



Canolfan PRIME Cymru PRIME Centre Wales

Long Term Condition Research Strategy

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Introduction

This document is the Long Term Conditions research strategy for PRIME Centre Wales. In November 2015 PRIME Centre Wales convened a consensus meeting at The Priory, Abergavenny with service users and individuals from academia, government, statutory, third sector and industry to set its Long Term Conditions research priorities for Wales (appendix 1). There were 34 people in attendance. The meeting was led by Prof. Joyce Kenkre and Dr Carolyn Wallace (University of South Wales).

Policy Context: There are estimated to be 800,000 (27%) of the population in Wales who have at least one chronic condition. It is acknowledged that the prevalence of chronic conditions increases with age and it is predicted by 2026 32% of the population will be aged 65 or older (Wales Audit Office 2014). Thus demonstrating the urgent need to address prevention, future management and provision of services. The Welsh Government (WG), under the umbrella of *Together for Health* published a series of policy documents to address a range of chronic conditions (WG 2011,2012a,2012b,2013a, 2013b, 2014). The Management of Chronic Conditions in Wales – an update (2014) showed that progress has been made by patient education for self- management, increased budgets resulting in more nurses working in the community. Unfortunately, the improvement has not been universal resulting in unmet needs which require attention for more effective care, identification of risk and the prevention of unnecessary unplanned admissions (Wales Audit Office 2014). These issues and many more can be addressed by the conduct and evaluation in the communities of Wales

The aim and objectives of the day were:

Aim

To agree the PRIME Centre Wales Long Term Conditions research strategy.

Objectives:

- To bring together researchers, representatives from government, local authorities, commercial sector, third sector, community members and their supporters/carers.
- To identify the research issues, prioritise these and establish how they can be collectively delivered.

Methodology & Method

A Nominal Group technique was used to develop the agreed research priorities.

This consisted of three phases

Phase one-Private discussions prior to the event. All participants were asked to consult with their colleagues and bring with them three priorities for research.

Phase two- The face to face interaction with background presentations and consensus workshops to be reported below.

Phase three- The dissemination and consultation of the findings which will result from this report into the final document with an action plan for future research development.

The face to face interaction

The background presentations included the following:

- Dr Nefyn Williams set the strategy into the context of the new PRIME Centre Wales.
 - ‘Long Term Conditions and Co-morbidities’ is one of PRIME Centre Wales’ eight work packages. The primary and emergency care system is characterised by principles which include person and family centred multidisciplinary care which is often complex. The challenges of reconfiguring the system require more evidence for example through systematic review methods, co-production, routinely collected data, randomised controlled trials and the development of complex interventions.
- Dr Dan Venables gave a Welsh Government Perspective.
 - Dan introduced the Health and Care Wales Research infrastructure within its law and policy context from 2007 to date. This included ‘Designed to Improve Health and the Management of Chronic Conditions in Wales’ to the ‘Social Services and Wellbeing Act’. Health and Care Research Wales vision is for integrated multidisciplinary, multi-sector research, with an increase on impact, informing policy and practice.
- Dr Judith Carrier identified research gaps in the management of Long Term Conditions.
 - People are living longer and living with long term conditions which have a physical, psychological and psychosocial impact on individuals. However patients continue to feel that they are not involved in decisions about their care. There is a paucity of information about the management of long term conditions and in particular self-

management. Patients and professionals need further research to support their decision making.

- Rachel Lewis presented Age Alliance Wales research priorities for addressing the needs of the ageing population.
 - Age Alliance Wales is a collaboration of third sector organisations such as Age Cymru, Carers Trust, Arthritis Care and Disability Wales. These organisations provide a range of community based services that reduce the pressure on emergency care services. Rachel Lewis asked all of the organisations for their research priorities which included an investigation of transactional costs of systems thinking in relation to delayed transfers of care, the impact of changes in eligibility criteria, transport, dementia and sight loss, hospital discharge social care support, building research capacity in stroke care and age discrimination in health and social care.
- Prof. Richard Neal set the PRIME Centre Wales industry perspective.
 - Richard highlighted that PRIME Centre Wales will continue to work closely with Health Research Wales and is committed to undertake work with commercial partners in primary, community and emergency settings. He gave examples of current work with industry for example developing online training for clinicians treating older women with breast cancer in collaboration with Smile-on. Other studies include Johnson and Johnson, GlaxoSmithKilne, Merck, Sanofi-Aventis, Philips, Plain Healthcare, Medusa Medical technologies, Ortivus and Datix.

