

Patient and Public Involvement (PPI) in Research – Case Study

Provided by:

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The study/group and how you were/are involved:

Oxford Vaccine Group (OVG) Patient and Public Involvement Group

My first involvement with the OVG was back in 2007 when they contacted me regarding a vaccine trial of the combined meningococcal vaccine. My daughter, my first child, was born in 2007 and I volunteered her to take part. I was very impressed throughout with the professionalism, enthusiasm and dedication of the team. Later I became aware of the OVG's excellent online information pages regarding vaccines; these are now branded as "The Vaccine Knowledge Project". I saw an online appeal at the end of 2014 regarding a trial of vaccines against Ebola, and responded online.

Whilst at the OVG premises in January 2015 as part of the Ebola trial I saw a poster regarding the PPI group, and volunteered. I attended my first meeting in March 2015. My point of contact was Sarah Loving, who has always been most helpful, friendly and informative.

The group has meetings throughout the year. We, as a group, are notified of the next meeting by email, the topic for discussion and potential dates. For example, the next meeting will take place in November regarding the OVG's involvement with a new research programme into collective responsibility for infectious disease. The OVG's new social scientist is about to submit a proposal to the ethics committee; this proposal will be forwarded to group members and we will feedback at the meeting. This is exactly the sort of project I am hugely interested in. Before I had my children I worked as a scientist (forensic DNA). It was only after my daughter was born that I really became aware of what the World Health Organisation (WHO) have characterised as the paradoxical and vociferous anti-vaccine lobby. I am fascinated by the reasoning of those who eschew vaccination, as well as by the arguments made by both sides. I am interested in the way such arguments are disseminated, and how they are presented to parents.

To give an idea of frequency of PPI meetings I have looked through recent correspondence. This year in January we had a hugely informative talk on the ethical side of vaccine trials, and the regulations involved, from Susan Tonks. Then in March we had a meeting at which we discussed a new typhoid study, and fed back on the documents. Apparently our input was much appreciated. In April we met and went through documents relating to the pertussis Periscope study, also a leaflet produced by research nurses at the Children's Hospital about volunteering for trials. In August we were contacted about the wording and format of potential recruitment adverts on Facebook and Twitter. Again, in September, we were asked for our feedback on revised versions on these possible adverts.

In addition to the above, Sarah Loving (knowing of my interest in this subject) has also contacted me and I have been involved as a co-applicant on a grant application for a respiratory syncytial virus (RSV) project; and I have provided feedback on a paper about the factors at play in vaccine innovation. Sarah Loving also makes us, the PPI group, aware of relevant online courses and resources which will be of use/interest to us and any local events.

The impact of being involved in the study:

We, as a group, can give a lay person's view of the information we are sent. I am a very interested and enthusiastic lay person! The teams involved in creating the documents we provide our opinions upon are experts, and hugely involved and committed in their projects. Our value is that we see it from the outside, we can point out that we (for example) don't actually "know" what enteric fever is, but understand what someone means by typhoid. Often the documents are very long and involved. Such detail is clearly important when issues such as informed consent are involved; but we act as a reminder that people like us will be reading the documents sent out to households. User friendly summaries are hugely important, being overwhelmed by technical terms and detail on the first page can lead to a carefully crafted document going straight in the bin.

We can explain when the wording is sometimes confusing, or frightening. I think that personally, as a mother of two children one of whom was actually part of a vaccine trial, I can give a mother's slant on how the leaflets read. I also know a lot of other women with young children (I am a very active member of my local community attending various weekly groups, regularly volunteering at two local schools, treasurer of the infant school PTA, and being involved in other community activities) and am aware of the sort of concerns my friends and acquaintances have.

I am also very much interested in the online perception of vaccines, and am an active member of a couple of online communities.

The benefits of being involved in research:

I have found my involvement hugely beneficial. It is fascinating and reassuring to see the attention and commitment of the OVG team. They are responsive to the comments from the group, both at meetings and via email communications. I have learnt a huge amount about vaccine trials, how they are designed and the sheer amount of planning and work that goes into them. I have now experienced the process as the mother of a subject, as a volunteer myself and also now seeing it "from the other side". The meetings are always interesting, informative and genuinely enjoyable. I have learnt a huge amount about RSV, about pertussis and typhoid and about the framework governing vaccine trials. I have become much more confident in my ability to understand the sometimes complex factors involved in discussion of vaccine safety.

Other comments:

I very much hope to continue with the PPI group. Personally I would love to be involved in further "outreach" work; talks at mother and baby groups or similar is something I'd be interested in. I would like to be able to somehow apply my enthusiasm for science communication at schools with my enthusiasm for communicating about vaccines.

I recently was heavily involved in my local junior school's Ada Lovelace Day; it would be great to see a future science week involving information about vaccines and vaccine trials. Inspired by the interest I have, which has been nurtured by my involvement with the OVG, I have recently co-authored a piece which will (hopefully, it has been through peer review) soon be published regarding a specific aspect of vaccine safety.