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Being a PPI representative: What is it like?

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Abbreviations

AMs – Anticipatory Medicines

NIHR – National Institute for Health Research

PPI – Patient and Public Involvement

REC – Research Ethics Committee

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ABSTRACT

I have a personal and professional background in healthcare and when I retired, I wanted to find activities to keep me engaged. I was told about a Patient and Public Involvement group at the University of Nottingham and joined in 2013. Since then, I have been involved in supporting a number of studies, but in 2015 a professor asked for someone to take on a co-applicant role on a new study exploring the management of medicines for those seriously ill and dying at home. This commentary sets out the ways in which I have been involved and how this experience has been for me.

Since taking on this role I have worked as part of the study team, alongside academics and clinicians to develop the study protocol, gain ethical approval, support data collection and help write the final report. Some of the key challenges for me have been to be involved in data analysis and report my interpretations to the rest of the research team, to help organise and deliver engagement events and to speak up for the 'patient and public' in team discussions. While initial set up for payment of my role was a particular area of complexity, I have enjoyed being involved in a research study as a co-applicant and I am keen to encourage other PPI representatives and researcher teams to undertake this kind of engagement in the future.

My Background

In 2011 my mum finally lost her life to dementia and assorted illnesses, aged 95. Mum's dementia became apparent after Dad died suddenly; it appears he had been compensating for her for some time. Mum not only had dementia, where she lost her speech and ability to care for herself or recognise family, she had strokes, transient ischaemic attacks, cancer of the skin and bowel, and developed epilepsy in her mid-nineties. Very early on in the dementia she lost the ability to understand the use of dosette boxes, mixing up days and times of medication and put herself at risk of overdosing.

During 2010 my wife started work at the University of Nottingham. Having settled in Nottingham I began to look at activities that I might get involved with and I became aware of the University of Nottingham Dementia, Frailty, Older People and Palliative Care, Patient and Public Involvement Advisory Group (PPI Group) after my wife had attended one of their meetings and mentioned it because of mum's dementia. It was during 2013 that I went to one of the meetings and have remained attending this group since then.

I have also had a career as Community Nurse for people with learning disabilities, providing support for patients, families and paid caregivers. This included supporting people with managing their medicines and I often thought that as a team we supported people well. I retired from nursing in September 2008.

Being involved with this research study, while a different area of care from the patient group I dealt with, allowed me to see how patients, families and carers felt supported or not dealing with medicines and the varied ways they administered both to the patient e.g., orally by tablet or fluid, or by injection etc and at specific times e.g., before or after food.

Patient and Public Involvement Group

The PPI Group was originally set up in 2012 for studies about dementia and older people's care in hospital (funded by a National Institute of Health Research Programme Grant for Applied Research). At the end of the initial study additional funding was secured alongside the expansion of the group to include palliative care, forming the University of Nottingham Dementia, Frailty, Older People and Palliative Care PPI group. The group is currently funded by contributions from individual research projects, covering travel and catering costs and providing meeting rooms. The group can be accessed by research teams across the Faculty of Medicine and Health Sciences and is regularly approached to give opinions on study focus, design and the wording for patient and public facing documents.

In 2015 the PPI Group was approached by Professor Kristian Pollock to discuss a proposed study aimed at researching medication at the end of life, titled "Managing medicines for patients with serious illness being cared for at home". This qualitative study aimed to:

1. Explore current practice regarding prescribing, access and use of medicines to support patients who are seriously ill and dying at home taking the wider network of care as a focus, and including professional, patient and carer perspectives
2. Identify mechanisms and processes for optimising medicines use and improving professional support and effective symptom control for patients who are seriously ill and dying at home.

