

Patient and Public Involvement

2019 update



Definition of Patient and Public Involvement

INVOLVE defines patient & public involvement in research (PPI) as research being carried out 'with' or 'by' members of the public rather than 'to', 'about' or 'for' them. This includes, for example, working with research funders to prioritise research, offering advice as members of a project steering group, commenting on and developing research materials, undertaking interviews with research participants. At the Wales Cancer Research Centre (WCRC), we have adopted this definition to shape our involvement work.

(National Institute for Health Research (NIHR) INVOLVE)

The Wales Cancer Research Centre's Approach to PPI

The WCRC PPI programme for 2014-2019 was built upon the work undertaken by the PPI leads within the centre's constituent members in previous years, principally the Marie Curie Palliative Care Research Centre (MCPCRC) and the Wales Cancer Trials Unit (WCTU). This foundation is most clearly evidenced in the centre's Standard Operating Procedures which had their first incarnation in the MCPCRC. The lesson had been learned from this experience that meaningful involvement of Research Partners (RPs, the local term for members of the public involved in research) within research requires the support and involvement of senior members of research teams, and the time for researchers to become invested in their relationships with

Research Partners. With this in mind, the aim was to promote a culture of patient and public involvement in the new organisation. With the support of the WCRC director and its operations team, it was possible to identify resources to apply previous knowledge to develop what was intended to be an integrated, iterative and adaptive model of PPI with large-scale implementation across the WCRC's four research themes. The model is being implemented and is now in its fifth year of operation.

Perhaps the most significant feature in the centre's approach to PPI has been that its RPs' role is unlike that traditionally undertaken by members of the public in cancer research. While RPs do, on request, comment

on protocols and other documents, their prime role is strategic and ambassadorial, to effectively co-lead with researchers on all aspects of PPI within each research theme.

This approach has been underpinned by the production and dissemination of a range of documents, tools and other pieces of work:

- ◆ A scoping tool to establish a baseline of PPI activity in the centre (latterly rewritten to take into account the National Standards for PPI)
- ◆ A policy statement
- ◆ A Partnership Agreement setting out the mutual expectations of researchers and RPs, linked to a mentoring scheme for RPs

- ◆ The establishment of a PPI Group to oversee PPI, led by a lay person
- ◆ A diary to record PPI activity
- ◆ A pathfinder scheme to assess the impact of PPI activity
- ◆ A set of performance indicators against which to assess progress against the baseline

Crucial to any progress made to date has been budget support for the work, principally in the form of the appointment of a dedicated, part-time Project Officer for PPI, the support of senior management and the embedding of RPs in the centre's management structures and any policy development it undertakes.



Progress made and lessons learned

We learned from our scoping exercise that there was already a wealth of good practice in PPI among members of staff funded by the centre. This derived from and thrived thanks to the enthusiasm of individual researchers and clinicians. It derived also from firm and committed leadership at all levels of management. However, its strength, the interest and passion of individuals, was potentially its weakness: existing without a framework and support to ensure its sustainability. The gaps found in the original scoping exercise were largely about a lack of links to information and structures which would make the 'roll-out' of PPI less time consuming and more consistently 'high quality'. Too often lack of linkages resulted in time spent on reinvention of wheels that already existed. Hence the initial concentration on production of documents and engaging in structures. A particularly challenging aspect of the work has been having to recognise that a prime cause of any reluctance in researchers committing to PPI is that it does not generally form part of their job descriptions nor therefore part of their annual reviews. In short, it is done out of goodwill. The origin of this situation seems to be a general lack of willingness of funders to pay for anything that might be described as infrastructure including that needed to develop and sustain research organisations' commitment

to PPI. Equally importantly, there is no money for PPI before a grant is awarded, unless they apply to the Health and Care Research Wales Support Centre and this funding stream is not widely known. This can prevent researchers involving research partners in the prioritisation of research generally and on its early development.

Having said all of this, the commitment of researchers in the WCRC is strong and growing. It is rooted in the culture of the organisation, the way it talks and acts, on which all else stands or falls.

Progress was initially judged against a set of Key Performance Indicators (KPIs). However, it was recognised early on that these KPIs only recorded input, process KPIs and outputs rather than improvement in outcomes. In an attempt to remedy this, it was decided to examine how the system of PPI was impacting on the quality of research undertaken in the name of the centre. A search was made of the literature on the impact of PPI and thought given to how existing models of measuring PPI could be adapted to the particular circumstances of the WCRC.

While some of these models were very well thought through and impressive in their reporting they offered at least two challenges to researchers and

RPs in the centre:

- ◆ they were very resource intensive, requiring time, effort and financial inputs which were not available to the centre
- ◆ they did not suddenly appear fully formed in the organisations using them but were built on strong administrative foundations and grew out of a local culture developed over time. They were not easily or quickly replicated in other organisations

There was a further issue which seemed important initially, but which was fairly quickly put to one side. Most funders of research are very interested in metrics i.e. ways of measuring things, applying numbers to them, which have apparent value, and against which progress on an issue can be gauged. Having tried various ways to provide some meaningful quantifiable impact

measures, it was decided that this approach could only offer some 'false' or meaningless numbers, which could not be defended as true measures of impact or even proxies for them. In a sense, the production of these numbers was providing a wrong answer to the wrong question. The real question was not 'can you provide some numerical measures of impact?' but rather 'can you produce an indication that impact has been made?'

