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Report on Patient & Public Involvement (PPI) Contributor Workshops

October 2019 (Updated March 2020)

Organisation

NIHR Collaboration for Applied Health Research and Care Oxford and Thames Valley NIHR Oxford Biomedical Research Centre NIHR Oxford Health Biomedical Research Centre PPI Lead staff member Lynne Maddocks **PPI Contributor** Cath Greehy

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Summary

The series of eight Patient and Public Involvement (PPI) training workshops was a joint venture between the two BRCs in Oxford and Oxford CLAHRC, and took place between January and August 2019. They were organised by a committee of one staff member and one patient, carer or member of the public from each organisation.

The aim of the workshops was to increase the confidence of PPI Contributors in carrying out the activities that they may be asked to do as part of their role. They focused on stages of the research cycle and how PPI can contribute to and influence research. Feedback from attendees and research staff was overwhelmingly positive with many attendees requesting more workshops in future.

We are planning a new series of workshops to begin in Autumn 2019.

What makes these workshops unique?

We think we are the only group of organisations in the country offering comprehensive training on the research cycle for members of the public who want to get involved in health research.

We believe this helps our PPI Contributors feel more confident and better able to contribute to PPI activities. The feedback demonstrates the topics and format of the workshops were interesting and valuable to the participants. The researchers who presented all reported finding it a useful experience for them too.

Content and format

Each workshop covered a different stage of the research cycle and discussed ways in which patients, carers, service users and members of the public can get involved.

Workshops ran for 2.5 hours, either 10.30am to 1pm or 1.30pm to 4pm, with a half-hour break for networking when refreshments were offered. Each workshop was a combination of presentation and practical group activity.

PPI contributors were emailed background information on the research cycle when they registered for one or more of the events.

Participants

A total of 87 individuals registered to attend one or more workshop. Attendance at each workshop varied from 16 – 34 people. A few people attended all 8 workshops.



Workshop participant feeding back after an activity at the 'Identifying research priorities' workshop in January 2019

We did not attempt to record which organisation people were 'hosted' by, as many people volunteer across all three organisations. Every workshop had at least one person attending their first workshop, some of whom were entirely new to PPI.

Speakers

ТОРІС	SPEAKER	SPEAKER'S JOB TITLE
Identifying research priorities	Dr Noémi Roy	Consultant haematologist
and designing a research		
question		
Writing and submitting a	Dr Sara Shaw	Qualitative researcher in
funding application		primary care
Designing a research study	Professor Paul Harrison and Dr	Professor of Psychiatry and
	Eleanor Leigh	Principal Clinical Psychologist
Carrying out a research study	Claudia Hurducas, Rowena Johns,	Research Delivery Team, Oxford
	Helen Jones, Jennifer Potts	Health NHS Foundation Trust
Analysing research outcomes	Dr Sana Suri	Alzheimer's Society Research
		Fellow
Publicising research outcomes	Dr Elizabeth Tunbridge and Dan	Associate Professor of
	Richards-Doran	Psychiatry and Communications
		Manager
Influencing clinical practice	Dr Michele Peters	Associate Professor within the
		Health Services Research Unit
Monitoring and evaluation	Dr Teresa Finlay	Registered Nurse and
		Postdoctoral Qualitative
		Researcher

The speakers, who were not paid for their time, all prepared presentations and activities in advance; some brought hand-outs and they all provided their slides afterwards (something which was requested by many of the people attending).

Publicity and registration

Publicity for the event was designed by the CLAHRC Communications Officer and registration links to the Eventrbite booking page were hosted on the CLAHRC website.

The workshops were advertised to people who were on the mailing lists of the three organisations and in <u>Involvement Matters</u>, a monthly ebulletin to which all three organisations have an input.



Registration was managed via Eventbrite, and when people registered they were asked to share how long they had been involved in research.

Venues

Two workshops were in the Holiday Inn, two were at the Quaker Meeting House and the rest were in various University departments and colleges, all in Oxford.

Costs

The costs for delivering the workshops have been shared equally between the three organisations.

