PUBLIC AND PATIENT INVOLVEMENT: Weaving the golden thread through research
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FOREWORD

We hope you enjoy and find useful the first Public and Patient Involvement Annual Report of the Wales Cancer Research Centre (WCRC). It records and showcases the progress made by researchers and Research Partners (RPs) in embedding Public and Patient Involvement (PPI) in the centre’s research portfolio. We have been fortunate in many ways: having solid foundations on which to build, receiving the wholehearted support of our senior management and and external staff, and the wholehearted support of our external advisory board and, most importantly of all, having a group of researchers and RPs who respect each other and are all focused on the benefits of research to the public of Wales and beyond.

We talked at the launch of the centre about PPI being a golden thread to be woven through the fabric of our work. We have made great progress towards this being the reality. This report can only sample the achievements of many colleagues since the centre’s inception. Apologies to those we may have failed to acknowledge by name or study area. Many thanks for all your efforts and support. We look forward to working with you in the next two years and celebrating your achievements in our next report.

WELCOME

Dr Annmarie Nelson
Academic Lead for PPI and Paliative & Supportive Care Work Package Lead

Dr Jim Fitzgibbon
Lay Lead for PPI

Kate Cleary
PPI Project Officer

BEFORE THE WALES CANCER RESEARCH CENTRE

The WCRC PPI programme for 2014-2017 was built upon the work undertaken by the PPI leads across different organisations in previous years. We had learned that meaningful involvement of RPs within clinical research requires the support and involvement of senior members of research teams, and the time for researchers to become involved in their relationships with RPs. With this in mind, we aimed to promote a culture of patient and public involvement in the new organisation. Together with the support of the WCRC Director, and the operations team, and eight RPs, we were able to access the resources to apply our knowledge to develop an integrated and adaptive model of PPI with large-scale implementation across the four WCRC themes. The WCRC model is up and running successfully and is now in its second year.

DEFINITION

INVOLVE defines public involvement in research 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. (National Institute for Health Research INVOLVE)

GLOSSARY

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Wales Cancer Research Centre

Research Partners (RPs)
Term used to describe the role undertaken by the lay people recruited by the project

PPI
Public and Patient Involvement

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Ymchwil llechyd a Gofal Cymru
Health and Care Research Wales

Llywodraeth Cymru
Funded by Welsh Government
Launched in 2015, the WCRC is funded by the Welsh Government and is a vital part of Health and Care Research Wales’ infrastructure. Based in Cardiff University, we have an all-Wales brief. The centre works alongside numerous partners within the cancer community including NHS Wales, other Welsh universities, cancer charities and the pharmaceuticals industry.

The WCRC is split into four themes and is further separated into specific sub-groups called work packages to cover the breadth of cancer research:

**Pre-clinical Theme**
This Theme supports laboratory studies that define the mechanisms of cancer development and progression and identify potential diagnostics, biomarkers and treatments that can then be taken into clinical research settings to improve patient outcomes. The Work Packages are: Cancer genetics and genomic instability; Cancer immunology; Signaling and stem cells; Drug development and model systems.

**Translational Theme**
Translational research brings discoveries from the lab bench to the bedside and from the bedside to the bench, in return. This theme will “translate” findings into therapies for patients, and enables scientists, using samples from patients, to understand cancer better.

**Clinical Theme**
Clinical research involves implementing the findings of pre-clinical and translational research, and is the first stage where new therapies are brought to patients in trials. The work packages are: Early Phase Clinical Trials; and Trials Through to Practice.

**Community Theme**
The Community Theme focuses on three areas of strategic importance in improving patient outcomes and experience: Screening, Prevention and Early Diagnosis; Integration & Informatics and Palliative & Supportive Care research. This theme builds on existing strengths of methodological innovation and grant capture across the cancer care pathway.

**Public & Patient Involvement: Our ‘Golden Thread’**
From the outset, there was a clear aim that PPI should be central to all that we do; therefore rather than create a fifth, separate, PPI & E Theme alongside the four research Themes, the decision was made that PPI & E should be an integral part of the centre. At the centre’s launch the description ‘golden thread’ was used to highlight how PPI & E would be woven into everything the Centre did and since then, this description is constantly referenced to depict PPI & E’s role in the Centre: a clear indication of how valued PPI & E is within the WCRC.