The PPI group uses a two-page summary for researchers to complete prior to the meeting. This is used to outline the study and has a section asking what advice/support/help do you want to get from the group? Professor Pollock requested the following: -

Initial advice about the scope and focus of the study:

- Specific to prescribing and use of anticipatory medicines (AMs) in the last few days of life, or more general support for medicines management for dying patients being supported at home over a longer period of time (and to include AMs).
- Focus on patients and carers specifically, or wider network of care (including different professional roles: including scope for extending input of community pharmacist)
- What methods of data collection would be acceptable: e.g., observation, interviews, audio recording, review of medical records? Would a longitudinal case study involving some follow up be possible?
- Scope for group involvement and support in developing the study.

The PPI group and Professor Pollock discussed this proposal and several suggestions were made, helping to formulate and develop the study. At the end of the time allotted for this Professor Pollock

asked if anyone in the group was willing to be a co-applicant for the study, if so to please contact her at the University of Nottingham for further discussion.

Becoming a PPI co-applicant

Over the next few days, I considered this proposal and felt that it was of interest to me both from my family and professional experience. So, I contacted Professor Pollock. It was agreed that we should meet and explore what would be expected of a co-applicant, what I could or could not take on and what I was comfortable with doing. So, about a week later I ventured into the one of the great academic institutions of Great Britain, namely the University of Nottingham for a chat about PPI involvement!

The meeting with Professor Pollock lasted about two hours, we had a far-ranging discussion about my background and why I wanted to be involved with this project. Professor Pollock explained the reasons behind the proposal and how she thought the research would be undertaken. We also discussed how I could have input into the project and we agreed that this would be developed over time as I became more involved with the research team. At the end of the meeting, I agreed to be involved and more importantly, from my point of view, Professor Pollock felt that I would have something to offer to the research team. My agreed contributions are outlined in Box 1.

The research proposal needed development and it was decided to put an application for funding to the National Institute for Health Research (NIHR), there was a lot of work to do to prepare the proposal and all the necessary documentation. I became a study co-applicant as PPI member, and member of the project team. At this time, I contributed to and approved the 'plain English summary' section and also undertook to review and comment on the protocol and associated documents.

Box 1 PPI Involvement as agreed

- Involvement in the design of the research
- Inputting into the development of research protocols
- Being a co-applicant for funding applications
- Being an active member of the study management group
- Involved with the conduct, analysis and interpretation of the research findings
- Contributing to the study reports and supporting the development of dissemination strategies
- Stakeholder involved as participant in the different work packages as appropriate.

Once the application form to the NIHR was completed and submitted it took almost a year before I received notification from Professor Pollock that we had been granted funding and it was full-steam ahead. Once the funding was in place, we needed to apply for ethical approval from the NHS Research Ethics Committee (REC). This meant a further application form and the development of a number of documents for participants such as patient information sheets, carers information sheets, consent forms, letters posters and plain English summary. All of these I reviewed and commented on, sometimes adding one comment, but usually several. I took the position that my comments may

or may not be acted upon, and I never worried about whether they were pertinent or not, and I was always thanked for any input by all members of the team.

Eventually the application for ethical approval was completed along with all supporting documentation and sent to the REC co-ordinator, a few weeks later our application was dealt with by Derby Research Ethics Committee at one of their monthly meetings. I volunteered to go along to the meeting with Professor Pollock in my role as PPI representative and we both duly arrived at the building where the meeting was being held. After waiting for our turn, we were asked into the meeting room, holding about eight committee members. We were greeted and asked some questions which Professor Pollock answered. I was asked one question directly but had also supported Professor Pollock on a couple of queries when PPI involvement was mentioned. At the end of the meeting we left, it did seem strange to leave a room of people in silence, but further discussion about our application would occur after we vacated the room.

Around ten days later I received news from Professor Pollock the REC had given an approval subject to minor alterations, so the research could start very soon.

Managing Medicines at Home study: what did I do and how did I do it?

Now to begin to earn my keep! The application for funding also included payment for my input and I aimed to be involved as much as I could not only to help, support and query the research when appropriate, but also to keep the PPI group I belong to up to date with how the Managing Medicines study was progressing. I also felt that receiving money for any input meant that I should be involved as and when I could, either through meetings, or any aspect of the research I was asked to undertake.