The workshops were free to attend and people booked on Eventbrite. Meeting participants were given refreshments and had their travel and carer costs reimbursed. We had not specified eligibility in terms of geography so found that some people attended from Lancashire and similar distances, which increased our costs. Venue charges varied; catering costs were similar, whichever supplier was used.

Volunteer members of the committee were paid for their time in the planning and for the workshops at which they had a support role.

The average cost for a workshop was £885 (this figure does not include the cost of paying volunteer members for their time in planning the events).



Online resource

In order to offer these valuable workshops to a wider audience a Weblearn (University online teaching resource)

Staff from the NIHR Oxford cognitive health Clinical Research Facility presenting at the 'Carrying out a research study' workshop in April 2019

site was developed. Some technical issues were encountered in terms of recording the sessions on the University purchased software (Panopto) and the Weblearn page is still under development.

A fourth volunteer, Gihan Wanigasekera, gave valuable support in this element of the work, as he had expertise in the field.

Shared organisation

The organising committee developed the overall plan for the workshops, including selecting the topics and designing the information that was provided to participants and speakers.

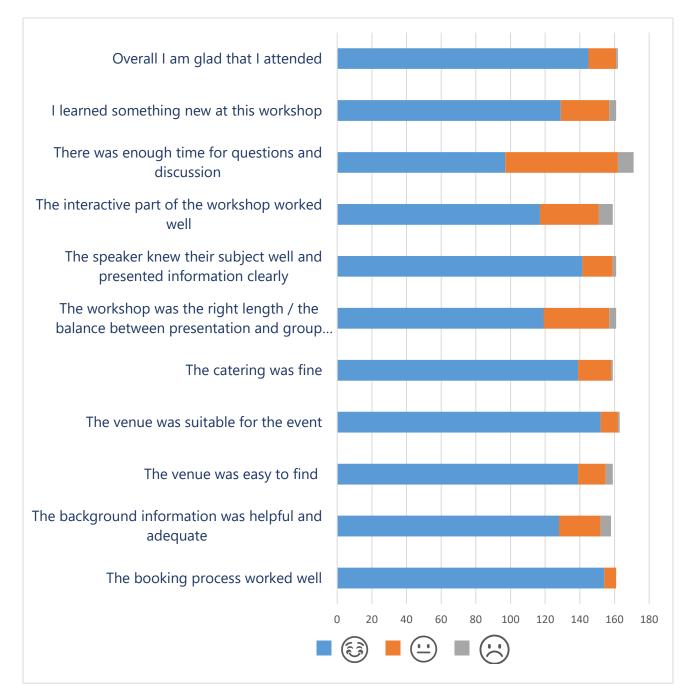
Shared communication between the organising committee happened largely through email and Google Drive. We set up a shared Gmail address for communicating with attendees and setting up the Eventbrite account: Oxfordppitraining@gmail.com

For each workshop a 'host' organisation was agreed. The relevant staff member then became responsible for liaising with the speaker and venue, and communicating with participants, for that event. Each workshop was also supported on the day by a volunteer member of the committee. For all of the workshops, two or more of the staff organisers were present.

The 'host' was also responsible for recording the session and uploading the content onto the Weblearn site.

Workshop evaluation

At each workshop we asked participants to complete an evaluation form. The overall results are shown in the table below.



We were delighted that the workshops delivered value to the PPI contributors who participated.

"I have enjoyed and appreciated the course of training on the research cycle. As someone who has only ever been involved in the odd survey and very basic analysis the opportunity to hear and learn from experts in the field of research has been very useful and informative. The people attending came from very varied and interesting backgrounds, some had a lot of knowledge others very little, the small group sessions were good for sharing ideas and knowledge.

I liked the fact that many of the professionals involved in speaking at the sessions were also from different areas of research as this broadened discussion and interest. The speakers tried to leave out too much 'technical' language and were happy to take questions from the attendees when appropriate.

I do feel much better equipped now to offer to help in a research project, as I feel I have a better understanding of the areas involved throughout the research process."