Our vision is: “To work with cancer patients and other partners to develop and deliver research excellence which benefits the health and welfare of people in Wales and beyond.”
OUR APPROACH

‘FUN’ FOUNDATION ON RESEARCH

We endeavor to make PPI involvement useful, enjoyable, and easy for both researchers and Research Partners (RPs).

We have always worked jointly with Health and Care Research Wales and the Involving People Network so that our RPs and research teams are able to access guidance, training, and support. The success of our model is a combination of all of the above, and the pragmatic approach we took to develop and progress the model. This work started with a scoping exercise of all of our research areas. From this we learned what the barriers and obstacles were, and where good practice was already in place. We were able to tailor PPI support to each research area with creative input from our RPs. Our PPI policy was the last document to be written as part of a comprehensive suite of accessible documents to facilitate PPI by researchers and RPs.

We are a research organisation and all good practice needs an evidence base; to this end, we are also active in contributing to the research base for PPI. Aside from regular evaluation of our work in situ, we are also committed to formal research. Our research colleagues in the UK have recently completed a prioritisation exercise to establish important research topics in PPI. In the next few years, we will be contributing our knowledge to these topics, as well as working to the new PPI national standards, to ensure that we continue to support and undertake PPI in the most effective way possible.

The METHODOICAL study identified research priorities to improve how we do PPI in clinical trials. They organised a survey which ran between October 2015 and March 2016.

The final set of priorities include:

- Developing strong and productive working relationships between researchers and PPI contributors.
- PPI practices in selecting trial outcomes of importance to patients.
- A systematic review of PPI activity in improving the accessibility and usefulness of trial leaflets and information sheets for clinical trial participants.
- Adapting PPI to the particular needs of individual clinical trials.
- The resources needed for PPI activity including time and money.
- PPI practices to address the challenges of recruiting and retaining participants.
- PPI practices in selecting how to measure trial outcomes.
- How is PPI involved in the dissemination of results and assessment of effectiveness?
- How do PPI contributors achieve and maintain an authentic patient perspective?

Perhaps most significantly in the way we have been working, the role that our RPs undertake 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 ambassadorial and strategic, to co-lead on all aspects of PPI within our research Themes. This annual report celebrates the achievements of all those working in PPI and highlights some of the excellent projects currently being undertaken.

OUR VISION FOR PPI & E

Our vision for PPI is to deliver:

An active partnership between the public, researchers and others, to develop cancer research in Wales to improve their health and well being.

In line with the provisions of the Research Governance Framework for Health and Social Care in Wales, we are committed to full active involvement of the public in our research.

OUR AIMS

Our aims are to:

- Work with key partners in the public and third sector to bring together expertise, insight and experience in the field of public involvement.
- Identify and maximise the appropriate opportunities for public involvement in cancer research in Wales, avoiding tokenism and ensuring involvement happens wherever it can add value.
- Embed public involvement across all aspects of our work (including work streams, advisory, governance reviews).
- Work with key partners to develop capacity and capability for public involvement in cancer research in Wales.
- Learn and share knowledge and experiences of best practice in PPI.
- Enable the public to influence policy, practice and research priorities.

OUR APPROACH

In shaping our approach to this aspect of our work, we aimed to build upon the progress already made by our partner organisations. However, we aimed for it to be a hallmark of PPI in our trials and studies that it should be based upon a statement of:

- The impact expected of it.
- How that impact might be achieved.
- Whether the impact was achieved.

OUR OBJECTIVES

In practice this meant:

- Working with the Health and Care Research Wales Support Centre to communicate with the public and research communities about the commitment to this work.
- Developing mechanisms to evaluate and disseminate the impact of public involvement.
- Establishing realistic budgets to support this public involvement work.
- Confirming public involvement by working with partner organisations to develop a standard approach and disseminating best practice through agreeing standard operating procedures, guidance and supporting paperwork.
WHAT WE HAVE ACHIEVED

WHO DID THE WORK

Our PPI achievements could not have happened without the leadership and commitment to PPI demonstrated on a regular basis by the our Executive Group and our research themes’ PPI Liaison Nominees (this title describes a nominated staff member who is the main contact for any theme-specific project queries for RPs). This commitment and enthusiasm for PPI was communicated very clearly to other researchers and clinicians. In turn, the progress working groups for our four research themes embraced the challenge and invited RPs into their membership. Both symbolically and practically, this gave a profile to PPI that would otherwise not have existed. Researchers and clinicians throughout the structure were equally welcoming of support for PPI.

