## Patient and Public Involvement: Variations on a Theme Panel

***Lesley Griffiths***

My experience is rather different as I experienced patient and public involvement first as a qualitative researcher with a keen interest in patient and carer experience of health and social care.

On my first independent funded study I collaborated with a health professional who was sure his patients would be willing and happy to talk to us about their experience-as it turned out many of them were reluctant but we weren't allowed to speak with them until he had. Original idea to advertise for patients with experience wasn't followed up until very late on in study but when we did interview patients and carers they were very keen to describe their experience, but some were concerned about their interviews being available to the health professional who would have been able to identify them.

In future studies I always tried to speak with patients and carers informally while writing the bid. if possible to understand what was important to them-this wasn't formal involvement-just a belief that research was better and raised different issues if I spoke to patients and carers.

Opportunity to do literature review funded by Wales government which then allowed me a platform to preach about involvement citing English experience with INVOLVE.

Led to Involving People in Wales, I am now retired and participating in some research as a member of public but also to become a lay member of a policy implementation group which has allowed me to experience very sharply the discomforts of being involved in a group which has little experience of involving patients or members of the public as active members in its business.

I am the only patient/lay member-I have no contact with the other members of the meeting outside the meeting-no identified responsive contact with whom I can discuss issues or queries – it's a large meeting almost all of whom do have contact with each other in other contexts-when I have raised issues nothing is fed back- when I have asked questions for clarification the members of the meeting have not always been comfortable to share the answers with someone they clearly regard as something of an unknown quantity. I have worked hard to build positive relationships with several members of the group. I am well aware of the many of the difficulties of implementing policy against a difficult financial background, but it is clear that a research group which shares an explicit goal of researching a particular topic with potential benefits for patients and with well supported lay members is a very different animal from a policy implementation group with (sometimes) cross-cutting interests.

Given my own informal and formal contacts with involving patients in research I expected a very different experience but it clearly is the case that there is some way to go in Wales with a coherent policy or practice guidance for involving patients and the public in policy design and implementation, or service design and re-design. Sharing the experience of research involvement and highlighting some of the benefits gained could facilitate this. There is now a large body of research which could allow many of the advantages and benefits as well as the disadvantages and challenges of allowing 'outsiders' in to be shared and used to strengthen any co-production leading ultimately to better and more prudent healthcare.

Top tip-offer all lay contributors an 'insider' link person-a contact always available to support involvement-to translate difficult language/practice/ explain seeming no go areas.

***Julie Hepburn***

When I retired from my job in the Careers Service at Cardiff University nearly 4 years ago I knew I wanted to do something meaningful involved with the Community, which could use the skills and experiences I had developed through my working life, but wasn't sure what was available. I became ill immediately on retirement with stage 3 colon cancer and after my surgery and treatment I realised that I could use this experience to do something productive, useful and interesting in the form of PPI work through the Involving People Network and also through the NIHR and NICE.

I was quite surprised at how useful my work experience was once I became a member of research groups. Experience of Committee work, Quality Standards and service evaluation, questionnairing and report writing have all been of help in addition to my experience as a patient. The groups I have been involved in seem happy for me to question things and make suggestions on a number of aspects of the research and I think that sometimes it is useful to have a person who can stand back from the research a bit and see things from different perspectives – a bit like wearing several of Edward de Bono's Thinking Hats all at once. A Chief Investigator did say to me recently that she sometimes felt that she was too close to the research and it was helpful to have someone who could stand back and see things in a different way.

An example of this is perhaps something which happened recently in an ABACus Trial Meeting. ABACus is looking at cancer awareness in disadvantaged populations. The QOL questionnaire EQ-5D-5L had been proposed to be used in the research and I pointed out how similar the questions were to those on the PIP application form and that this might cause suspicion in participants on benefits as to where this information was going and whether someone from the DWP might be checking up on them. This hadn't been considered by the researchers, but it was felt to be an important point and the questionnaire was subsequently withdrawn from the research.

