meeting aimed to encourage new collaborative research between clinicians and basic scientists, and between various research units. It was attended by 20 researchers who reported that the meeting would increase their chances of submitting a grant application.

In addition, a new process is being developed to target calls for new studies to individual centres, or clinicians, with support in place for delivery of those studies.

A range of activities have provided an excellent platform for ongoing communication and further development. This will help increase patient recruitment and enable discussion of challenges and solutions.

Case Study



Impact of commercial research

Abertawe Bro Morgannwg University Health Board completed a study to compare the outcomes of a standard treatment with or without the addition of an immunotherapy treatment in patients with relapsed or refractory multiple myeloma (a type of blood cancer).

The study, which was sponsored by Celgene, a biotechnology company, and coordinated by the National Institute for Health Research (NIHR) feasibility service, aimed to establish whether the addition of immunotherapy would benefit patients, through being more efficient, prolonging survival and improving quality of life. Patients in the study continued to receive treatment as long as they benefited from the study drugs and did not suffer severe side effects.

Singleton Hospital was one of eight sites in the UK and recruited six patients in total. Three patients continued to receive treatment as a result of the study and have received better treatment options as a result.

Case Study



Working together to support the delivery of social care research

The Confidence in Care Evaluation is a social care study run from the South East Wales Trials Unit. The purpose of the study is to establish whether attendance at a 12 week programme called 'fostering changes', delivered to foster carers or kinship carers, improves care at 12 months compared to usual support. This training programme was offered to foster carers in all foster care provider agencies across Wales. Support from research nurses was coordinated across the south east.

The study team provided Health and Care Research Wales' local research delivery teams with a list of potential participants who had been approached by their social workers and had expressed an interest in the study. The delivery staff then contacted the foster carers on the list to provide information about the study, answer any questions and take consent. Where participants agreed to take part, delivery staff carried out a baseline assessment either via telephone or at a home visit. During 2016-17, local research delivery teams recruited 224 participants from across all local authority areas in Wales into the study.



Involving the public

Public involvement is members of the public working in partnership with researchers to plan, manage and carry out research. All our groups aim to ensure public involvement and engagement is central to what they do and is visible in all elements of it.

The Public Involvement and Engagement team is based within the national support centre. They support different models of public involvement across Health and Care Research Wales, as well as coordinating public involvement activities. They provide advice to researchers on involving members of the public in studies to make the research more relevant, reliable and likely to change practice. A signposting service, directing researchers to relevant training and guidance is also provided, as well as financial support to involve the public in research development.

The team also supports the Involving People Network, which brings together members of the public from across Wales who are interested in working with researchers to improve treatments and care. Support includes advertising involvement opportunities, providing training, a weekly bulletin, a regular newsletter, and an online introduction for new members.

In March 2017, the Network’s annual event included interactive opportunities for researchers to pitch their ideas for comments from members of the public.

“ We are extremely proud of our model of Patient and Public Involvement (PPI) at the Wales Cancer Research Centre (WCRC). With the help of our eight PPI theme research partners and the WCRC research teams, we have implemented a rigorous and supportive PPI framework. Our public representative, Barbara Harrington, is currently working on the development of an impact measurement tool and this example, from the community theme, is just one of the many case studies we are developing across all themes.

Dr Annmarie Nelson, Scientific Director, Marie Curie Palliative Care Research Centre

At the end of March 2017 Involving People Network



In 2016-17



new opportunities offered to the public



...and over three quarters (76%) of new opportunities were appointed to.

Public Involvement Delivery Board

The Public Involvement Delivery Board is responsible for overseeing public involvement and engagement in health and social care research in Wales.

During 2016-17 the Board developed:

- **A set of seven core principles to guide effective public involvement activity.**
- **National Standards for Public Involvement with the Welsh Government and partners in England, Scotland and Northern Ireland. The Standards, which will set the benchmark for best practice in public involvement across the UK, will be officially launched in late 2017.**
- **A Public Involvement Achievement Award to recognise and celebrate excellent public involvement across Health and Care Research Wales.**
- **A close partnership with HealthWise Wales (see page 34), assisting the team to ensure the aim to be 'with the public, for the public' is fully realised.**

In 2017, the Public Involvement Delivery Board welcomed a new Chair, Barbara Harrington.