The beginning of the development of our PPI team was led by a volunteer Academic Lead and a volunteer Lead Research Partner, supported by a Project Officer. The latter quickly became knowledgeable about PPI and skillful in supporting this aspect of our work. By August 2016, eight RPs (two per theme) were appointed to respond to the agendas for action identified in the scoping exercise. These RPs are key agents for change: not only what they do, but how they do it, in a spirit of partnership, has been, and will continue to be, crucial to the achievement of our vision for PPI.

As we come towards the end of our first three years of operation, there is a need for a renewed drive towards our vision. This will be partly fueled by the need to implement our revised Standard Operating Procedures (SOPs) but also by repeating the scoping exercises that will, alongside the data collection exercise, provide a new agenda for action. The work on impact measurement and public involvement in priority setting for research are likely to be part of that agenda.

However, most important and useful of all, will be the publication of the National Standards for Public Involvement in Research. In the autumn of 2017 we will benchmark ourselves against them as an aid to ensuring that we continue towards delivering the best we can in all that we do.

To ensure that objectives are met and the RPs’ work is supported, a mixture of formal and informal management controls have been set up. A PPI Advisory Group was created to guide the development of policies and formal documents and to monitor progress. Meeting every quarter, the group evolved once all the RPs were recruited, and the majority of formal documents were finalised. The meetings then became an opportunity for the RPs to feedback on their work, share best practice and problem-solve together. To reflect this, the word ‘advisory’ was dropped and the meetings are now known as ‘PPI Group meetings’.

Each RP was assigned a ‘mentor’ (either the Academic Lead or the Lead Research Partner) should the RP need any advice or clarification on any aspect of the role. Rather than setting up specific times for meetings to take place, the mentorship was offered in an informal capacity; the mentor and RPs are in regular contact.

A modest PPI budget was established to fund the RPs’ time and expenses. All of the RPs record their activities using an online diary system, which is used to qualitatively collect data, and also provides an opportunity for RPs to voice their thoughts and opinions on the work they carry out. RPs record any activity that they feel is relevant as their role: often they find that the boundaries of organisations are blended together, so sometimes they might contribute to a project that overlaps with the work of other organisations. Rather than focusing exclusively on the work of our themes, we support collaboration and embrace the ethos that any work that contributes to the development of public involvement in cancer research should be encouraged and celebrated.


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A TOOLKIT TO SUPPORT RESEARCHERS NEW TO ENGAGING WITH THE PUBLIC

- Jim Fitzgibbon

When we established, in April 2015, it seemed sensible as a first step towards developing a comprehensive, high quality system of PPI to try to discover what was already happening and then put together a plan to build on good practice and to fill in gaps.

It was clear from the scoping exercise that within our Pre-clinical Theme there were outstanding examples of engagement with the public, but there was no system or mechanism in place to share this good practice, particularly with researchers new to presenting their research to the public.

It was decided, therefore, to develop a toolkit to be used in the development and training of, initially, PhD students new to presenting their research to the public. Its production was to be overseen by a group including RPs, a representative of the Health and Care Research Wales Support Centre and led by a senior researcher with a particular interest in engagement from Cardiff University’s Institute of Medical Genetics.

Over a period of two years the toolkit has been developed and refined to produce something which will be of immediate use to its initial target audience but also, it is hoped, to researchers more widely. It has three components:

- A standard presentation incorporating advice on how to relax before a presentation, examples of, and advice on, possible visual and auditory aids, advice on writing a lay summary, a game to play (see below) and tips on things to think about (and to avoid) in preparing a presentation.
- A handout of top tips for preparing presentations.
- Examples of games that can be used to engage with audiences including a ‘keep or trash’ exercise of words sometimes used in lay summaries. This last resource was provided by Cancer Research UK (CRUK).

