CONTRIBUTION FROM THE FIELD

Patients and Professionals as Research Partners: Challenges, Practicalities, and Benefits

SARAH HEWLETT,[1] MAARTEN DE WIT,[2] PAM RICHARDS,[3] ENID QUEST,[3] ROD HUGHES,[4] TURID HEIBERG,[5] AND JOHN KIRWAN[3]

Introduction

Patient or consumer involvement in research is widely recommended, but although guidelines for researchers and patients have been produced, few practical experiences have been published and involvement remains fragile. This article reports the combined experiences of researchers and patients who are collaborating in rheumatology research, and the working model that has evolved. The article provides one example of a practical model for collaboration based on experience.

Background

Patients have a personal experience of disease that is not available to most researchers, but that complements researchers' analytical skills and scientific perspective. Patient or consumer involvement in research is therefore recommended, with theoretical benefits being that research grounded in relevant clinical need, patient perspectives, and patient priorities will enhance study design, practicality, recruitment, data interpretation, and dissemination (1–3). Patients can be involved in research by identifying and prioritizing topics, reviewing grant applications, analyzing and interpreting data, and disseminat-

ing findings. Involvement can mean consultation, collaboration, or consumer-led research.

Consumer involvement in research is supported nationally in the UK by the Department of Health's INVOLVE unit, which develops and evaluates consumer involvement and has produced guidelines for both researchers and consumers (3,4). These publications are excellent guides to beginning consumer involvement and are based on workshops with consumers who are experienced in research. However, practical reports of real-life situations reported in a rheumatology journal are more likely to be accessed by rheumatologists who might have considered consumer involvement but are unfamiliar with the literature. Recently, a consensus has been achieved on assessment criteria for measuring consumer involvement (5), but practical reports of the features and challenges of successful involvement in the field are rare (6,7). This article reports the combined experiences of researchers (SH, RH, TH, and JK) and patients (MW, PR, EQ) who have been collaborating in rheumatology research (8–13) and provides one model that could be used as a practical guide. The phrase "patient research partners" reflects the status of the lay contributors who are current patients rather than potential consumers, and describes the relationship between researchers and patients. Partnerships among the authors have been formulated through either membership of research project steering groups (9–13) or the workshop-based conferences of Outcome Measurement in Rheumatology Clinical Trials (OMERACT) (8,12). For simplicity, patient research partners are referred to as "partners" and clinical researchers are referred to as "professionals" throughout the article. We report the challenges we have faced, the practical approaches we developed to address these challenges, and benefits that have been experienced.

Challenges

The first challenge was enabling contribution, which can be hindered by difficulties with access and communication. Partners needed access to terminology, steering group meetings, training in research, and funds (e.g., travel expenses). Communication challenges included the routine use of e-mail, conferences, and corridor meetings by professionals to discuss research, all of which could exclude

partners. Professionals also e-mailed consultation documents at the last minute and expected rapid responses, whereas partners needed time to review unfamiliar material.

The second challenge related to relationships. In the clinical relationship, patients seek professional advice from clinicians, even when decision making is collaborative. The research partnership changed this traditional clinician-patient relationship because now they meet as colleagues: collaborating, arguing, challenging, and then socializing. Partners tended to manage the situation by compartmentalizing their patient and research roles and quickly adapted to these 2 different identities, considering themselves patients in clinic and colleagues in research meetings. Some chose to demarcate these roles by using professional titles in clinic but first names during research meetings. Interestingly, it was some of the professionals who were more challenged by these varying relationships. For example, a professional automatically enquired about a partner's rheumatoid arthritis (RA) disease status during a research meeting, until the partner pointed out the inappropriateness of clinical discussions when the partner was present as a colleague rather than as a patient. Another aspect of altered roles was the exposure to confidential information such as research participants' names and health problems. Partners need to be aware of confidentiality issues.

The third challenge we were concerned about was tokenism. Some professionals may collaborate with partners for political correctness (e.g., to satisfy a research-funding body). Such professionals may also make uninformed assumptions about partners' knowledge and ability to contribute, leading to tokenism and a belief that partners' views need not be considered seriously.

The final challenge, reported by the partners, highlighted the anxieties of taking on a new role, which are similar to those of anyone moving into a new field of work: concerns about the ability to contribute, the value of any contribution, unfamiliarity with technical terms, lack of clarity about their role, and not wanting to appear foolish. Although professionals know that the only way to voice an opinion in lively academic discussion may be to interrupt the professor, this can be difficult for partners when that professor may be their clinician. Some partners expressed concern that their close working relationship with their clinicians may lead other patients to assume they receive preferential clinical care.

Having experienced these issues and developed ways of working in partnership, we now report the practical approaches that we used to tackle these challenges. This is a working framework that has evolved in response to our experiences over 3 years, and that we have developed through discussions at research meetings and conferences. Other groups may have developed other methods of partnership.

