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A research note on the benefit of patient and public involvement in research: The experience of prostate cancer patients regarding information in radiotherapy.

Introduction & Background

Increasingly there is a requirement for researchers to involve patients and the public in the design and implementation of their studies. This has been labelled 'patient and public involvement' (PPI)¹. While this requirement has been seen positively from a political perspective^{2,3}, there has been criticism that some researchers accord little value to PPI and often, because of the way it was implemented, conclude that it made little difference to their research instead paying so called 'lip service' to the requirements of funding bodies or trial steering committees⁴. Public involvement in research has been defined as "research carried out 'with' or 'by' members of the public rather than 'to', 'about' or 'for' them"¹. This definition moves beyond describing public or lay involvement in research merely in terms of those involved as research participants and recognises that non-academic and non-health professional people can have a valuable and sometimes profound influence on research design and processes.

As far back as 1995 an article in the British Medical Journal stated that "patients should be at the front of researchers' minds when they design, conduct, and report medical research"⁵. It gave seven ways in which patients and public can be involved: to help set the research agenda, be the best people to advise on the outcomes to be studied, comment on the design of the study, assess the quality of consent to be sought, help with publicity to encourage recruitment, insist on publication of research, and counter the issue of results of research not being put into practice. Since then an increasing body of work has considered the role of PPI in research, variously reporting on its impact, values and benefits⁶⁻⁹. There is consensus in the literature that inclusion of PPI is empowering to the PPI contributors^{4,10} and that the quality of the relationship between researchers and PPI contributors is important in determining the impact of inclusion of PPI^{4,11}. Additionally, a prospective case study reported the following emergent themes when considering service users: trust and commitment, impact on the wider study, mutual learning and timing of service user involvement⁹. Yet regardless of the growing evidence related to PPI in research, it is still the case that most peer reviewed

reports of UK-based health research do not mention how or whether PPI informed the research process. One systematic review of health and/or social care studies found only 66 studies across a 15 year period that reported the impact PPI had on the research¹². This is despite the fact that applications to many research funders are expected to demonstrate inclusion of PPI as an integral part of the research design and that the Department of Health recommends that “relevant service users and carers or their representative groups should be involved ... in the design, conduct, analysis and reporting of research”¹³. For example, National Institute for Health Research (NIHR) decisions on whether to consider funding a study may in part be influenced by whether and how PPI has been integrated into the study design¹⁴ and one of the requirements for applicants to the CoRIPS (College of Radiographers Industrial Partnership scheme) fund is to demonstrate how PPI has informed the study design¹⁵.

One of the disadvantages highlighted by previous literature on PPI is the difficulty in monitoring the impact it has had on individual studies. In particular, Staniszewska et al. highlighted the lack of quantitative measurement of impact⁸. Other research has indicated a general perception of the importance of evaluating impact but acknowledged the complex evaluation process and the impetus linked to accountability⁹. Furthermore, in one qualitative study where chief investigators (CI), trial managers and PPI contributors were interviewed, over half of informants indicated that PPI had made a difference within a trial but that this was influenced firstly by whether the CI had goals/plans for PPI and secondly by the quality of the relationship between the research team and PPI contributors⁴. The authors of the study acknowledged the inherent limitation related to quantification in qualitative research. The message from these studies therefore is that although the impact of PPI is not easily measurable quantitatively, there is evidence to support the inclusion of PPI as being beneficial to PPI contributors, researchers and the participants.

The aim of this paper is to consider PPI in one piece of research being carrying out in fulfilment of a Doctorate of Health Research offered at the University of Hertfordshire. It will explore the development of a reference group and how the group informed and commented on aspects of the research design. It will also

explore how advice from a local Public Involvement in Research group (PIRg) further refined the research documentation in preparation for submission for ethics review.

Overview of the doctoral research study.

The doctoral research will explore the experiences of men with prostate cancer (MPC) regarding information they receive related to their course of radiotherapy. Previous research has addressed information in cancer, information in prostate cancer and information in radiotherapy but mainly using quantitative or review-based research methods¹⁶⁻¹⁹. An extensive search and review of literature identified no evidence related to in-depth exploration of the experience of prostate cancer patients specifically related to information received during a course of radiotherapy. The research has a qualitative descriptive methodology, which allows an approach that is not guided by a specific set of established philosophical assumptions and allows rich, straight description of experiences in language similar to the participants' own²⁰⁻²³. The research will recruit participants from a single radiotherapy department in England. There will be two participant groups: firstly, MPC who have radiotherapy as part of their management will participate in semi-structured individual interviews and secondly, therapeutic radiographers will participate in semi-structured focus group interviews. Data generated will be analysed thematically within and between the participant groups.