Project Team meetings and Project Oversight Group Meetings were held throughout the research study (March 2017 – March 2020 after an extension). I attended all the Project Team meetings, a total of nine, and all the Project Oversight Group meetings, a total of five. At both these types of meetings I was an active member, asking questions, raising issues and also being involved with discussions. At both types of meetings, I was always treated with respect and not once was I made to feel uncomfortable. I suppose if anyone could ask what might be a silly question, the PPI person could certainly fill that place! I felt I must have been doing something right as my views were asked for on all sorts of issues and subjects and my replies or thoughts were given due consideration. As a PPI representative, I always tried to put forward the patient, families or carers views. I summarised progress in this study project to the University of Nottingham Frailty, Older People and Palliative Care PPI Group of which I am a member and represent the group in this particular study. Any comments from discussion at the PPI meetings where I gave feedback, I would report back to the project team meetings.

One particular challenge arose concerning the recruitment of a patient for whom proxy consent would be needed as the individual had a learning disability. This was brought to the Project Team meeting. I was keen to have them included, as in my view, this person added considerable value to

the study. I supported the decision to request an amendment from the ethics committee to allow us to include this person and this was subsequently granted. While only one case, including this individual added important research material to the overall data and I was glad to have contributed to this decision-making process.

I was also involved with analysing data from a small cross-section of interviews with patients, family caregivers and professionals. I spent a total of 47 hours over a few months reading the data and making comments. From this analysis, I gave two 10-15 minute presentations to both the Project Team Meeting and The Project Oversight Group around my perspective of initial analysis of project data and areas that I considered to be of interest. This identified a range of key issue for patients, family caregivers and health professionals. My feedback was reported in the NIHR progress report dated 17.09.2018.

I continue to be involved with contributing to study reports, having been asked to produce an outline of my involvement throughout the study for the final report for the funders. I have looked at and commented on proposed articles for publication concerning this study and its findings. As mentioned, I gave the Frailty, Older People and Palliative Care PPI group updates throughout the study and passed any comments back to the researchers.

I have taken a key role in engagement and dissemination events throughout the study such as organising and being present at a workshop for the PPI group where the research team presented an in-depth case to the group. This session was devoted to discussing the extended case study as part of the ongoing PPI engagement with the study to seek their feedback and advice on the data and how it might best be reported. As part of the study two one-day workshops for professionals, participants of the study and other interested parties, were held in Nottingham and Leicester. I attended both these workshops and was the person who greeted people as they arrived, completed the register, gave out the workshop pack and ensured attendees received a claims form for travel and expenses. I was also involved in roundtable discussions which were audio taped. When the study was extended for six months in order to publish some of the data specifically aimed at pharmacists. A half day workshop to develop a poster for use in the pharmacy setting was held in Nottingham for PPI members and professionals. This session was led by the pharmacist from the study team with me supporting this session by greeting and logging attendees; engaging in the roundtable discussions on poster development and handing out of vouchers for those attending at the end of the session.

Challenges of PPI involvement

The main issue was around payment for carrying out the role of the PPI representative. It is the expectation of funders that PPI input should be paid and this was costed into the application. The University decided that I should be paid as an independent organisation and sent me a document for signing. This I did and was known throughout the document as “The Caswell”. I rather naively thought I would be paid by being put on the payroll. At the end of my first three months, I had to invoice the University and was paid the full amount without any tax deductions.

I contacted the person who I had been dealing with and was told that I would need to speak to the tax office re payment of tax. So, I telephoned the tax office and explained what I was doing and how I was paid, at the start the tax official explained as a one off payment my tax code could be altered but when she realised that I would be getting this amount every three months for two and a half years she said I would need to complete self-employed tax returns. I had never done this in my life so I asked if I got the University to agree to employ me for this set time period could it be taxed through PAYE and the answer was yes. As this was at the start of the financial year, I had time to sort it out and it was agreed I would keep the tax office informed of any developments.