“ I am delighted to be working with such a dedicated and experienced group of public members and professionals. We are committed to enhancing the quality, relevance and impact of research through effective public involvement for the benefit of the people of Wales.

.....
Barbara Harrington,
Public Involvement Delivery Board Chair

The impact of effective public involvement

Marie Curie Palliative Care Research Centre were working on a study to support those bereaved through advanced illness. After personal experience of bereavement, Kathy Seddon, a member of the public, volunteered to get involved. She joined existing public contributor, Jim Fitzgibbon, who had already contributed to its success in being awarded funding. Before the first study meeting, Kathy met with the researcher, Emily Harrop, who provided the background to the study. Emily clarified the role Kathy would take in representing the interests of bereaved carers and providing a public perspective. They talked about the difference her involvement could make, by improving the experiences of study participants, increasing recruitment to the study, ensuring the study outcomes were those that really mattered to patients and carers, and making sure the results of the study were communicated widely to the public.

Kathy and Jim regularly contribute to study management group meetings including:

- **Improving communication materials for public audiences**
- **Identifying and recruiting bereaved carers to participate in the study**
- **Ensuring the public attending a consensus day fully understood the purpose of the day**
- **Supporting the public in making effective contributions**

A study survey was significantly changed, following feedback from Kathy, to use language that better reflected the emotional experience of bereavement.

Using their knowledge and networks, Kathy and Jim are looking forward to ensuring the findings of the study are widely shared.

“ The consensus day was for me something very special. I felt we could give some real direction to the debate and some balance.

.....
Jim Fitzgibbon,
Involving People Network member

HealthWise Wales

HealthWise Wales collects data on health and lifestyle that are not available from routinely available health and social datasets.

This includes information about sociodemographic characteristics, family make-up, caring responsibilities, cigarette smoking, alcohol consumption, physical activity, diet, mental health, and health during pregnancy.