Discussion

The following section discusses the implications of recommendations made firstly by an informal reference group of patients and secondly by the formal Public Involvement in Research group (PIRg) based at the University of Hertfordshire. Interestingly, both groups focussed their comments and advice only on the patient participant involvement. Throughout this section the doctoral student is referred to as 'the researcher'.

Involvement of the informal patient reference group.

Very early on in the design and development of the research, it became clear that there were questions related to the method that could not be answered by using the usual literature based resources. Wilson states that when defining what makes an

expert patient, knowledge and understanding is derived from experience²⁴.

Therefore given this definition, it seemed practical to 'ask the experts', i.e. a selection of people who had been diagnosed with prostate cancer and experienced radiotherapy. Contact was therefore made with the St Neots Acorn Cancer Support group who gave permission for the researcher to attend the group to talk about and invite comment on the proposed research. This particular group is a social support group that offers a venue once a month for people who have been affected by a range of cancers (whether as patients or relatives/carers) so that they can socialise together over tea, coffee and sandwiches and receive advice and support as they require. A holistic therapist is available for reflexology/ massage; representatives from other support organisations attend and guest speakers are regularly invited to deliver short presentations related to living with and beyond cancer.

A core group of three MPC offered to comment on the proposed research and subsequently made general comments that influenced the design of the research. The conversations about the research were held during the regular group meetings. The first topic they were asked to comment on was whether they felt that there would be an issue for interviews with men to be conducted by a female researcher. This issue was identified for consideration due to noting some potentially sensitive topics that might arise during interviews. With prostate cancer being inextricably linked to the function of the male genitourinary system, some of the information received by MPC is likely to involve reference to urinary continence or sexual functioning which are potentially embarrassing or sensitive topics to discuss with someone of the opposite gender. The issue of gender in the interview situation has been discussed at length in the literature. For example, Broom, Hand and Tovey argue that men may mediate their response depending on the gendered performance of the interviewer²⁵, and Henderson and Weisman reported that sensitive or personal issues can be difficult for men to discuss with physicians of the opposite gender²⁶. Some research suggests that men may find it easier and more acceptable to discuss personal matters with a female interviewer, with the 'traditional discourse of femininity' meaning that a female interviewer is viewed as unthreatening by male participants^{27,28}. However other research suggests there is an assumption that only a man would be interested in hearing men's stories²⁹. The men in the Acorn reference group felt that the gender of an interviewer was not as important as being confident

that the interviewer had a knowledge and understanding of cancer and its management. One member stated that *'if you weren't a radiographer I probably wouldn't talk to you as I wouldn't be sure you knew your stuff'*. Therefore for this small group, the researcher's positioning as a health care professional (HCP) was more important than concerns about their gender. This led to considerations concerning the conduct of interviews with regard to the researcher's 'insider/outsider' status. This phrase is generally accepted to denote how a researcher is similar or different to the group being researched³⁰. In relation to the patient participants, the researcher's insider status as a state-registered therapeutic radiographer conveys in-depth knowledge and understanding of radiotherapy and the typical cancer patient pathway, but as the researcher has never suffered cancer and is female, they are an outsider in terms of the experiences of the participants who will be recruited to the study. The insider/outsider dilemma has been discussed by other authors but tends to focus on ethnographic and observational research³¹⁻³⁴. Dwyer and Buckle point out that being an insider does not make for a better or worse researcher, merely a different one due to the perspective it may give, however in the same paper they note that participants may question an outsider's capacity to understand their experience, which in part contradicts the comment from the Acorn reference group³¹. Nevertheless the insight gained from the reference group's comments regarding positioning as a HCP was valuable and the researcher will introduce herself to potential participants as a researcher who is also a state-registered radiographer. Consideration of insider/outsider status will be integrated in the reflexive interpretation and analysis of the data generated during the study. Without these comments from the reference group this aspect of reflexivity might have received less consideration.