After the initial presentation it is planned that the PhD (and other) students will be asked to produce a second session:

- A lay summary to be critiqued by their peers.
- A one minute film clip to be used as part of a potential presentation to the public but also to be retained as part of the resource for future recipients of the training.

It is anticipated that this toolkit will be tested in the winter of 2017 and be available more widely from January 2018.

When I became an RP for the WCRC, my first project was to investigate Good Clinical Practice (GCP) training for lay consenters for the Wales Cancer Bank (WCB). This would allow me to start a piece of work which would require some measurable input and allow me to get started as a Research Partner for the Translational Theme. A comprehensive training programme had been set up and delivered since August 2015 by the WCB manager to train lay people in consenting cancer patients to donate tumour samples to the biobank. I met with her to discuss what she wanted to achieve from the exercise and we agreed that the following questions needed to be answered:

- Is anything missing from the current training to prepare consenters for the role?
- Are there other types of consenting being carried out which fall into the same non-drug area (e.g. questionnaires, observational studies, physiotherapy procedures) which together may produce numbers which justify a GCP training specifically aimed at this type of consenting?
- Would it be possible to provide a certificate recognising the training consenters have undertaken?

The manager provided me with full documentation about the training including a Standard Operating Procedure and Powerpoint presentation, and I reviewed the resources from GCP course I had attended previously in preparation for a meeting with the GCP Training Manager at the Health and Care Research Wales Support Centre.

I met with her for an initial discussion on the training, followed by a meeting with the WCB manager and Public Involvement and Engagement Managers from the Support Centre to discuss the non-drug GCP training for consenters and any wider training issues for the WCB. As a result of both meetings it was agreed:

- The training materials were excellent and could stand on their own with some small additional material on data security and definitions regarding consent.
- Full GCP certification would not be appropriate as the GCP course was developed by the National Institute of Health Research to cover consent for a much broader area including drugs.
- If the slides were reviewed by the GCP Training Manager, then the course could be badged as ‘reviewed by Health and Care Research Wales’ on the certificate.

Lay Consenter Training for the Wales Cancer Bank

- Julie Hepburn

A Public Involvement and Engagement Manager subsequently attended one of the training days and delivered some slides on the Involving People Network and participated in the role play exercises. New certificates are now being created and the first ones will be given to consenters currently in training.

I feel that my role as an RP in this project was a very appropriate one of facilitator, as we are not employees and therefore not in a position to make decisions on the way forward. I felt totally involved at all stages of the project and communication was good with all the professionals involved. Writing this case study has confirmed for me the necessity of keeping organised notes and e-mails regarding meetings and progress. In any future project I will write a short summary for myself of what has been agreed and the intended outcomes, if only to be able to follow up at a later stage whether a change in practice has actually happened or to enable me to write a case study. In this case I am confident that the agreed steps have happened and that an improvement has been made which will benefit the WCB, the volunteers on the lay consentor training courses and the patients who are consenting – ultimately improving the support to researchers worldwide who apply for samples and/or data.
ASSESSING IMPACT - Jim Fitzgibbon

Our PPI team has been working on a toolkit to support the assessment of the impact made by the inputs of members of the public in various studies and trials. As part of this project, Jim Fitzgibbon and another RP, Sue Campbell, worked on a study to evaluate the potential benefits of automated Intensity Modulated Radiotherapy (IMRT).

Half of all cancer patients receive radical radiotherapy as part of their curative treatment. IMRT is an advanced form of radiotherapy which, whilst it is an effective treatment, is also more complex and requires additional resources compared to standard treatments. A solution to this barrier is the field of automated treatment planning, where plans are generated by computer algorithms. This has been shown to minimise time requirements and improve planning computer productivity by a factor of two.

The two RPs were offered an in depth induction to IMRT, met a range of personnel involved in the treatment who demonstrated to them the historic method used to plan it. They were invited to all the advisory group meetings and great care was taken to ensure that they understood in some depth what was a very technical area of medical science. In addition to support received from the study lead, an experienced clinician helped to ensure that the RPs felt engaged and valued.

