

A case study to demonstrate how the WBFGA has been used to deliver long term positive health and social care impacts and outcomes

What is the case study about?

Research in NHS Wales is overseen by the Welsh Government R&D Division and directly funds NHS research activity through a ring-fence, protected budget. Each Welsh NHS organisation is charged with enabling as much research to be offered to as many patients, staff and its public as possible, providing equitable access to research.

The Welsh Government's current strategy for research mandates metrics for performance that includes annual increases in the quantity of research projects and an increase in the numbers of patients participating in research.

Sitting alongside and complementing the 'WBFGA' the policy document '*A Healthier Wales*' draws attention to the importance of research in Clinical Research to *enable 'longer, healthier and happier lives'.....'support and anticipate health needs, to prevent illnesses and to reduce the impact of poor health'*. In generating evidence and understanding research in the NHS has a broad range of objectives including improving health outcomes; generating wealth through employment; upskilling, educating and developing staff and the wider population of Gwent; increasing commercial and business opportunities and supporting the sustainability of the environment.

ABUHB has opportunities for patients, staff and its public to participate in research. One such project is a programme of research, the programme is in its 4th year, focuses on patients with dementia and their carers when this population is admitted to acute care settings. £1m funding from the National Institute for Health Research has been awarded for this research to be undertaken. This research was led by Wales (with 4 further English sites). This programme of research was designed and developed by Dr Katie Featherstone from Cardiff University in partnership with a carers group and ABUHB R&D Department and the ABUHB Dementia Board.

Whilst much is known about the care of people living with dementia in the community and Care Home setting, the experiences of people admitted to Acute Care Hospitals has not been researched. Using Ethnographic approach the finding included the high levels of resistance, refusal and rejection of care by people living with dementia when they were admitted to hospital. Such responses by patients were considered routine, normal and everyday behaviour by healthcare staff. Here, the rigid timetabling of care in the acute hospital setting was found to trigger patterns of resistance, and the acute clinical areas (across all the sites) were not set up to accommodate people living with dementia, especially when they had acute medical illnesses. Nursing staff struggled to respond to the needs of this population on acute areas. The commonplace cycles of resistance across the UK acute clinical areas were observed to be a response to the organisationally mandated timetables of care. This was observed to result in poor care experiences for patients, and emotional and physical burnout for staff.

Featherstone, K., Northcott, A., Harden, J., Harrison Denning, K., Tope, R., Bale, S., Bridges, J. (2019) Refusal and resistance to care by people living with dementia being cared for within acute hospital wards: an ethnographic study. Health Services and Delivery Research volume 07, number 11

The Featherstone et al project should be considered in the context of other research that has and continues to be undertaken into dementia, and ABUHB is playing its role as a leading site and also as a

participating site for national and local research projects. Doing so builds the strongest evidence to inform future practice.

How has applying the principles (5WoW) of the WbFGA been helpful?

Dementia has been a growing challenge across the health and social care settings in Gwent. Until this research was undertaken we have not understood the experiences of people living with dementia and their carers when they are admitted with acute ill health into acute healthcare settings.

Dementia is the biggest health and care challenge the UK faces. It can devastate the lives of people with the disease and their family and friends, and negatively impact on healthy living. Dementia often reduces the opportunity to live an independent life, where health outcomes are frequently poor. In recent years ABUHB has offered research opportunities in:

- NIHR funded project (£500k, with ABUHB as the lead site) jointly with Cardiff University (Dr Katie Featherstone) exploring resistance and refusal of care for people with dementia and their carers, when admitted to acute hospital at RGH.
- NIHR funded project (£500k, with ABUHB as the lead site) jointly with Cardiff University (Dr Katie Featherstone) exploring the care of people with dementia and their carers, of continence when admitted to acute hospital at NHH.
- The genetics of patients with early onset Dementia with Swansea and Cardiff University through the National Centre for Mental Health research.
- NIHR funded project (£30k, with ABUHB as the lead site) jointly with Cardiff University (Dr Katie Featherstone) exploring interventions to improve the experiences of people with dementia when admitted to acute hospital.
- NIHR funded project (£2.1m, with ABUHB as a site) including patients with dementia. A randomised, controlled trial of hospital at home with usual care at home.
- Equity of record keeping in patients with dementia (£20k, with ABUHB as a site) with the University of South Wales.

Dementia is having and is likely to continue to have a significant impact on the well-being of people living Gwent today and in the future. The 7 Well-being Goals provides an opportunity to enable partners across the system to clearly see their role and contribution to generating evidence and understanding of dementia to inform decisions about health, care and wider social impacts that are delivered in AUHB, Gwent and the wider UK. Nationally and internationally the findings of dementia research is being disseminated to inform policy and future care. Locally, the findings have been presented to the Dementia Board where health and social care staff come together to develop and deliver services across Gwent.

Applying the principles of the WbFGA i.e. the ways of working provides a unique opportunity for all partners to be focused on working in such a way that supports the multi-sector, system-wide approach that is required to tackle dementia.