I contacted several people over the next few weeks at the University and I must say they were reluctant to employ me. I did speak to Professor Pollock and she thought it should be possible for this to happen and she put me in touch with the person responsible for the budget for the study. From this point on it began to appear that it was possible to be employed on a short term contract, but it was not easy to achieve and at one point I indicated that I would not put any more claims in but would continue as the PPI representative and at the end of the project the University could explain why the PPI was not paid. After several months it was agreed that I could be on a short-term contract for the study only and I completed timesheets thereafter and tax was taken at source.

I informed the tax office and they altered my tax code for that year to allow the outstanding tax to be paid.

Reflections of PPI Work

I found the whole process of research interesting and would encourage any person who is part of a PPI group to get involved as a PPI representative on a research study, but would advise that it should be a topic that you want to be involved with. Having a background in health care and caring for my mum towards the end of her life gave me a good insight into the aims of the study. In my background of having been a nurse all my working life I am used to communicating with a range of health professionals. During this study I felt that care was always taken to include my voice in discussions.

From the start I decided that whatever I was asked to do, if I felt I had the skills or could develop the skills I would have a go at it. Throughout my involvement in the Managing Medicines research study, I felt well supported by all the research team. Whenever I was asked to be involved it was always made clear I could say no or if I found the task to demanding or felt not able to complete, I could withdraw from that particular task at any point. I never felt that it was expected that I would automatically say yes. I was always thanked and sometimes this was both verbally and via emails. Overall, I enjoyed being involved and have since become involved in another research study about end of life care.

Box 2 Reflections from the principal investigator

Patient and public Involvement (PPI) is integral to our research. As Alan's account illustrates, our research group has been fortunate in working with an established PPI group for nearly a decade. Members advise on every stage of the research process, from early discussion of topic, design, ethical issues, content of information sheets and interview schedules. They also contribute to data collection, analysis and publications, including review of the final project report. However, this is the first project I have led in which we have benefited from inclusion of a PPI representative as a co-applicant. This has enabled greater integration and continuity of PPI involvement from the outset and has enabled Alan to develop a deep understanding of the study and its challenges. As researchers, we have benefitted from Alan's involvement in many ways. His perspective as a public advocate has allowed us to see the study from a different perspective and I believe this has improved the way in which the study was planned and delivered. He has embraced working with clinicians, researchers and academics and has been considered by the team to bring considerable expertise as well as collegial support. From the outset we agreed with Alan that he should only take on elements of study engagement to the extent that he felt comfortable in doing so. However, his involvement has been considerable and has extended throughout all stages of the research. Alan's confidence has grown as he has taken on active roles in data analysis, dissemination and public engagement. I have particularly welcomed Alan's support as a very level-headed 'critical friend' as well as his encouragement and ongoing support through all stages of the study.

Kristian Pollock

Conclusion

For me, being involved in a research study from the early proposal writing stages has been very rewarding. I was given the opportunity to shape the planning, delivery and outputs of the study as well as work with a range of academics and health professionals. While my involvement in this study has been extensive, this does not always need to be the case. PPI engagement can be at a range of levels and can include commenting on study documents as part of a PPI group, providing perspective on lay summaries for funder reports, offering option on how a study might be set up, helping share the work in the community or acting as a member of a study team as I did. It is a great way to meet people, be involved in the direction of research and health care improvements and help make sure findings are communicated to the right people.

There is some progress to be made in University processes to iron out the practical elements of employing a non-staff member on a research study. However, this kind of work presents great opportunity for all involved and can only lead to better quality research. This paper is part of the dissemination process, as a way of explaining how I was involved as a PPI representative. I hope that my experiences will encourage other PPI representatives to take on wider roles in research and researchers to consider the benefits of a PPI co-applicant.