

An example of involvement of a public contributor on a cancer study

Human papillomavirus (HPV)- Related Cancers: My involvement with this study

I became a member of the Management Group of this study in 2014. The project was just beginning. My role on the National Cancer Research Institute Primary Care Clinical Studies Group linked me with the Principal Investigator for the study, Claire Wilkinson. She invited me to take on the role of Patient Representative (this would be described as a Public Contributor by People in Health West of England).

In terms of my suitability as a member of the Management Group of the study I had been interviewed and accepted for the role of Consumer Member (like a Public Contributor, Patient Representative) on the National Cancer Research Institute Primary Care Clinical Studies Group. I had experience in Patient and Public Involvement work since 2010 and would be described as experienced in the role. I did not have a role description for the work within the Management Group although when I met Maggie Hendry, Lead Researcher, she went through what I would be doing. With my experience, and the discussion I had with Maggie, I understood what was expected of me as a member of the Management Group.

I live in Gloucester. Other members of the Management Group were spread throughout Wales, England and Scotland. With the researchers based in Bangor, North Wales, meetings took place by teleconference quarterly. Knowing the Principal Investigator and the Lead Researcher helped greatly when emailing and on the phone. The Lead Researcher invited me to attend the Management Meetings in person. I could have attended all the meetings or just some of them. However, living in Gloucester and having to get to Bangor for the meetings, teleconferencing seemed the best option and the most economical. Expenses were offered and discussed.

Once I agreed to join the Management Group I was sent the study protocol. High-risk types of HPV cause all cervical cancer and the majority of vulvar, vaginal, anal, penile and oropharyngeal cancers. Although HPV is the most common sexually transmitted infection, public awareness of this is poor and many clinicians lack the confidence to discuss sexual transmission and related sensitive issues. The study was seeking to produce resources to guide these highly sensitive and difficult consultations, answering questions identified by patients in a clear, digestible, honest and salient way. I took my role seriously. I always made sure that I read papers, minutes, and draft papers ready for the tele-conferences. I didn't find the tele-conferences easy as it was sometimes difficult to hear but we all managed and co-operated. The Chair of the meetings always asked me if I had anything more to add. I felt that I was part of the group, I was treated equally alongside the health professionals and researchers on the group. All members of the group seemed to acknowledge the importance of having the patient perspective in the study. I always felt that I could ask questions if there was something that wasn't clear to me.

At the start of my involvement with the project I was concerned that I was not someone with the experience of an HPV related cancer. Should it have been someone with an HPV related cancer, I asked myself? I am, however, someone with personal experience of breast cancer and of cancer of unknown primary which my

mother had. I know that research is fundamental to improving treatment and services for patients and I believe that it is important and useful for patients to be involved with researchers in the research process. It wasn't until towards the end of the project I realised that it was more appropriate and helpful for me to have a 'general' experience of cancer in terms of the patient representative's role in the Management Group of the project. The patients themselves were the subject of the research and were co-producing the material that they needed. I don't think that it would have been appropriate for one of them to have been on the Management Group because they were too close to the situation. None of the clinicians taking part in the research (i.e. those treating the patients with HPV related cancers) were on the Management Group. I was impartial in terms of the cancer but still represented the patient perspective alongside the project researchers. This realisation was a learning experience for me in terms of Patient and Public Involvement in health research.

My experience of being part of the Management Group was a positive one. I felt valued and welcomed by the group. I had a good relationship with the Principal Investigator and the Lead Researcher and through them with others in the group. Paperwork came to me in good time. I enjoyed being part of the group. I have tried to support the researchers in disseminating the results using my networks both locally, regionally and nationally to encourage use of the information sheets produced from this study. This work is continuing. Disseminating the results is important to encourage implementation and something that patients can help researchers with.

This project was a good example of co-produced material. The researchers worked between the patients needing the information to understand their condition and the clinicians who were providing the information. The final information sheets were right for both patient and clinician and a good example of research for patient benefit.

If you would like to find out more about the research study here is the link to the final published paper and to the information sheets for patients and health professionals:

<http://bmjopen.bmj.com/content/7/6/e015413>

Comments from the Lead Researcher, Maggie Hendry, about Patient and Public Involvement:

Maggie said, "the PPI person (patient representative, public contributor) is part of the research team and has a responsibility to represent, as far as is possible, the views of patients/carers/the public in general, and not just focus on their own individual experience (though obviously their own experience will inform their views)".

Maggie also said that I have described my role in the Management Group well.

Referring to Patient and Public Involvement on a personal level, *Maggie said*

“I enjoy working with PPI reps. It helps at different levels, in different ways with different projects - but it always helps, never hinders. I think the more involved they get, the better.”

Funding for the project:

The HPV research study was funded by Health and Care Research Wales (i.e. Welsh Government funding), via their Research for Patient and Public Benefit scheme.

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22 February 2018