Where needed, the RPs fulfilled their role as a critical friend and raised their concerns when some aspects of the study failed to meet its requirements. Perhaps not unsurprisingly, given the technical nature of the study, requests were made (and responded to) more than once to simplify language in documents such as the study protocol.

Both the RPs felt listened to in meetings and involved in decisions. They felt that some members of the advisory group had moved considerably from an initial position of suspicion of PPI and its usefulness to the realisation that inputs from RPs could be very useful. Given this progress, it was suggested that it would be possible to engage the RPs even more deeply in the technicalities of any extension of the study.

The study lead, Dr Phil Wheeler, felt that the presence of the RPs helped to keep the study focused on patient benefit. This was particularly important when the progress was not as swift as he would have wished. The RPs shared the collective aim of successfully completing the project and helped to keep it focused and patient centered.

While there was much that was positive for all parties in the project, there were a few things which might help to improve the impact of PPI on any extension of the study. These include:

- Having a clear role description for the RPs.
- Considering training and support needs.
- Refining the diary to link it to the tasks identified for the RPs and completion of the diary by the study lead and the RPs in ‘real time’.
- Consolidation of the final review meeting around the completed diaries and the minutes of the advisory group.

RAISING THE PUBLIC PROFILE OF CANCER RESEARCH AND CLINICAL TRIALS AT VELINDRE CANCER CENTRE

– Jeffrey Horton

This project examined the means of improving communication on cancer research and clinical trials to cancer patients, either prior to their referral or during their attendance, at the Velindre Cancer Centre (VCC).

The current project follows on from a previous study which reviewed the current practice of introducing the concept of research to cancer patients. This former study was known as ‘Tell Me More’ and was funded by Ténovus Cancer Care.

The output from the ‘Tell Me More’ project resulted in many recommendations, mainly focusing on raising awareness of cancer research and clinical trials amongst the public.

Key outputs from this previous study indicated that although there was a high level of trust in the clinical staff from the NHS, and in the NHS as an organisation, knowledge of clinical trials and research concepts amongst patients at the VCC was relatively low.

Because of this significant problem in general patient communication on cancer research and clinical trials, it was felt that some patients were not always presented with all possible options that may influence or assist long-term cancer care, together with possible alternatives for those patients who may be eligible for novel forms of treatment.

Largely because of lack of funding, the many recommendations from the ‘Tell Me More’ project have not yet been implemented at the VCC.

Thus, the aim of the current project was to secure funding to implement, in full, the recommendations from the project, working with Velindre to achieve this.

To control costs, it is our suggestion that the key activities that arose from ‘Tell Me More’ should be outsourced to a professional marketing agency who would manage the project on a day to day basis (over an initial six-month period) and this agency would drive the project through to early completion.

It is hoped that funding will be secured via the Velindre Charitable Trials. This project was to secure funding to implement, in full, the recommendations from the project, working with Velindre to achieve this.

- Philip Wheeler, Study Lead, Velindre Cancer Centre

“Working with RPs was a first for many in our team and due to the highly technical nature of our project it was initially difficult to envisage how the dynamic would work. We were fortunate to have two highly experienced and enthusiastic RPs (Sue Campbell & Jim Fitzgibbon) join our team and together we were able to successfully navigate this new experience. As project lead I found that RPs brought an important extra dimension to the group, such that the patient perspective was considered throughout what was a very technical project. RPs brought a level of independence to the project board and brought confidence and weight to unanonymously agreed group decisions. Finally and most importantly, RPs helped ensure a continual focus on our primary end goal, that of improved patient care.”

- Philip Wheeler, Study Lead, Velindre Cancer Centre

Finally, as part of our strategy, we will be supporting ongoing trust in the NHS proposals, its services and its staff.
PACT STUDY
– by Kathy Seddon and Mirella Longo.

The Marie Curie Centre at Cardiff University received funding from Velindre NHS Trust to conduct a study about the information patients may need when considering treatment options following a diagnosis of lung cancer, and any support they may require when making decisions. Research Partners (RPs) were involved in key stages throughout this study and played an important role in the study’s output.

SUMMARY OF RESEARCH
There are various stages to this study.

