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**Consumers as researchers - innovative experiences in UK National Health Service Research**

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## **ABSTRACT**

Consumer involvement is an established priority in UK health and social care service development and research. To date, little has been published describing the process of consumer involvement and assessing 'consumers' contributions to research. This paper provides a practical account of the effective incorporation of consumers into a research team, and outlines the extent to which they can enhance the research cycle; from project development and conduct, through data analysis and interpretation, to dissemination. Salient points are illustrated using the example of their collaboration in a research project. Of particular note were consumers' contributions to the development of an ethically enhanced, more robust project design, and enriched data interpretation, which may not have resulted had consumers not been an integral part of the research team.

## **KEYWORDS:**

patient and public involvement, consumer involvement, research.

## INTRODUCTION

Consumer involvement is an established priority in UK health and social care service development and research.(Boote, Telford, & Cooper 2002;Department of Health 1999;INVOLVE 2004;Research and Development Directorate 2005;Telford, Boote, & Cooper 2004) Although numerous terms are employed to represent the consumer group (i.e. public, patients, users, lay-persons etc.), this paper adopts the term 'consumer'.

The North Trent Cancer Research Network Consumer Research Panel (NTCRN CRP) is a locally based group which was established to encourage cancer and palliative patients and carers, to engage with health professionals and academics. Providing the opportunity for consumers to influence the research agenda and contribute to the research process from the outset - from the generation of research questions, through to protocol development and advice on issues such as ethics and patient recruitment, to participation as researchers, co-presenters at conferences and co-authors of peer-reviewed papers.(Collins & Ahmedzai 2005;Collins, Stevens, & Ahmedzai 2005) Although there are a small number of papers on the experiences of such collaborative working i.e.(Thornton, Edwards, & Elwyn 2003), very few studies have provided an account from the perspective of both the academic and patient viewpoint specifically exploring process and outcome.(Collins & Ahmedzai 2005;Collins, Stevens, & Ahmedzai 2005;Telford, Boote, & Cooper 2004)

Additionally, until recently very few studies explored the impact of patient and public involvement in health research.(Staley 2009)

This paper describes the successful collaboration between professional and consumer members of a research team, and how their working relationship can enhance multiple stages of the research cycle, including both the process and outputs. Salient points are illustrated employing the example of their partnership in a Cancer Research UK funded, Multi-centre Research Ethics Committee (MREC) approved, mixed methodology study, to elucidate the reasons for UK hospitals highly variable surgical treatment of women with breast cancer: Incorporating a clinical practice audit, survey of clinicians' treatment beliefs, survey of patients' involvement in treatment decisions, and semi-structured interviews with patients and their clinicians. The paper focuses on the process and consequences of consumer participation, rather than the findings of the illustrative research study.

## **THE CLINICIANS' AND RESEARCHERS' EXPERIENCE**

### **Consumer recruitment**

Two consumers were recruited to the research team from the NTCRN CRP in February 2002, following completion of the NTCRN CRP induction training course designed to provide a basic overview of cancer research and research methodology,

to assist consumers' effective engagement in the research process. This process is described in Collins et al.(Collins & Ahmedzai 2005;Collins, Stevens, & Ahmedzai 2005) The selection of consumers appropriate for a specific study and their training are considered crucial to their successful inclusion. Training provided a degree of confidence in the research environment, facilitating consumers' provision of a different, but complementary, and equally important perspective to that of other research team members.

The research team operated according to Telford et al's eight key principles of successful consumer involvement in research.(Telford, Boote, & Cooper 2004) An initial meeting between project staff and consumers provided a forum to discuss the intended research, negotiate mutual needs, expectations, roles, remuneration for involvement, and support mechanisms. Early negotiation provided a platform of mutual respect, trust and confidence in each others' skills, and established two-way communication.

### **Involving consumers at different stages of the research process**

#### *Research staff recruitment*

As integral members of the research team, consumers were members of the interview panel. They brought a fresh perspective to the process, focussing discussion closer to the project's prospective patients' standpoint. For example, the project involved interviewing women newly diagnosed with breast cancer about their treatment decision-making experiences. Consumers' were specifically interested in how the researchers' background and gender could affect interactions with participants.

#### *Development of research documentation and ethics application*

Consumers played a key role in the development of the research proposal, support documentation (letters and information leaflets) and tools (questionnaires and interview schedules). Their discerning contributions proved invaluable; enhancing acceptability to the target group through improvements in design and phraseology. Consumers' co-development of the project and documentation was highlighted under the 'scientific critique' section of MREC and research governance applications.

Concordant with Ham et al's findings,(Ham et al. 2004) consumers guided the research team from several potential pitfalls. This included the development of a more sensitive recruitment strategy. During final MREC preparations, consumers instigated a meeting to discuss concerns regarding the timing of patient recruitment. The project focused on decision-making among women newly diagnosed

with breast cancer who were eligible for a choice of therapeutic surgery. To minimise recall bias and *post hoc* cognitive justification, the researchers wished to interview women between diagnosis and surgery. Consumers were concerned the strategy could increase patients' decisional conflict and therefore psychological distress, and adversely affect the patient-healthcare professional relationship. Of specific concern were women technically eligible for inclusion, who might feel they were offered less choice than the documentation described. A strategy was devised to address the concerns. A consultation exercise among breast cancer follow-up patients prompted amendment of the recruitment procedure, to the period immediately following surgery.