There were four rounds of consensus within the structured workshop where participants undertook the following which resulted in agreed research priorities:

1. Individuals wrote down their three identified key priorities for research on pink paper provided.
2. They were asked to pair with another person and present their ideas to each other. Then jointly agree on the most important three ideas out of the six originally presented. They wrote these three ideas onto the blue paper provided.
3. The pairs were then asked to regroup with another pair of participants (who had completed the same process) present and discuss their collective six ideas. The four participants were

then asked to narrow the six ideas down and agree three priorities. They wrote these onto the green paper provided.

4. The four participants regrouped with another four participants who had completed the same process and further presented and discussed their collective six ideas. As there were three groups in the previous round, this next stage resulted in two groups of 11 people with nine ideas each. These were negotiated and reduced to three in each group. These were written onto the yellow paper provided.
5. These six research priorities were transferred onto flip chart paper provided for the next stages, which were to agree the priorities and rate in order of importance.
6. The two flip chart lists of six priorities were then discussed and through agreement rated in order of importance. This resulted in the following research priorities.

Agreed Research Priorities

The six priorities were considered and negotiated down to five priorities because two priorities in round four were very similar. Delegates were invited to vote for their top three priorities.

Consequently, the following research priorities were agreed in this order.

1. To improve physical/mental function in patients diagnosed with a long term condition, could a holistic needs assessment facilitate
 - o Personal goal setting and action plan
 - o Self-monitoring/technologies enabled care
 - o Medication management
2. How to improve data sharing infrastructure in all health or social care environments. Using emerging technology in promoting prudent healthcare and social wellbeing, ensuring that there is an efficient technological infrastructure in support.
3. Engaging the communities in contributing to their own health and social wellbeing.
4. Engaging practitioners and people with long term conditions in the value of their participation in generating research evidence and information dissemination.
5. Examine the effects of sensory loss on people with dementia, stroke survivors and their carer's.

Identified Research Themes

The individual research priorities gathered in Step 1 above were analysed into research themes

The identified themes are as follows:

- Data sharing infrastructure and technology
- Self-management
- Interventions and outcomes
- Assessment and tools
- Sector and service access and transitions
- Research Engagement and capacity building
- Workforce, roles and community

Consultation Period

The draft documentation was distributed to all participants and to a wide selection of those who were not able to attend on the day. Those additional organisational representatives who responded have been included on the participant list in appendix 1. The consultation period occurred from 15th December 2015 until 25th January 2016.

Consultation Questions

- Question 1: Do you agree with the content of the consultation document?
- Question 2: Are there any disparities?
- Question 3: Are you currently leading, or undertaking research in any of the themes or priorities identified in the document?
- Question 4: Are there any areas of research you would like to take forward which are identified in the document?
- Question 5: Should we develop a steering group to take this strategy forward?
- Question 6: Are there any further suggested actions you would like to add?

Respondents to the draft document commented that:

- It was an accurate record of the day's activities.
- Very interesting, was adult focused. However, importantly, that said the areas for research selected are equally appropriate for third sector in children's services.
- Reassured that the emerging themes distinguished between service priorities and research priorities.
- Specific interest was shown in the wider use of Digital opportunists and Telemedicine as an economical way to improve health management services and improve interactions between patients and all health support services - from GP to Social Care.

- Volunteers for future involvement were received from the third sector and lay representation. Particularly in themes such as data sharing infrastructure and technology.
- Further suggested actions included a request to ensure a good standard of feedback between PRIME researchers and participating service users.

Next steps for PRIME Centre Wales Long Term Conditions Research

- Develop a steering group to take the research strategy forward.
- Identify people who are currently working within the research themes.
- Disseminate ideas, information on funding opportunities, research training and research outputs.
- Apply for funding grants for key areas including studentships.