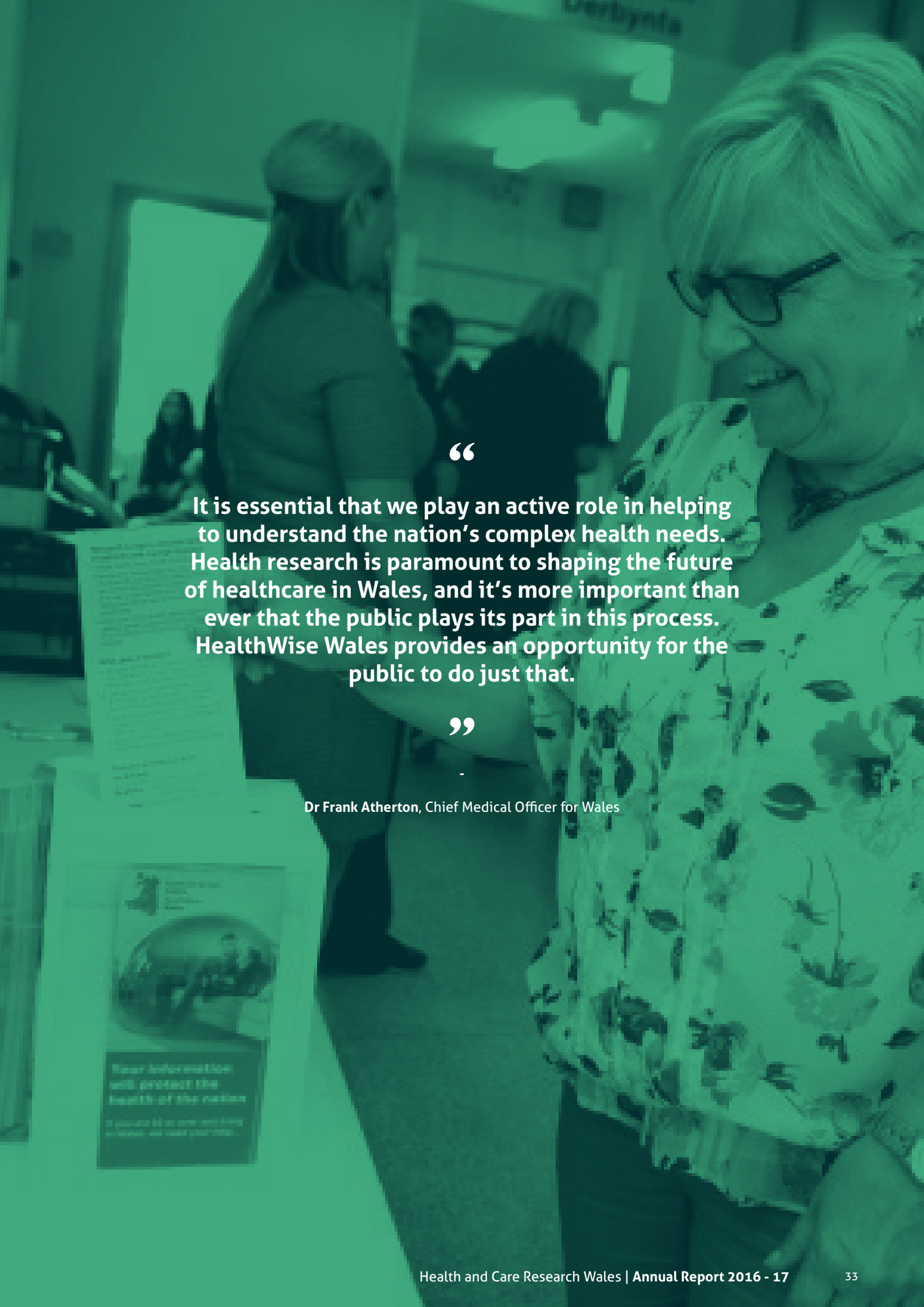
The HealthWise Wales study has also been used to support data collection for bespoke research studies. Researchers from the Wales Centre for Primary and Emergency Care Research (PRIME) are using HealthWise Wales to collect data on health seeking behaviour associated with coughs and colds to inform primary care services. HealthWise Wales has also supported recruitment to three other studies in Wales, including a National Centre for Mental Health study. Analysis of data from the first 10,000 HealthWise Wales participants will be completed in the autumn, with plans to feed back research findings to participants.

An NHS focused recruitment strategy is up and running, utilising the Support and Delivery Service to undertake promotion and recruitment to HealthWise Wales alongside other recruitment activities. Andrew Goodall, chief executive of NHS Wales, wrote to NHS chief executives in March 2017 to encourage all organisations to support recruitment. The General Practitioners Committee for Wales has signalled its support for the initiative and each GP practice in Wales has received a HealthWise Wales recruitment pack. Six dedicated HealthWise Wales recruitment posts have been advertised and will lead face-to-face recruitment to HealthWise Wales, both within the NHS and in other settings.

HealthWise Wales' network of champions has been busy promoting the study, helping with recruitment at a number of events including the Cardiff Food and Drink Festival and the Royal Welsh Show. The maternity modules have recently been launched and plans are in place to target public and private sector employees during the next year.



Doeth am Iechyd
Cymru
HealthWise
Wales

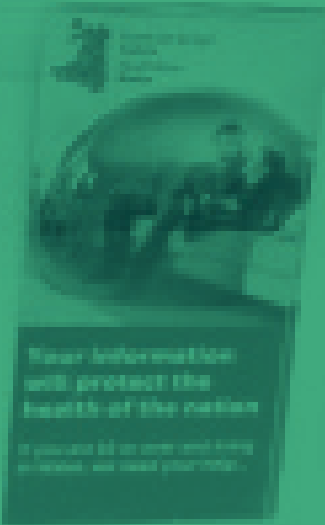


“

It is essential that we play an active role in helping to understand the nation's complex health needs. Health research is paramount to shaping the future of healthcare in Wales, and it's more important than ever that the public plays its part in this process. HealthWise Wales provides an opportunity for the public to do just that.