### *Data Analysis and Interpretation*

Increasingly, UK consumer organisations (i.e. INVOLVE) are advocating consumers being involved in all stages of the research cycle, including data analysis. However, very few studies report this level of participation.(Cashman et al. 2008;Cotterell 2008;Rosenbaum 2005;Tuffrey-Wijne & Butler 2009) Consumers participated actively in the early stages of the illustrative project's qualitative data analysis. With appropriate levels of support, following basic training in qualitative research provided by the NTCRN CRP induction training course, clear specific guidance regarding the remit and process of the early stages of thematic qualitative data



analysis, and an open dialogue to discuss uncertainties regarding it, consumers and other members of the research team familiarised themselves with anonymised patient and professional interviews; listening to audio-recordings and reading verbatim transcripts. By individually identifying recurrent themes and discussing overlapping interview subsets as a group, the initial steps of thematic analysis commenced. Consumers enriched data interpretation, facilitating more comprehensive analysis through the incorporation of the patient's perspective to that of health service researcher and clinician members of the research team. For example, when analysing healthcare professional interviews, clinician and health service researchers' initial themes focused primarily around team structural and process factors, such as consultation styles, teamwork and patients' progression through the department, whereas consumers' themes centred on professionals' attitudes, characteristics and interpersonal skills.

Consumers also participated in preparation of data for dissemination, and co-presented relevant aspects of the project in conjunction with researchers to professional and lay audiences. The supplementary perspective provided by consumers has been well received.

## **THE CONSUMER'S EXPERIENCE**

Following recruitment to the North Trent Cancer Research Network Consumer Research Panel (NTRCN CRP) and having completed an intensive induction/training programme (the importance of which cannot be overestimated) I joined the steering group of the project. Initially I had some apprehension as to the usefulness of a consumer's contribution, but there was assurance that a clinician or other research professional would be available to explain or answer queries when necessary. This proved to be correct.

There was involvement from the beginning of the project, reading and commenting on the research proposal, the synopsis for Cancer Research UK in the funding application and the patients' interview schedules and other research tools. We were asked what we felt would be key benefits of the project, and conversely where we felt there were any major weaknesses in the proposal. Detailed responses to these and other questions were given and evaluated in later meetings. Similar processes were enacted after reading the project protocol. There were ongoing reviews of all the project documentation going to the healthcare professionals and patients alike. Our opinions were listened to, and where appropriate our suggestions were implemented. Letters of recruitment to patients and patient information leaflets at this stage were areas where both Gillian and I had a good deal of input and, after discussion, the wording of some of these was altered and the content considerably restructured.

One area where there was a very strong feeling that things could be altered for the well-being of the patients potentially taking part in the project was in the timing of approach and information-giving in connection with project participation. On our part it was felt that the timing could be inappropriate for some patients and considerable consultation and work went into this aspect of communication to adjust the method and timing of these approaches. I felt that this was a very good outcome stemming from our ability to be able to make suggestions and then seeing these observations acted upon for the benefit of the patients.

Data analysis for the project was, in many ways, the most interesting and challenging part of our assignment. There were guidelines given by the professional research members of the team as to the important areas to note when reading the anonymised interview transcripts of both the healthcare professionals and patients. These guidelines proved important when highlighting dominant and emerging themes and explicit/implicit meanings. There was much fine detail and complexity of responses to analyse and similarities and discrepancies coming from within, and across, the units taking part. The result, as patterns began to emerge, was absorbing, and the prevailing ethos in each unit became gradually apparent. I felt that it was extremely important to not only relate the content to my own experiences in a breast care unit but to disconnect myself, as it were, on further readings, to try to obtain an objective overview in order to assess the overt/covert

influences which might be taking place, and how they interact with the different types of patients presenting.

Upon reflecting on my involvement, I feel that when differences of interpretation of the data surfaced between the researchers and consumers in the group, these were discussed, and in some cases, resolved, in an amicable, but robust manner. The time spent on this project has been interesting and absorbing. I am sure that the published results of the project will be of great benefit to patients and clinicians alike. It has certainly benefited me from the point of view of personal development and has also given me great insight and appreciation of the diversity, breadth and commitment of the clinicians' roles. I am also now more aware of the wide range of work which researchers and other professionals do in studies of this type.

## DISCUSSION

Consumers can successfully integrate into a research team and contribute effectively to the optimisation of all stages of the research cycle, from development to dissemination. In the described study their remit included a role in data interpretation, which led to richer elucidation than may have been possible, had consumers not been an integral part of the research team.

The constructive expression of consumers' opinions is central to their effective engagement. This is facilitated by the provision of a basic understanding of the research process, guidance and support from the research team, and an environment of mutual respect.

Some commentators are critical of consumers' ability to provide objective scientific critiques of research, arguing they can only provide a non-scientific subjective view based on their individual highly variable experiences, which is counter to the medico-scientific paradigm of knowledge development.(Canter 2001) This paper proposes, though individual consumers cannot be assumed to represent the views of all members of the relevant patient group, their incorporation into a research team can provide an added dimension to the conduct and outputs of a research project which would otherwise be lacking.

To achieve the greatest benefit from the involvement of consumers in research their participation should be integral to the entire process from the outset, rather than appended to it. It is also important that researchers considering involving consumers in their research should seek guidance from professionals and organisations who have substantial expertise in this field (i.e. INVOLVE, NHS Research Design Services, funded by National Institute for Health Research) to ensure good practice and optimise mutual benefit from the collaboration.

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## FIGURE 1

### Summary of what this paper adds to current literature

#### What is already known on this subject

- Active partnership between consumers, health care professionals are increasingly being encouraged and incorporated into UK research initiatives.
- Evidence about the impact of active consumer involvement in health research is beginning to emerge from the current literature.

#### What this paper adds

- Consumers should be regarded as an expert resource and equal members of the research team. Their inclusion encourages a closer patient focus within health research, and adds depth to data interpretation.
- High quality training and support optimise effective consumer involvement in research.
- The integration of consumers into a research team can enhance the research process from development to dissemination.
- Accounts of the collaborative process and contributions made by consumers, from the perspectives of both consumers and professional researchers.



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