Researchers observed multidisciplinary team (MDT) meetings, held by clinicians responsible for the care of lung cancer patients, to see how clinicians decide which treatment options to recommend to patients. They also observed consultations between patients and clinicians to see how treatment options and information about treatment options are given to patients. They interviewed patients face-to-face to explore their views on the available treatment options.

Researchers also interviewed the clinicians face-to-face to explore how much patients are included in discussions and decisions about their treatment.

The analysis of this data has enabled identification of areas where patients and clinicians may benefit from information and/or support to help them discuss and decide on treatment options. The next stage was to use this information to design an intervention that patients and clinicians can use in their consultations to support them when having these conversations.

Patient representatives and clinicians were invited to attend a consensus day where a presentation of the study results was followed by a group discussion around the important aspects that the interventions should include. Participants were asked to help finalise the list of elements that the intervention should include, and the best way to deliver the intervention.

This successful consensus day took place in January 2017 and the research is now focusing on creating the intervention.

RESEARCH PARTNER’S INPUT
The RP input included:

PPI involvement in the development of the research proposal.

Normal practice at the Marie Curie Palliative Care Research Centre is to appoint RPs after funding is secured. Dr Jim Fitzgibbon who is a co-applicant of the Marie Curie core funding acted as an interim RP until RPs dedicated to the study were appointed. Dr Fitzgibbon commented on the following documents:

♦ The consent form.
♦ The patient information sheet.
♦ The study protocol.

The RPs appointed to the study attended and actively contributed to the group discussion around the analysis and interpretation of the data in the following forms:

♦ Information available to patients and their families.
♦ Jargon used at the MDTs meetings.
♦ Insight of MDT meeting discussions (e.g. hierarchy of roles).
♦ Referral patterns of patients.
♦ Patient recruitment.
♦ The RPs also valued the importance of having the clinicians perspective at study meetings.

The RPs were also involved in the discussion around the analysis and interpretation of the data in the following forms:

♦ They read a sample of transcripts of patient-clinician consultations.
♦ By highlighting the sensitive nature of some of the information reported and the need to support data analysis.

The RPs commented on DELPHI questionnaire developed for phase five of the study, the comments led to:

♦ Reducing the jargon to make it easier for carers and patients to understand.
♦ To add contextual information to the questionnaire to make it easier to follow.
♦ To simplify the DELPHI questionnaire length and make it less burdensome on the patient.

The RPs read and approved the protocol paper. They also acted as patient representatives at the consensus day group discussions, and made key comments around both the patient and the carer perspective such as:

♦ Reduce the jargon to make it easier for carers and patients to understand.
♦ Identify the main carer as an important element of the patients’ pathway.
♦ The role that the clinicians might play to help the patients include the carer in the management of the condition.
♦ One of the RPs made a presentation of her experience of being involved in the PACT study.

The RPs supported networking by:

♦ Helping to identify key stakeholders.
♦ Helping to recruitment of key stakeholders.
♦ Participation to conference.

During the training, the RPs showed high interest in understanding their role and acquiring any relevant training which would equip them with the relevant skills to fulfill their role. Both RPs received tailored training and found it beneficial.

“The Research Partners were of particular help in looking at transcripts of consultations to highlight jargon or inaccessible language, that we researchers have become blind to.”

Dr Annmarie Nelson, Chief Investigator
BEREAVEMENT CASE STUDY – Kathy Seddon

This case study looks at supporting people bereaved through advanced illness: a systematic review of the evidence and development of a Core Outcome Set (COS) for bereavement research in palliative care.

SUMMARY OF RESEARCH

Organisations, which provide palliative and end of life care have an important role to play in providing bereavement support to the loved ones of patients.

This research project sets out to systematically review the evidence on supportive interventions for people bereaved through advanced, progressive illness, answering these questions:

♦ What interventions are used to support which groups of people?
♦ What outcome measures have been used to measure effectiveness?
♦ What evidence is there for the effectiveness of these interventions for different groups of people?
♦ What are the critical features of these interventions?
♦ What evidence is there on the economic outcomes of these interventions?

The next stage involves two rounds of a DELPHI survey. All outcomes identified in the review and all outcomes ranked as ‘important’ on the consensus day will be included in the survey. Two more stages are planned to achieve a COS.