”

Dr Frank Atherton, Chief Medical Officer for Wales



Moving social care forward

The new Wales School for Social Care Research focuses on critical areas such as increasing and improving social care research and supporting the use of evidence in social care policy and practice. Directed by Professor Fiona Verity, the School is providing support and leadership in social care R&D across Wales, with staff at Swansea, Cardiff and Bangor Universities.

The School will provide a range of capacity building grants in 2017. These will include small grants, as well as academic PhDs, which will complement the ongoing joint-funded Health and Care Research Wales/ESRC Doctoral Social Care Studentships provided through the ESRC Doctoral Training Programme at Cardiff University.

The School will continue to expand its flagship 'Developing Evidence Enhanced Practice' (DEEP) programme, and it will also host ExChange, a Wales-wide programme of seminars to promote evidence-based practice in social work.

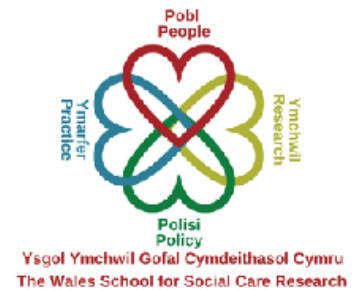
Joint governance arrangements have been developed with Social Care Wales to ensure social care R&D funding is directed towards areas of national priority, whilst maintaining the highest academic research standards.

Health and Care Research Wales, Social Care Wales, the School, and a range of stakeholders have developed a draft Social Care R&D Strategy for Wales. It identifies critical areas for development in social care R&D and describes a vision for Wales to be internationally recognised for excellent social care research that supports the people of Wales by informing and improving social care policy and practice.

We continue to support a broad range of social care research across Wales through our centres and units. At the Wales Centre for Primary and Emergency Care Research (PRIME) at the University of South Wales, a recent study has provided new insights into understanding male domestic abuse.

The South East Wales Trials Unit is conducting a number of trials in social care and the Centre for Ageing and Dementia Research (CADR), together with the Wales School for Social Care Research, will take over from Age Cymru as the new host of 'My Home Life Cymru' - a UK-wide initiative that promotes quality of life and delivers positive change in care homes for older people.

Social care research and links with practice are steadily being increased and improved across Wales with our support.



Case Study **Developing Evidence-Enriched Practice (DEEP)**

Health and Care Research Wales and the Joseph Rowntree Foundation funded the DEEP project, which identified five themes that need to be addressed for research to impact policy and practice:

- **Value and empower people**
- **Value and use diverse types of knowledge (policy and organisation evidence, research, practitioner knowledge and service user/carer voice)**
- **Capture and present knowledge in meaningful and engaging ways, e.g. storytelling**
- **Talk and think well together to support collective learning**
- **Tackle the things that get in the way, e.g. inappropriate policy, risk aversion and excessive bureaucracy.**

The DEEP project worked in one practice site (Carmarthenshire) to explore how to best support people with dementia from a human rights perspective. While local changes to workforce training and practice took place as a result of the project, DEEP also informed the production of 'Good Work: A Dementia Learning and Development Framework for Wales', which was commissioned by the Care Council for Wales and NHS Wales and launched in November 2016 by Vaughan Gething, Cabinet Secretary for Health, Well-being and Sport.

DEEP's five key themes were included in the framework, together with research findings about how best to work with, and support people with dementia.

The framework is currently being used across NHS Wales and local authorities to shape their dementia service and workforce developments.



Looking forward

“

The past year has seen us take some major steps to establishing ourselves as a model of excellence in Wales. It is now important to maintain the positive momentum generated and build on achievements to date. Supported by Welsh Government and the passion and commitment of its community, Health and Care Research Wales is well placed to realise its true potential and facilitate the delivery of high quality, innovative and evidence-based services and other initiatives that enhance the health, wellbeing and prosperity of the people in Wales.

”

Professor Jon Bisson, Director, Health and Care Research Wales





Image taken from:

'What is research?', Health and Care Research Wales' latest video. Visit the Health and Care Research Wales YouTube channel to find out more.

Today's Research; Tomorrow's Care.

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