



Involving People

Pathways for involving people in social care and health research in Wales: a signposting document

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The research carried out in this document was carried out in Autumn 2007 and was last updated on 3 December 2007.

This paper highlights the ways in which people are being involved in the NHS and the voluntary sector across Wales

Background to Involving People

The Clinical Research Collaboration Cymru (CRC Cymru) was established in 2006 by the Wales Office of Research and Development (WORD) in order to improve the quality, quantity and the processes of health and social care research in Wales.

Involving People: Cynnwys Pobl is part of the CRC Cymru Co-ordinating Centre, which supports the collaboration.

Involving People's role is to support and encourage patient, service user and carer involvement in health and social care research in Wales. Its aim is to do this by developing a skilled, patient, carer and service user network.

The Mapping Exercise

In 2007, *Involving People: Cynnwys Pobl* set out to a 'mapping' exercise to improve its understanding of the policies, structure, opportunities and approaches to involving people across all sectors in Wales.

Involving People: Cynnwys Pobl need to understand how people are being involved at the moment in health and social care across Wales and specifically how they are being involved in research in this area.

Involving People: Cynnwys Pobl should be using the existing structures to help it recruit patients, carers and service users to its network but to do this *Involving People: Cynnwys Pobl* needed to understand where and how people are currently being involved.

In order to understand the existing involvement structures, *Involving People: Cynnwys Pobl* carried out a mapping exercise. Barbara Moore of WCTN (Wales Cancer Trials Network), assisted to map pathways for involving people specifically in cancer related research.

Data gathering

Data was gathered by creating a database of contacts across CRC Cymru, the NHS, the voluntary sector and cancer specific services. These people were contacted and asked specific questions relating to their involving people activities and approaches.

The authors have recognised that the existing pathways for involving people in NHS and social care research in Wales are considerable, and it was not possible with our limited resources to report on everything. We therefore decided to limit reporting at this stage to the following:

- Pathways via CRC Cymru Thematic Research Networks/Infrastructure Support Services
- Pathways via NHS bodies
- Pathways via Third Sector Organisations which have existing links and relationships with CRC Cymru

We also recognise that the pathways and routes to involvement will change over time. On this basis, we intend for this report to be used as a working document, to be updated as and when new links and developments are made.

Pathways via CRC Cymru

We are aware that since the research for this report was conducted, the extent of patient and public involvement in CRC Cymru research has greatly increased. Here we report on what was found at the time of the mapping exercise.

The following points can be made:

- Few networks are currently actively involving people in their research activities
- Networks are however making plans to involve people in research, particularly in the capacity of the Research Development Groups (RDGs)
- A number of networks are keen to work closely with *Involving People: Cynnwys Pobl* to develop a framework for involving people in their research

Some examples of active involvement include:

- Service User representation on Mesur Iechyd Cymru RDG of LLAIS (Language Awareness Infrastructure Support Service)
- Service User representation on Stroke RDG of OPAN (Older People and Ageing Network)
- Service User representation on Advisory Group for TRUST (Thematic Research Network for emergency and UnScheduled Treatment)

NHS Wales Involvement Structures

We are aware that since the research for this report was conducted that the structures of the Trusts in Wales have changed. We believe however that it is important to discuss our results in terms of the structure at the time when the mapping exercise was carried out.

A few brief overall points can be made:

- LHBs across Wales are involved in planning and allocating health services therefore we would expect that their involvement activities revolve around planning and strategy and this is as we expected.
- Health Inspectorate Wales Reports have been used to get a general idea of their PPI (patient public involvement) activities.
- Research and Development Committees in Wales do involve patients in research but this tends to be on a small scale, with few numbers.
- Research and Development (R&D) departments differ in the manner by which they involve people in research, but in general it can be said that on the whole, patients are involved in the R&D process within NHS Trusts.
- R&D committees often include patients, and some of these people sit on scrutiny committees and research risk committees. Patients are often involved in reviewing project proposals and patient information resources. Their role is to give their view from the perspective of the patient.
- Community Health Councils were also included in this area of work.
- Not all LHBs or Trusts responded and therefore there is an absence of information for certain regions.