Thus, a decision was taken to attempt to do two things:

- ◆ To develop a methodology based on case studies which could demonstrate reasonably rigorously that the involvement of the public in research has impact on its quality
- ◆ To produce a way of demonstrating this impact which was not 'resource hungry' and could therefore, be used without



resources additional to those already available.

In other words, the way of measuring impact had to be both credible and usable by those responsible for using them in the centre.

At the time of writing, the system adopted is still in its pathfinder phase. However, early indications are that it is producing useful results without imposing unreasonable burdens on those using it. It comprises four elements

- ◆ The agreement of role descriptions and person specifications for RPs
- ◆ The compilation of a list of tasks to be undertaken by RPs in particular trials or studies
- ◆ The completion by both researchers and RPs of diaries recording progress against tasks
- ◆ Formative and summative joint reviews of completion of tasks by both parties where success (or not) and actions to take to improve the process in future is

recorded

All of this takes place in the context of the centre's Partnership Agreement (between researchers and RPs) document referred to earlier.

This process, as it stands, is not the finished product and it will certainly not satisfy those demanding impact metrics. However, what it does seem to establish is some reasonable expectations of RP impact, a means of recording them in a practical way and a framework which allows safe, unthreatening reflection on progress and the possibility of continuing improvement in practice.

Finally, it has become apparent that we need to do more to prepare our RPs for their tasks. As already indicated, they are allocated a mentor. They are also offered an induction which concentrates on the results of our scoping exercise and identifies priorities for future work. However, there is an identified need for a generic 'science of cancer' element in their induction.





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WITH THE NHS
AGAINST CANCER**



Future priorities

At the time of putting together the tool used in the initial scoping exercise there was no set of National Standards to inform it. The questions included in it were an attempt to tease out whether (then) current practice approached (then) acknowledged good practice for PPI.

The exercise, as indicated above, generated useful examples of good practice, awareness of things that needed to be improved and action plans, with support, to address them. When the centre came to rerun the exercise to determine progress in improving practice, the draft National Standards were available to help improve the tool. In the event it was relatively easy for the PPI team and RPs to map the standards against the tool and add in or clarify some questions which the original version did not address. Undertaking this 'rerun' in an audit has enabled the centre to identify priorities for action in any next phase of its contract with Health and Care Research Wales.

There are a number of individual actions arising from the scoping exercise being picked up and acted upon in the current individual themes. However, the major cross theme issues we have concluded we need to address are:

- ◆ Further refinement and roll-out of the impact assessment scheme for all RPs
- ◆ Increasing the diversity of the

pool of RPs available to the WCRC. This is something being worked on with colleagues in Health and Care Research Wales and more widely in the UK

- ◆ The further dissemination of our work both within and beyond the WCRC
- ◆ Improvement of the induction and training process for RPs
- ◆ Improving feedback to participants in research

One of the further conclusions that arose from the scoping exercise was that the PPI model cannot be exactly duplicated in each theme: a consequence of the wide spectrum of research in the centre is that the PPI model has to be adapted to better fit 'local' needs. For the pre-clinical theme in particular, there seems to be a need to reshape the approach to PPI quite radically and steps are being taken to create a lay faculty, a pool of RPs to be able to respond quickly to individual requests for help across a range of studies and trials.



Conclusion

There is much in current practice in relation to PPI in WCRC which needs to continue and be built upon e.g.:

- ◆ Further embedding of the centre's PPI policy and associated suite of documents
- ◆ Continuation of its PPI (steering) Group
- ◆ Inclusion of RPs diary system as part of a scheme to assess the impact of PPI
- ◆ The budget for support for both RPs and to fund the Project Officer for PPI
- ◆ The core role of RPs as 'consultants' to researchers
- ◆ Support to researchers wanting to use the National Standards in their work.
- ◆ Involvement in strategic planning bodies for WCRC such as CUICR and CReSt Cymru
- ◆ Development of a workshop for early researchers on how to involve PPI effectively in your research

However, there is a need, partly in the light of the new National Standards, to devote more effort to the following:

- ◆ Assessing the impact on research of PPI activity. As already indicated, we have a pathfinder

model for this which needs to be rolled out more widely. There is a need also to ensure it is used by all RPs working under the umbrella of the WCRC

- ◆ Addressing the issue of diversity in the cadre of RPs generally but more particularly in relation to individual trials and studies. Some work has already been done on this which will be enhanced by the centre's membership of NIHR's Diversity working group
- ◆ Development of training opportunities for RPs, particularly in ensuring that all have a good basic knowledge of the science of cancer
- ◆ The dissemination of the centre's work on PPI. As already indicated, it has been published in the award-winning book *Problem Solving in Patient-Centred and Integrated Cancer Care* through its own publication 'Public and Patient Involvement: Weaving the golden thread through research'. Opportunities have also been taken to share practice with other centres and units and by presentations at conferences. However, there is a need to consolidate this through journal publication. This will be a major priority for 2020 and onwards
- ◆ Reshaping the PPI model to meet more flexibly the needs of a diverse centre

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