Solutions: FIRST

We have used the acronym FIRST to describe our approach because professionals and partners need to consider how they will Facilitate, Identify, Respect, Support, and Train (Table 1).

Facilitate: inclusion and contribution. We have found the principal investigator (PI) to be the key to facilitating the inclusion of partners in the research and their ability to contribute to the study. Ideally, partners should be included at the early stages of protocol design, because their suggestions may result in a revision of the goals, methods, or outcomes. For example, in a study to test a new disability impact scale, a partner suggested a different and potentially useful method of patient recruitment (9). Project steering group meetings need to be timed to suit both professionals and partners, and those with a disability require accessible and appropriate facilities and breaks. Partners need to be reimbursed for costs such as travel expenses or printer cartridges for downloading e-mail documents. Partners' reluctance to claim legitimate expenses should be challenged.

The PI's chairing of research meetings is crucial in enabling partners to contribute, particularly initially when partners may require additional support, such as being specifically asked for their experiences to enable them to enter the discussion (which might otherwise be daunting). This quickly becomes unnecessary as confidence grows, but the facilitation of the PI cannot be underestimated because it sets the standards and expectation of collaboration for the whole team.

We found that when research tasks are allocated, partners could be considered equally alongside professionals: who is the best person for this task in terms of experience and skills? In a qualitative study of fatigue, the analysis was more robust because a partner acted as a third reviewer (10). In a multicenter study of a new outcome measure, it was appropriate for the partner to give a presentation and co-lead a session on recruitment at the investigator meeting (11). The criteria for authorship or being a grant coapplicant can be applied equally to all individuals who contribute, whether they are professionals or partners, so that there is appropriate recognition of contribution and responsibility. The partner coauthors of this article are also coauthors on other articles and abstracts (8–14).

Identify: projects, patients, roles. When identifying research projects for partnership, researchers could consider studies or systematic reviews that address clinical interventions, outcomes, or service delivery issues, because these could benefit from partnership with individuals who have personal experience of the issue. To identify partners, professionals could either approach individual patients to gain their personal views or approach patient organizations to obtain not only personal views but also representation of the organization's views. The latter, for example, may carry more weight during research into policy or political issues of health care. The partner coauthors of this article were identified from a patient organization (MW) and from clinical practice (PR and EQ). When we reviewed the attributes required to be a partner, we found that potential partners need in-depth experience of the health issue concerned, an ability to review and discuss verbal and written information, and the confidence to step outside the normal patient role, perhaps to question or

| Table 1. FIRST (facilitate, identify, respect, support, train) considerations in partnership ||
Issue	Consider
Facilitate	
Inclusion/contribution	How can the attitude of the principal investigator (PI) drive collaboration?
	Is the venue and timing of meetings accessible?
	Is the conduct of meetings inclusive and encouraging?
	Will costs be reimbursed?
	Is the partner's expertise recognized?
	Can the partner be considered for tasks, authorship, coapplicant?
Identify	
Projects	Does this project have a clinical component?
Potential partners	Does the patient have relevant experience of the issue?
	Is the patient willing to review and discuss material?
	Will the patient develop the confidence to step out of the patient role?
	Can the patient commit the time?
Roles	Could we clarify a brief job description?
Respect	
Contribution	What are the partner's personal and clinical experiences of this issue?
	How can we develop the partner's skills?
	How might we pay the partner for time? Honorarium? Conference?
	Can they have an honorary staff contract?
Confidentiality	Have they signed an official confidentiality agreement or staff contract?
Support	
Communication/working	Has there been a one-to-one meeting between the PI and the partner?
	Has the partner received the protocol, etc. in good time to review them?
	Has the PI given early feedback on contribution?
	Is there a desk, phone, computer, Internet access, stationery available?
	Does the partner have e-mail or should contact be by postal mail?
	Can we establish a partner network or buddy system?
	Does the partner have contact details of a researcher for support?
Train	
Research	How can we facilitate understanding of research processes?

disagree with professionals with whom they have a clinical relationship. Partners need to feel confident that their experience is important, believe that they can make a valuable contribution, have time, and, in common with researchers, be unbiased to possible results.

We believe that a brief job description might clarify roles and responsibilities for partners, reinforce the equal but different contributions of partners and professionals, and create realistic expectations on both sides, and we intend to develop a job description for the next research study. The roles of our partners have grown and developed over 3 years and now include reviewing draft protocols, interventions, outcomes and questionnaires, supportive analysis of qualitative data, reviewing and interpreting results, giving presentations, attendance at conferences, coauthorship, and grant coapplicants.

Respect: contribution and confidentiality. Partners report concerns that their views will not be important, and are surprised that their input may provide new information to researchers. The PI plays a key part in reassuring partners of the value of their unique contribution: personal experience of the disease is the one thing that most researchers do not have. For example, in a study of fatigue, a partner mentioned that fatigue is not only present during inflammatory flares but is almost a constant feature of RA, which altered our entry criteria for the study (10). However, the partner mentioned being reluctant to state this

"obvious" point because the partner assumed professionals already knew.