North-West Wales

In North-West Wales it appeared that the situation was varied, LHB's seemed to be involving patients in planning and in the reviewing of information. The Health Inspectorate Wales reports, for North West Wales area in general, suggest that their PPI (patient public involvement) activities need strengthened.

Gwent

In Gwent the Health Inspectorate Wales reports suggest generally, that there are well developed PPI processes. In Gwent there are positive examples of patient involvement in research, with 2 patients sitting on the Research Scrutiny Committee of a Research and Development Committee (R&D Committee) and an expert patient is also on one of the research groups of the R&D Committee.

Cardiff and Vale

In Cardiff and Vale there are mixed reports from Health Inspectorate Wales regarding PPI, with some organisations showing improvement, while others have less well developed activities. However in Cardiff and Vale there have

been opportunities for patients to become involved in research and one R&D Committee has 22 projects from the end quarter of 2007, which involve patients.

Bro Morgannwg

The Health Inspectorate Wales reports from this region are mixed with some evidence of mechanisms of patient involvement in place but there is no particular strategy. Also some areas show well developed patient involvement approaches. The R&D committee has a Patient Focus Group which is involved in research and feedback.

Carmarthenshire

Little information made available to us from this region. There is one lay representative on the R&D committee.

Ceredigion and Mid Wales

A number of PPI activities are taking place. There has been involvement of patients in Cancer Trials.

Conwy and Denbighshire

There are many patient involvement activities taking place in this region. There was involvement by patients in an out of hours evaluation exercise. The Health Inspectorate Wales Reports suggest that PPI activities need to be developed.

North-East Wales

There is a public members group in this region whose members sit on committees and are trained in patient involvement and research methods. These public members have conducted research. The Health Inspectorate Wales reports show that there are well developed PPI processes in place.

Pontypridd and Rhondda

Little information made available to us from this region. Health Inspectorate Wales reports suggest that PPI activities are improving.

North Glamorgan

There are well developed PPI processes in this region and all patient information from the Trust is reviewed by patients. Two lay representatives sit in the R&D committee, they get a say on the projects being reviewed and have full involvement in the committee.

Pembrokeshire and Derwen

Little information made available to us from this region. The health Inspectorate Wales reports suggest that PPI processes are in place but there does need to be mainstreaming of PPI activities. We were not made aware of any patient involvement in research taking place here.

Powys

THE CHC's suggested that people are recruited to represent parts of the community where services are missing, such as the Parkinson's Support Group. Health Inspectorate Wales suggests that engagement of PPI is not embedded yet.

Swansea

The Health Inspectorate Wales Report suggests that PPI activity is fragmented. The R&D Committee has a Patient Focus Group which is involved in research and feedback.

Velindre

Little information made available to us from this region

Voluntary Organisations

Contact has been made with third sector/voluntary organisations which have an existing link or relationship with the Thematic Research Networks of CRC Cymru (as identified by network coordinators).

The organisations we approached were found to have a strong element of PPI, with the majority having access to a considerable number of patients and carers who are willing to get involved in activities.

In general voluntary organisations are involving patients, carers and service users. Some exciting examples are highlighted below.

- The Alzheimers society has a register of service users and carers who help review summaries of research proposals.
- Epilepsy Action have a network of people with epilepsy and their families/carers who have a say on research funded by epilepsy action.
- Age Concern has undertaken several projects that involve older people in different ways.
- RNIB Cymru and Shelter Cymru both involve the public in various activities.
- Funky Dragon involve young people and there has been some involvement in research to date.
- Save the Children Cymru don't have lay representation but plans for it are underway.

Conclusion

It can be said that many organisations across Wales are involving patients, carers and service users in many different ways. As yet however, there only appears to be a small number of patients, carers and service users involved in research. Hopefully this document gives an indication of the different approaches and opportunities available.

In addition to the mapping exercise we found that many people who we contacted were interested in *Involving People: Cynnwys Pobl* and we have been invited to meet with several contacts that have been made and this is an unintended yet positive outcome of this exercise.

This Mapping Exercise has given Involving People a sound understanding of how patients, carers and service users are involved in health and social care research in Wales at present. It has also allowed *Involving People: Cynnwys Pobl* to make contacts and continue communicating with the wider health and social care community. These contacts and links will be strengthened and developed by *Involving People: Cynnwys Pobl* to assist in the creation of new opportunities, support mechanisms and training.