Appendix 1 - List of participants

First name	Surname	Position	Organisation	Signature
Judith	Carrier	Senior Lecturer/Co-Director Postgraduate Studies (Taught) Community Nursing Research Strategy Board	School of Healthcare Sciences, Cardiff University Director Wales Centre for Evidence Based Care Programme Manager BSc CHNP (Overseas)	√
James	Champion	Program Manager, Europe	Qualcomm Life	√
Vera	Clement	Palliative Care CNS CHILDREN &YP	Cwm Taf UHB	√ Community Nurse research Network
Jayne	Cross	Workforce Development Officer	Care Council for Wales	√
Christopher	Davies	Service User	Involving People	√
Jan	Davies	Lay Representative	SUCCESS	√
Justin	Davies	Solutions Consultant	TBS GB	√
Susan	Davies	Primary Care Development Manager	ABMU	√
Ruth	Davis		Heb Ffin	√
Robert	Harris-Mayes	Lay Member	Involving People	√
Sarah	Hicks	Clinical Lead for Telehealth	Hywel Dda University Health Board	√
Karen	Hodson	Programme Director MSc in Clinical Pharmacy	Cardiff University	
Owen	Hughes	Consultant Psychologist	Powys Teaching Health Board	√
Hayley	Humphries	Head of Governance & Quality	Ty Hafan	√
Claire	Hurlin	Head Chronic Conditions Management	Hwyel Dda University Health Board	√
Janet	Ivey	Head OT	Cwm Taf UHB	√
Ceri	Jenkins		University of South Wales	√
Chris	Jones	Project Manager	Gwalia	√
Joyce	Kenkre	Professor of Primary Care Associate Director / Chair, Community Nursing Research Strategy Wales Board	University of South Wales PRIME Centre Wales	√
Carol	Killa	Director of Care	Ty Hafan	√
Rachel	Lewis	Manager	Age Alliance Wales	√
Gerrard	McCullagh	Clinical Lead Eating Disorders Service	ABUHB	
Nikki	Lloyd-Jones	Senior Lecturer	Glyndwr University	√

Social Care Research Strategy

Richard	Neal	Professor of Primary Care Medicine, Director of the North Wales Centre for Primary Care Research; Associate Director, PRIME Centre Wales	PRIME Centre Wales , Bangor University	√ GP
Rachel	North	Professor of Optometry	PRIME Centre Wales, Cardiff University	√
Jonathan	Richards	Clinical Director Visiting Professor	Cwn Taf University Health Board University of South Wales	
Ruth	Richardson	Continuing Care Manager	Aneurin Bevan University Health Board	√ Community Nursing Research Network
Gaye	Sheridan	Professional Officer	BASW	√
Mostyn	Toghill	Lay Representative	SUCCESS	√
Alun	Toghill	Lay Representative	Service User Research Partnership	√
Dan	Venables	Health and Care Research Wales Social Care Research Policy Lead	Welsh Government	√
Carolyn	Wallace	Reader in Integrated Healthcare and Frailty	PRIME Centre Wales University of South Wales	√
John	Watkins	Consultant in Public Health Medicine	Public Health Wales	√
Jeanette	Wells	R & D Manager	NHS	√
Jonathan	Whitman	Carer		√
Shirley	Whitman	Lay Representative Secretary	SUCCESS NPC Cymru Wales	√
Nefyn	Williams	School of Healthcare Sciences Clinical Senior Lecturer and Associate Director NWORD	PRIME Centre Wales Bangor University	√ GP

References

1. *Together for Health: A Five year vision for the NHS in Wales.* Welsh Government 2011; Cardiff.
2. *Together for Health, Stroke Delivery Plan: Our Vision.* Welsh Government 2012a; Cardiff.
3. *Together for Mental Health: Delivery Plan.* Welsh Government 2012b; Cardiff.
4. *Together for Health – a diabetes delivery plan.* Welsh Government 2013a; Cardiff.
5. *Together for Health – a heart disease delivery plan.* Welsh Government 2013b; Cardiff.
6. *Together for Health, Cancer delivery plan.* Welsh Government 2013c; Cardiff.
7. *Together for Health-a respiratory health delivery plan.* Welsh Government 2014; Cardiff.
8. *The Management of Chronic Conditions in Wales – An Update.* Wales Audit Office 2014.