We find including partners to be valuable when developing the skills of the research team. For example, partners have taken up opportunities to utilize training courses on lecture presentation software and give conference presentations. Partners have also brought other useful skills and experiences to the research, such as business or information technology skills.

Respect for partners' contributions means acknowledging their value. It should not be assumed that everyone wishes to be altruistic and give their time for free as research partners when professionals are paid employees. Our policy on payment to partners has been to reimburse expenses only. One center raised a grant to pay for the time that a patient-partner coordinator spent assisting with development, support, and training of partners and professionals, but it was found that accepting payment could affect some state benefits because patients may be regarded as having the capacity to undertake paid employment. One way of managing this has been to fund a partner to attend a conference where the research project is being presented.

Finally, the need for partners to respect confidential information that is revealed during meetings has been safeguarded by an honorary staff contract, and a specific confidentiality agreement with the hospital within which the research is based.

Support: communication and working. We found that initial input from the PI was crucial to support the partner's ability to communicate and work with the research group. This included an early one-to-one meeting to discuss the project and the partner's role, and an opportunity to ask questions. We provide the protocol, a research guide developed by INVOLVE, and a glossary of research terms (4,14). These meetings were more effective when an experienced partner also attended to give support. Partners have found access to the Internet to be helpful, and a desk with a computer, telephone, and stationery has been made available. Honorary staff contracts with the professional's university have given partners access to an e-mail account, library facilities, and staff training courses, and also reflect a legitimacy and value to partners' contributions.

Partners believe that early feedback from the PI on how the partnership is working is crucial in developing confidence and enjoyment in being a partner. Peer support has developed among partners through an informal partner network, with regular e-mail contact, newsletters, and occasional meetings to discuss common issues, and the group has developed material for new partners (14). Partners report that the opportunity to discuss issues with another partner enables them to clarify and define their views, enhancing their contributions; and they recommend appointing 2 partners to each project.

Training: research methods and processes. Research is an unknown territory and partners need to develop some understanding of the process, such as how we collect and evaluate evidence. Although the aim is not to train partners as researchers, they are better able to contribute if they have an understanding of quantitative and qualitative research methods, the basic concepts of statistics, and measuring outcomes. We have covered these issues in 2 training sessions designed by professionals together with an experienced partner. However, a survey by INVOLVE found that training opportunities vary widely and are often informal or only organized for individual projects (15).

Conference Considerations

Partners who collaborate by participation in conferences (e.g., OMERACT workshop-style conferences) have particular needs, such as appropriate access and seating, and a lounge or refuge separate from the busy delegate area. Programs need to be planned so that, for example, partners are not scheduled for 8:00 AM sessions and have sufficient breaks between important events. Partners need to receive preconference reading material early to familiarize themselves with the information, and appreciate meeting the professionals beforehand to clarify queries. Partners also need to arrive a day early to recover from transatlantic flights, and consideration should be given to paying costs in advance rather than providing reimbursement many months later. As partners gain experience, they contribute to planning and running future workshops.

Benefits

Our experience is that the benefits of the projects have included a fresh insight into issues, altered study designs,

Table 2. Examples of benefits of partnership experienced by the authors

Benefits
Project benefited because partner:
Peer reviewed grant application
Clarified research question
Extended patient cohort to include new group
Suggested reasons for low recruitment
Reviewed qualitative transcripts and categories
Raised new outcomes of importance
Renamed outcome categories
Co-led investigator meeting
Partner benefited from:
Empowerment
Fulfillment
Confidence
Contribution
Effort rewarded
Friendship
Professionals benefited from:
Greater understanding of rheumatoid arthritis and its impact
Respect for partners' knowledge and commitment
Beliefs and attitudes challenged
New research areas opened up
Effort rewarded
Friendship

and novel outcomes (Table 2). Sometimes the firmly held beliefs of professionals have been challenged (e.g., a belief that partners could not analyze qualitative data), as have the beliefs of partners (e.g., a belief that medicine is always evidence based). Partners report benefits such as being able to contribute and give something back, having something to offer that is valued, and creating something positive from their illness. They report gaining self confidence, empowerment, and a sense of equal partnership. Professionals report benefits such as research being grounded in patient relevance, being given a wider perspective, and the opening up of new research topics. Both professionals and partners have expressed pleasure in new partnerships and a feeling that efforts have been rewarded.

Conclusion

Professionals and partners bring different skills, values, and experiences to research. We report some of the challenges experienced when putting collaboration into practice, and we have proposed some practical solutions (FIRST: facilitate, identify, respect, support, and train). Although this is only one model, it is based on experience and may provide useful and practical help to researchers and patients in the beginning. Truly successful collaboration is achieved when these issues no longer need to be considered because they have become automatic ways of working.

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