Active participation in each study management group meeting – asking clarification about issues such as:

♦ Project methodology.
♦ Database searches.
♦ Project phases.

Making constructive comments on relevant documentation:

♦ Ways to improve the lay summary of the draft protocol.
♦ Need to have a specific Patient Information Sheet for some stakeholders (e.g. bereaved carers).
♦ Piloting of the DELPHI questionnaire adding contextual information and details to make it easier and less burdensome for the lay respondent to understand.

♦ Reviewed information to be sent to key stakeholders ahead of meetings.
♦ Facilitating discussion groups with key stakeholders.

Supporting networking:

♦ Helping to identify key stakeholders.
♦ Help recruitment of key stakeholders.

RESEARCH PARTNER’S REFLECTION

It has been a pleasure and a privilege to help with this excellent and important research. The Chief Investigator leads a talented team and has always indicated that she values and makes use of the RP contribution. The consensus day was a particular highlight. Rich discussions were captured and used effectively. The research still has further phases so conclusions will follow on completion. This does however provide an excellent template for further COS work.

“For me the overarching (or underlying) thread is that the research partner’s focus on taking the patients, carer or lay person perspective, makes sure that research ideas, methods, conduct of studies work around them”

- Dr Emily Harrop
Chief Investigator

IMPROVING PPI CULTURE THROUGH PARTNERSHIP

– Kate Cleary

One of the areas of need identified in the Pre-clinical Scoping Report was how to increase the pool of Research Partners (RPs) available. RP Dr Jim Fitzgibbon met with Prof Andrew Westwell (Lead for our Drug Development & Model Systems Work Package) and RP Stephen Thomas to discuss how members of the public could be involved in the prioritisation, development, conduct and dissemination of research and put forward potential ideas.

Following on from these conversations, a new initiative has been developed to establish a lay faculty associated with the research and engagement functions of the Cardiff University School of Pharmacy and Pharmaceutical Sciences: a completely new project for the School of Pharmacy. This is a great example of how conversations can develop to encompass public involvement work broader than the WCRC and highlights a developing, positive PPI culture which is bedded down across and beyond our work.

The research scope of the School of Pharmacy is very wide ranging, including cancer research as a major area of focus. The priority of the lay faculty will be research funding and outputs, specifically activities such as reviewing and inputting (lay summaries) to grant applications. They anticipate that the size and diversity of School-based activities should keep a lay faculty of four to six people busy and engaged and the team are currently recruiting for the positions.

This new faculty will also work alongside the excellent pre-existing lay faculty in the Systems Immunity Research Institute in Cardiff University, established in 2015 by Matthias Eberl with three members, it has now grown to include six members and is a core component of the Institute’s engagement and involvement work. The goal is that both groups will help to develop a wide-ranging public engagement activities to the benefit of both the School of Pharmacy and the School of Medicine in Cardiff University.
EXAMPLES OF FURTHER MEMBERSHIP OF GROUPS & RESEARCH PROJECTS

Member of Centre for Trials Research Steering Group and Trial Review Group
Reviewer for Centre for Trials Research funding bid to Cancer Research UK
Member of Trial Management Groups for various cancer related clinical trials (HART, PARIS, PIPEAC, ABCacus)
Co-applicant for two cancer related research trials, ABACus and RAMAN
Reviewed Protocols for BICC, MICC, CORINTH and Bowels Inside Out trials
Member of Steering Committee for SAILOR trial
Member of group looking at Rectal Cancer Platform Study
Lay member of Management Committee for Swansea Trials Unit
Offered lay support to the following cancer trials: EAGLE, PIVOTALboost, VIM, SCALOP2 and COPALIA
Collaborated on the WCRC’s funding rebid
Raising the Public Profile on Clinical Trials (the Tell Me More bid)
Member of Health and Care Research Wales Public Involvement Delivery Board
Co-Applicant for the Marie Curie Palliative Care Research Centre Infrastructure Grant
Member of the HealthWise Wales Executive Group
Member of the CUICR Strategy User Group
Member of the Health and Care Research Wales Support Centre Involvement and Engagement Operational Working Group
Member of the Health and Care Research Wales Board
Member of the Wales School for Social Care Research Advisory Committee

WHAT WE LEARNED

We learned from the scoping exercise was that there was already a wealth of good practice in PPI in the WCRC. This was derived from and thrived thanks to the enthusiasm of individual researchers and clinicians. 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 we found in the original scoping exercise were largely about lack of links to information and structures which would make the roll-out of PPI less time consuming and more consistently of a high quality. Too often lack of linkages have resulted in time spent on reinvention of wheels.