The main challenges raised in the evaluation forms were around the length of time for questions and discussion, and the balance between presentation and group work. During the early workshops in the series, we (the organisers and presenters) encouraged questions from participants during the presentations. This however meant that it was hard get through all the planned content and activities, and that was a frustration for some participants.

In response to this we introduced, to the later workshops, a system where we asked participants to record questions on a post-it note if they were not directly related to the points being covered. At the end of the session, when time allowed, the speaker answered these questions; or, if we had run out of time, the host for the event gathered written answers to the unanswered questions, and these were shared by email with all participants after the event.

Feedback from participants following this change was positive, in that there was a space created where questions could be asked and answered, whilst also allowing all the planned content and activities to be delivered.

We also asked the presenters for feedback on their experiences in preparing for and delivering the workshops. Overall each presenter enjoyed the workshop, and derived value from engaging with this diverse group of patient, carer and public members. One presenter commented:

"I genuinely found it valuable, as it made me reflect on the fundamentals of research design from the perspective of the participant and interested lay persons...The questions from the audience were similarly valuable, since they highlighted areas where I had not explained myself well, as well as bringing up concerns or views which I had not thought about." Several speakers commented that it did take some time to prepare material for the workshop as they had not previously presented on the topic area to a public audience. But they reflected there was benefit to this as they now had a set of materials that could be used in the future.

Some speakers felt that it would have been useful to have more information about workshop participants ahead of time and what their expectations were.

Six months after the end of the series we asked people to reflect on the longer-term impact of attending the workshops. Reponses included:

- Increased interest in PPI.
- More confidence to offer help and get involved with a research group.
- Increased awareness of the issues researchers face and feel input is more useful.
- Better informed and more able to ask questions related to topics that were covered by the workshops.
- More insight into how research projects are developed and which factors which are taken into account when deciding how to approach a piece of research work.

We created a poster to share learning about the workshop series that was shared at two BRC Open Days in May 2019.

Requests for future training

As part of the evaluation we also asked participants about what research topics they would like future workshops to address. Topics of interest included:

- How to develop a research question
- Project design and how PPI views could be taken into consideration
- Understanding research papers
- How to participate in studies and deciding which?
- How you conduct literature review and evaluate/critique research
- Ethics
- More opportunities to be a co-researcher
- Examples of research projects showing how data is collected and analysed
- Role of PPI and co-production in research / skills needed for PPI or co-production member
- Types of research tools, looking at what is statistically significant
- How PPI contributors can contribute to systematic reviews
- How to do action research; participatory research
- Other countries' experience of working with PPI

Lessons learnt and recommendations

There are a number of things that we adapted as the series progressed based on feedback from attendees and our own observations and experience. These include the system of asking people to

write questions on a post-it note if they weren't directly related to the topic being covered so they could be addressed later. Other changes we made and considerations for the future are described below.

- We discussed not using Eventbrite as a registration tool as it didn't reduce the amount of work the organisers did. However, it appears that a couple of people only attended one workshop because they had seen it on Eventbrite - therefore, it may be helpful in reaching a wider audience.
- As staff organisers, we could be firmer in stepping in when attendees are taking the discussion off-track or repeating questions that have already been asked (eg because of arriving late).
- In our next series, we will hold at least one workshop on a Saturday with the aim of appealing to people who aren't able to attend during normal working hours.
- We will make a number of spaces in each workshop available to researchers based on several requests to attend workshops in this series.
- We are considering whether we need to limit the number of spaces available to people from outside the areas served by our organisations in order to manage costs.

Conclusion

As organisers we believe that the feedback from attendees and speakers justifies the work that goes into putting on these workshops.

Involving a PPI contributor from each organisation, from the start of the process, was key to the content and format that were devised, how we evolved the workshops during the series, and the positive feedback the workshops received.

Sharing the work between our three organisations has worked very well. We have pooled our skills, resources and networks, and developed closer relationships between our PPI programmes. Through working together we have developed a sustainable model for delivering workshops for PPI contributors and have a new series planned for winter 2019/20.

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