What have you found to be most challenging?

1.1 Obtaining sufficient funding to undertake high quality research. The projects summarised above are examples of success in an environment where a research project takes many months to pull together and make a robust application. This is achieved largely through working with academic partners, (ABUHB is a University HB and has strong and strengthening collaborations), patient and carer groups, Trials Units and Industry.

- 1.2 Enabling access to clinical areas and supporting the extremely busy acute, hospital clinical areas and staff to participate in research with a vulnerable group of patients and carers.
- 1.3 Direct funding Social Care research is not made available to ABUHB and its performance metrics do not acknowledge the value of Social Care research but focuses purely on health research. These metrics do not support the wider policies in Wales to integrate health and social care.
- 1.4 Supporting the various research projects boards where R&D Department staff need to be active participants to ensure that high standard of conduct is maintained, funding is deployed correctly and staff remain engaged.
- 1.5 As research in ABUHB covers many aspects of patient and staff areas, topics and specialities equitable distribution of scarce research resources are distributed to ensure the maximum gain for our population. However, research to date has been concerned with:
 - Improving patient outcome through randomised controlled trails that investigate the latest and most innovative drugs and interventions.
 - Topic areas such as wellbeing of staff, cancer, mental health & learning disability, stroke, midwifery & child health, heart disease, adult obesity, rheumatology, dermatology, dementia, muscular skeletal disease, palliative care, vascular surgery, general surgery, recycling, vending machines, immunisation take up, Social Prescribing and community dentistry.
 - Enhancing employment opportunities through hosting and funding PhD through the Knowledge Economy Skills Scholarship II (KESSII) £21m European fund. This scheme grows high quality employment opportunities in Wales.
 - Working with Industry to undertake commercial research to increase wealth in Wales.

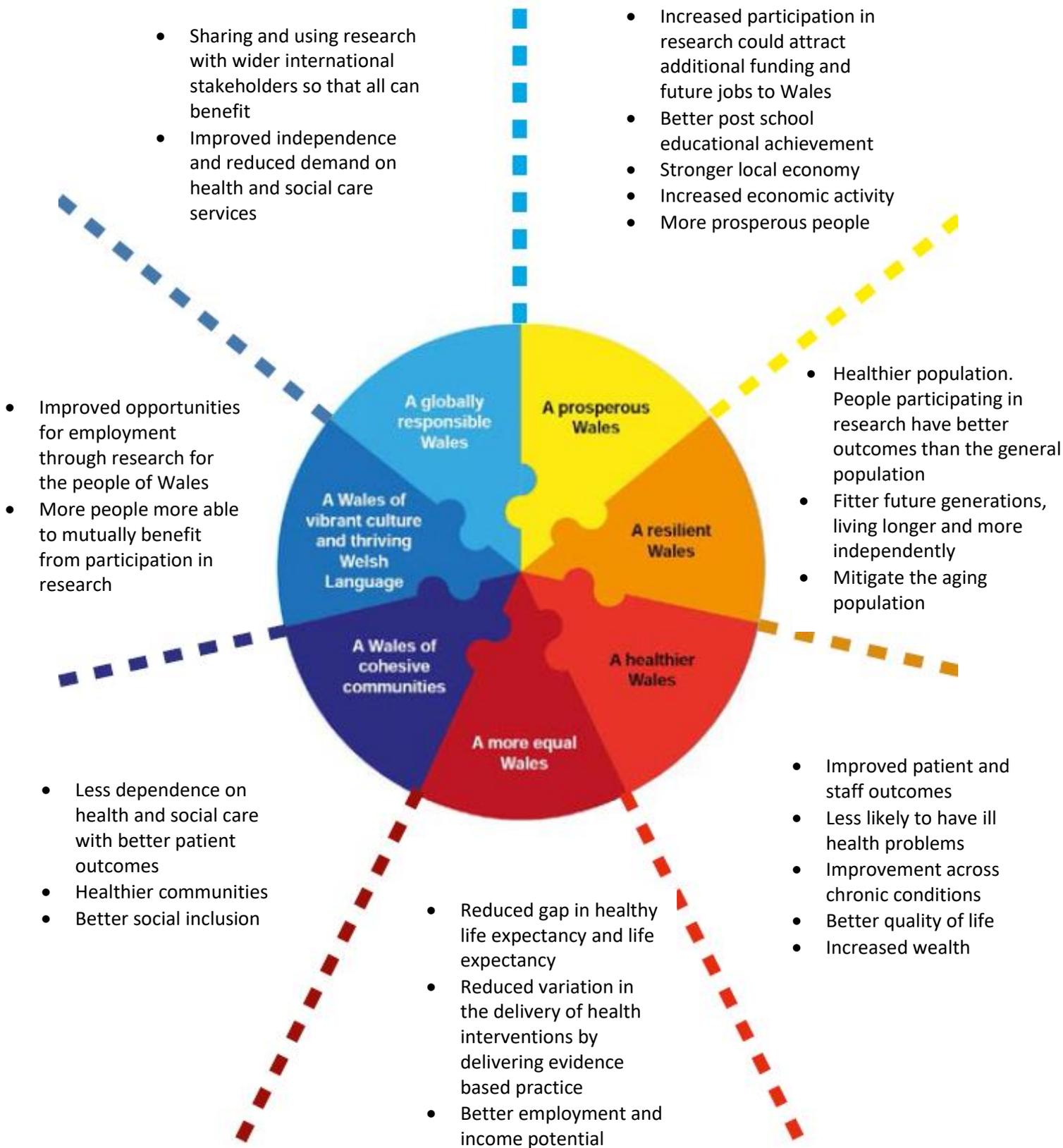
In meeting these challenges ABUHB, Social Care, Academic and Industry partners have a role to play in delivering high quality research to ensure a cross-system, multi organisational approach, with everyone playing their part (investing time and resource) and that this will take time and energy. We have started to map existing and forthcoming research projects against WFGA ambitions as an additional demonstration of how research absolutely fulfils its ambitions.