Hence our initial concentration on production of documents and engaging in structures. A particularly challenging aspect of our work has been recognising that a prime cause of any slowness 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. 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. Put succinctly, there is no money for PPI before a grant is awarded. This can prevent researchers involving RPs in the prioritisation of research generally and on its development in individual circumstances.

However, the commitment of our researchers is strong and growing as evidenced not only in the case studies in this report, but much more widely. When asked recently what he thought success would look like for PPI in the WCRC, our Lay Lead, Dr Jim Fitzgibbon, replied that instead of researchers running away from RPs, they would run towards them for advice and support. This has happened almost from day one of our existence.

WHAT NEXT?

By the end of 2017 we will review progress against the new National Standards for PPI and also against the agenda we set ourselves after our initial scoping exercise. However, we know that we also need to look at the issue of diversity in Wales’ pool of Research Partners. We aim to refresh and renew ourselves for the next two years of our Health and Care Research Wales funding. A significant point of this will be to more outward looking, seeking to share what we have learnt and promote our achievements wider. We will be sharing our work in journals and in a commissioned chapter in a book titled ‘Problem Solving in Patient-Centred & Integrated Cancer Care’, to be published by EBN Health. We will continue to work with external organisations building on our relationships with Aberdeen University and through the METHODICAL project based at Liverpool University. In particular, we are keen to establish a core outcome set for PPI linked to the new National Standards for public involvement in research.

We look forward to building on the relationships we have developed, and welcome working with new partners in the community.
Through our interaction with the PPI lay representative within my work package, I was introduced to a prostate patient support group. This contact has led us to host the patient group meetings at our Institute, through which we have disseminated our research activities to this lay audience on several occasions over the past 6 months. This has proven to be an invaluable relationship instigated through the PPI program. We hope to repeat this exercise for breast and pancreatic patient groups in the future, based on this very successful model.

DR RICHARD CLARKSON, TRANSLATIONAL RESEARCH THEME CO-LEAD

Involving members of the public in our research is truly eye-opening and inspiring. Discussing ongoing projects, funding proposals and press releases with our research partners helps my colleagues and me enormously in retaining focus on real patient need and explaining our findings in a language that non-specialists can understand.

DR MATTHIAS EBERL, PRE-CLINICAL PPI LIAISON NOMINEE

We have been lucky to work with two research partner leads in our community theme. The experience has been overwhelmingly positive, and the impact stretches way beyond the confines of hard metrics. Our research partners have engaged as confident and enthusiastic colleagues. They have not wished to simply occupy a job title but have actively sought to redefine how they can become immersed in the work of the theme and become an inherent component of everything we do. They are brilliantly inquisitive and challenging – but want to bring solutions to the table as well as questions. They actively seek to make themselves available for the challenge and to support getting the research done. More than any figures and metrics can describe, their approach, attitudes and skillsets define their added value as colleagues invested in patient and carer focus research.

DR ANTHONY BYRNE, COMMUNITY RESEARCH THEME LEAD

I would say that Jeff’s involvement in the Tell Me More project has been absolutely critical. He adds two main perspectives – one from his history as a cancer patient and one from his career in business. He is able to recall his memories about the level of research/trial promotion within Velindre and is able to refresh this as he walks around Velindre as it is now. He completely endorses the underlying messages from the Tell Me More report: Velindre does not come across as research or trial active. Secondly his experience in business is completely different to the experience of people embedded in the NHS or University. It was his suggestion to seek outside professional marketing advice that we are pursuing. He balances the skillsets that the rest of the team have.

PROF JOHN STAFFURTH, CLINICAL RESEARCH THEME LEAD