I certainly don't expect all my suggestions to be taken on board, but my experience so far is that they have all been thoughtfully considered which is all I would want.

We don't always get things right though and sometimes getting it wrong is just as useful. I recently made some comments on a questionnaire and completely misinterpreted what was being asked by the researcher. This quickly became apparent, but raised the issue that if I got it wrong; probably some of the participants would too. The next version was crystal clear about what was required.

As patient representatives we are in a privileged position as we can say anything as long as it is in the patient's interest, but sometimes being honest is not easy. I once felt I had to tell a researcher whilst I was reviewing his research proposal that the term 'watch and wait' sounded rather inhumane to me from a patient's point of view, even though I accepted that this had to be the path for the control group receiving standard treatment. The term was left in the protocol, but when the funders letter was received after submission, they too pointed out that patients don't like watch and wait as it sounds like 'watch and wait till I die'. They preferred the term 'active monitoring', and the next version of the protocol adopted this. This brings me to another point which is that PPI representatives can sometimes find it difficult to know if they are getting it right, particularly when our views are challenging. Confirmation and positive feedback can help to give us more confidence in putting forward controversial suggestions and views.

I have heard it said that if someone sits on a lot of these groups that they become a semi professional lay representative and are therefore no longer true members of the public – they go 'native' and become too cosy with the researchers. My opinion is very different to this. I feel that the more I do the more knowledgeable I become about the research processes and the acronyms and therefore I am more able to understand the discussions in the meetings and make useful observations.  Experience also helps to develop the lay person's confidence in making suggestions or critical comments.  The only problem might be if we stopped putting the patient voice first, which I think is very unlikely given that representing the patient is the reason most of us do this work.  This might be a topic you as researchers might want to express a view on in the question time afterwards.

This question of whether we are truly representative links in with efforts made by the newly formed SUPER Group to increase the diversity of its membership to better cover the population of Wales (Elevator Pitch)

In conclusion, I would just like to reiterate how much I enjoy the work I do and how much satisfaction it gives me to be able to contribute to medical and social care research.

***Robert Harris-Mayes***

Good afternoon ladies and gentlemen. As many of you know, I have been a lay contributor for a number of years initially with the former SUCCESS group which had an emphasis on chronic conditions. Since then I have become involved with a number of projects with PRIME the latest being the ERA project looking at electronic records in ambulances.

I am pleased to say that the challenges I have faced as a lay contributor have not been arduous. The greatest challenge is standing here in front of you! The benefits to me personally have been great as I get the chance to meet interesting people (like you) but more importantly I get the chance to make a small difference to health research.

I like to think I have made a difference to the projects over the years. It would be very nice to stand here and say: "But for my intervention this that or the other would have happened and so a such and such disaster was averted" But this has not happened to me though there seem to be many cases reported in the media

In my experience, my contribution seems to have been more subtle: such as talking in general conversation about my personal experiences of being whisked off in an ambulance. In the early stages of the ERA project I suggested that patient responses should be considered when paramedics are using electronic reporting devices. I can still recall lying in an ambulance for the first time wondering why the paramedics spent what seemed like an eternity filling in a form when what I really needed was to be taken to hospital ASAP to be sorted out. I now know more about why the forms are filled in. I was able to emphasise the ignorance of the general public (of which I am a member) to the researchers in the project.

I have also been able to describe what it is like being a carer for someone who has bad mobility problems. Few researchers are over seventy and personal tales and anecdotes of the trials and tribulations of patients of this age were very relevant when analysing and discussing research into chronic conditions.

I hope that all medical research has the aim of ultimately improving patient well-being. Even if its primary aim is to save money or resources, then that should ultimately improve the health service for everybody. Therefore I feel having a patient or carer present at project meetings and available for consultation brings a greater emphasis to the importance of the project.

Apparently, the ancient Romans used to have skeletons or mosaics of skeletons in their dining rooms to remind themselves that they were mortal. I sometimes feel that I am that skeleton. I am there to remind researchers that it is the patient they are trying to help.

Thank you