What lessons/learnings would you share?

The Act alongside '*A Healthier Wales*' is helping to frame current and future research activity, it is helpful in enabling the team to:

- Map existing and future research activity.
- Direct the wider Gwent community towards the evidence that has been generated, so that services can be designed in light of this evidence.
- Identify opportunities for research in line with the WFGA ambitions to maximise the potential economic benefits business can bring to an area.

How research will positively impact all seven Well-being Goals



How applying the Sustainability Principle and the 5 Ways of Working is helping to deliver positive impacts and outcomes from undertaking research in ABUHB

Way of working	What positive impacts/outcomes can be achieved by this way of working	How will we achieve these positive impacts/outcomes
Balancing short and long term - needs	<p>Enabling the increase in the number of research projects ongoing in ABUHB and increasing the number of patient and staff participants in research studies is known to improve outcomes for this population.</p> <p>The more research undertaken the better the healthcare staffs' knowledge and skills, staff retention, job opportunities in ABUHB and outside. This would result in a positive impact on the health and well-being of the current population but will have a long-term impact on future generations by shaping and protecting the environment we live in, influencing treatment options, the capacity and future of the services we use, the prosperity of the economy and the resilience of communities.</p>	<p>Support staff and patients and the wider public to participate in research studies</p> <p>Continue to provide resource support into key services such as research nurses, research officers as the main departments and workforce delivering research</p> <p>Support clinical and non-clinical staff to take the roles as Principle Investigators (ABUHB project leads) and Chief Investigators (grant holders)</p>
Integration	<p>Current income for ABUHB from WG only supports health research and performance metrics do not include Social Care research. This main funding could be diminished and lost if the R&D Department were to deploy its resources in this way.</p> <p>Integration currently is focused on Universities and Industry to fund and support research in ABUHB, so that joint applications are made for research funding and that Industry research is hosted.</p> <p>We continue to work closely with our University and Industry partners to ensure we understand how their objectives complement our own objectives.</p>	<p>Continue to develop partnerships with the ABUHB University Partnership Board to obtain more grant funding and host more research projects.</p> <p>Continue to develop the ABUHB partnerships with Industry to bring in more commercial research so that patients and staff access the latest and best new interventions.</p> <p>Increase access to healthy foods and influence healthy food choices in our communities</p> <p>Continue to test research projects against the five ways of working and to map them in terms of their contribution to the Health Board's Well Being objectives.</p>
Prevention	<p>Bring in research that explores the prevention of ill health and poor outcomes.</p> <p>Reducing ill health and the promotion of better health and wellbeing outcomes will positively impact on healthy life expectancy by preventing the development of chronic conditions and</p>	<p>Map existing projects against prevention.</p> <p>Consider where there are gaps and seek to enable research that addresses prevention.</p>

	premature morbidity. Focusing on all aspects of health from maternal health, healthy pregnancy and the early years as well as middle age and older people will ensure the best possible outcomes for our population.	
Collaboration	With funding and delivery models collaboration is the key mechanism by which this is achieved. A multi-faceted approach to promoting and delivering more research is essential. That is, research that informs and generates evidence on the whole life, wellness system will have impact across all of the 7 well-being goals.	Through University and Industry partners. Through the infrastructure provided through the R&D department. Through the workforce across health and social care to deliver research and enable their populations of patients to participate in research.
Involvement	Funding bodies expect that new research projects that are being developed are led and informed by the patient population and that these people are part of the funding application, the research project board, the analysis of data, the report writing and the final dissemination of the results. Unless these mechanisms are clear and transparent the research is unlikely to get funded. It is also essential that health and social care staff are involved in the same way as patients are (as described above). This is to ensure that the right questions are being formulated, that the right methodology is being employed to answer such questions, and that the delivery mechanisms are sensible and achievable.	Promote and ensure public and patient involvement in formulating research questions and design and also to support the entire process of research. Promote and ensure staff involvement in formulating research questions and the conduct of the entire process of research.