The other main influence of the reference group was on the design of the study, which was amended to allow the option for the patient participants' wives/partners to take part in the interviews. There was very strong opinion in the reference group that wives/partners should be included, with one member stating that it would be "no good asking me anything about [my initial consultation] but my wife knows everything, so to get the fullest picture she would need to be interviewed too". This opinion is echoed in the literature indicating that MPC and their spouses typically face the challenges of the diagnosis together^{35,36}. The point was mentioned by other

group members but there was some disagreement as to whether they would want to be interviewed as a couple or individually. All the men in the group stated that it was important for the choice to be offered and given this consensus it became an issue requiring further investigation.

The methodological issue of interviewing couples together or apart is one which has been debated in the literature. Strengths of joint interviewing are the production of a single collaborative account giving insights that might be difficult to identify in individual interviews³⁷ and that couples can create meaning or supplement each other's answers³⁸. Interestingly, Bjornholt and Farstad point out that the ethical issue of anonymity and confidentiality is lessened in the joint interview scenario and can promote a productive setting in which the couple can tell their stories³⁹. Interviewing apart gives each person the opportunity to air their own point of view unhindered by the other, but this may create anxiety if the couple is worried about what each might say, especially regarding sensitive topics^{37,39,40}. There are also issues of one person dominating the conversation due to the power dynamic within the relationship³⁷, the dynamic between interviewer and interviewees changing due to the interaction between the couple³⁹ and ethical issues related to inclusion, intrusion and difference⁴¹. These are not necessarily negative issues, but may affect the data generated and will need to be considered both at the time of the interview (in terms of interview style and approach) and at the analysis stage. Because of the strong opinion of the group in favour of inclusion of wives/partners, a research aim was added to reflect their experiences and contribution. During the recruitment phase, participants will be given the option to have their wife/partner involved and the choice of being interviewed together or separately. The methodological consequences will be examined carefully during the analysis and post analysis phases.

This contribution of an informal reference group at the design stage appears to be relatively rare (or at least rarely reported) but should be considered as an integral part of research design due to the unique and personal perspective lay contributors can give⁴². The Acorn reference group is not likely to be offered further involvement in the design of the study, however any reports and findings will be sent to the group and their involvement has been, and will continue to be acknowledged in all conference materials and publications.

Involvement of a Public Involvement in Research group (PIRg)

The University of Hertfordshire PIRg was established by the Centre for Research in Public and Community Care in 2005 with a 'hub and spoke' design comprising 15 core 'hub' members and various networks, service users and PPI groups as the 'spokes'⁴³. The PIRg was approached for advice and support regarding the documentation to be submitted for ethics review and the researcher was subsequently invited to present an overview of the proposed research at a PIRg meeting in March 2016. The 20 minute presentation was followed by a discussion of around 30 minutes during which the PIRg members questioned various aspects of the study design. The PIRg members were complimentary regarding the general design of the study but felt strongly that the patient participants should be given the option of telephone interviews or interviews in their own home. This would reflect the likelihood that patients might still be experiencing the side effects of radiotherapy (e.g. frequency of urination, loose bowels, fatigue) and therefore feel less anxious if they were able to remain in their home environment. The method of telephone interviewing is addressed in a small body of literature. Advantages are cited as being cheaper cost, easier with dispersed populations, easier to ask sensitive questions due to lack of face-to-face contact and potential reduction of bias due to interviewer characteristics. Disadvantages are given as being the inability to judge body language, technical difficulties related to recording of interviews and generational differences in the way telephones are used (factually vs socially)⁴⁴⁻⁴⁷. In one qualitative study very little difference between face-to-face and telephone interviewing was found, with the amount, quality and themes of data being similar⁴⁸. Therefore should a mix of telephone and face to face interviews be undertaken in the study, the evidence suggests that the interview method might not have a significant impact on the nature of the data generated. The issue of interviewing in a participant's home generated some discussion on practical aspects of participant and researcher safety and these have been addressed by the drafting of a detailed risk assessment which complies with the researcher's host department's lone worker policy. Further involvement of the PIRg is planned as members also offered to review all ethics documents prior to final submission to IRAS.

Conclusion

This paper has outlined two facets of patient and public involvement in one piece of research. The involvement of patient reference and public involvement in research groups has been an integral part of the doctoral student's research journey and has provided insight into the value of patients and lay people giving practical and common sense advice to researchers. The involvement of PPI in this study has so far been extremely beneficial in strengthening the study design and informing methodological issues that would not otherwise have been considered. Indeed, the patient reference group members all mentioned that being asked to participate has given meaning and value to an otherwise difficult and stressful point in their lives. Involvement of PPI should be seen as standard practise to both ensure and support well-designed, robust research processes.

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2875 words

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