User involvement in the development of a research bid: barriers, enablers and impacts¹

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Abstract

Objective To involve users in the development of a research bid to examine parents' experiences of having a pre-term baby, and to examine the barriers, enablers and impacts of user involvement.

Design A mainly collaborative approach to user involvement was adopted, although different types of involvement were evident at different stages of the project. Users' experiences and perspectives provided the focus for the regular meetings which underpinned the writing of the research bid. The researcher acted as a facilitator in the development of the bid, with input from users and the wider advisory group.

Main outcomes User involvement had an important impact on the development of the research aims, methods and on ethical aspects. Through careful collaboration a research bid was produced which was rooted in users' experiences, whilst also addressing key research questions. Key enablers for involvement included good working relationships, funding for the lead researchers time. Barriers included lack of financial support for users, the time-consuming nature of involvement and the language of research.

Conclusions If user involvement remains an international policy imperative with little if any support at the vital stage of bid development, policy-makers, service user organizations, researchers, health service providers and commissioners will need to recognize the limited nature of involvement that may result and the impact this would have on the evidence base. Researchers will need to recognize the resource implications of involvement at this point, and user groups will need to decide whether to participate when there is the greatest chance of influencing research but little or no funding.

Introduction and background

Over the last decade there has been increasing emphasis on the involvement of users and the public in many different aspects of health care

the United Kingdom and internationally in countries such as Canada, Australia and America.^{1–3} The importance of the patient's role has become emphasized by health policy, recent legislation and by investigations of system

failures such as the Bristol Inquiry.⁴⁻⁸ The underlying message emerging from these different initiatives has been to place the patient at the centre of health care and to redesign the service according to patient needs. The importance of consumer involvement in health care has been strengthened in the UK by the Health and Social Care Act,⁹ which set out the way in which the public and patients should be involved in the NHS. The role of user involvement in research has also been increasingly emphasized, with the aim of developing research that is more relevant to user needs and so to the wider NHS.^{10,11} Use involvement has become integral to many research programmes and initiatives including the Health Technology Assessment¹² and the Cochrane Collaboration.¹³ Researchers wishing to involve users in studies are supported by INVOLVE, who were set up by the Department of Health. INVOLVE promote and support public involvement in all stages of the R&D process within NHS, health and social care, including deciding what research should take place; commissioning and undertaking research; and disseminating the findings (<http://www.invo.org.uk/>). The INVOLVE database¹⁴ lists an extensive number of projects that have focused on many different aspects of involvement including prioritizing, planning, managing, designing research instruments, undertaking, analysing, writing, disseminating and implementing. The Picker Institute also describes project relating to patient involvement in research (<http://www.pickereurope.org>).

One of the earliest acknowledgements of the different levels at which user involvement can operate was made by Arnstein¹⁵ with her ladder of participation, which ranges from non-participation to citizen control. More recently INVOLVE have suggested involvement can occur at three different levels; the first level is concerned with consultation, for example, by asking users for their views.¹⁶ The second level involves collaboration, a more active, on-going partnership with users. The final level is user-controlled research where users design, undertake and disseminate the results of a research project. To date there has been very little

user-controlled research that has been funded by the NHS, with most taking place within social care. In addition to involvement in the research process, user organizations can also become involved in more strategic ways, such as prioritizing, funding and undertaking their own research. For example, the Alzheimer's Society has a programme of research (<http://www.alzheimers.org.uk/Research/index.htm>).

While users can be involved in different stages of research, a key stage is the development of a research bid. This stage offers greatest potential for users to influence the aims, content, focus, methods and dissemination plans for a study. Researchers have reported that their research question was replaced or became more pertinent because of the involvement of users.¹⁷ While there is a growing body of literature that discusses user involvement at different stages of research, relatively few studies have focused specifically on user involvement during the development of a research bid.¹⁸⁻²¹ This study will address this deficit by describing the process of user involvement in bid development. By bid we refer to the document which sets out the project plan. The study will consider the impacts of involvement, the barriers that inhibit the process and the enablers that enhance involvement. Wider implications for commissioners, researchers, service user organizations, providers and commissioners and for funding bodies will also be considered.

A wide range of terminologies have been used within the context of involvement, including users, consumers, patients, consumers and the public.²² For the purposes of this study, the term users will be adopted and will relate to the parents of pre-term babies.

The development of the research bid

Study background

Of approximately 700 000 babies born each year, 12% of all babies born will need some level of special care at birth (about 80 000) and 2.5%, or around 17 000 of all babies born need some level of neonatal intensive care.²³ Overall,

studies indicate that the delivery of a premature infant and admission to a neonatal intensive care unit represents a crisis situation for the parents and parents of minimally ill premature infants have also been found to experience a range of emotions and reactions similar to parents of critically ill children, such as sadness, fear, anger, guilt, isolation.²⁴

It is possible that the trauma involved with the birth of a premature baby may affect parents' perceptions of the maternity and neonatal services, leading to more negative views than is usual among parents of a new baby. However, it may be that the needs of parents who experience the premature arrival of a vulnerable baby have particular needs that are not generally being met by the NHS at present. Many of the parents who belong to the Warwickshire National Childbirth Trust (NCT) Pre-term Support group (known as the support group hereafter) felt that important aspects of their care had been very poor. Examples included insensitive and inappropriate communication, poor provision of information and limited support in times of great need. As a result of their experiences the parents formed a support group to help each other, and contribute to some positive action to improve the services they felt were fundamentally unacceptable and inappropriate. The possibility of carrying out a research study to explore other parents' experiences arose from a chance meeting in 2003 between the organizer of the support group, Nicola Jones, and Sophie Staniszewska, who is a Senior Research Fellow at the RCN Institute and was the lead researcher on the bid. As a permanently funded researcher, she had the capacity to develop the bid as part of her role.

Starting the process – initial discussions

The lead researcher was invited to a support group meeting in 2003, where the possibility of undertaking a study on parents' experiences was discussed. The group meets each month in one of the member's houses and discusses a wide range of issues relating to pre-term babies, children and their experiences. They also maintain e-mail contact in-between meetings. Some

members of the support group have had their pre-term baby recently while others had their baby 2–3 years ago. At the first meeting attended by the researcher, the support group leader introduced the possibility of undertaking some form of research project to try and explore other parents' experiences. The researcher then met with the support group on a regular basis during the development of the bid to seek their opinions and thoughts about different aspects of the research study. All of these meetings took place in members' homes in the evenings and a total of four meetings were attended. The main development of the bid took 14 months and started in 2003, extending to 2004 and the final bid was submitted in February 2005.

Motivations for involvement

Understanding the reasons why users and researchers want to collaborate on a research project is very important. In this study, the motivations of the researcher and support group differed, although they were complementary. The researcher was motivated by the belief that involvement can result in more relevant research which enhances our understanding of parents' experiences, so contributing to the evidence base in this area. The users' motivation originated from the hope that their involvement would result in more parent-orientated services. Research was just one of their armoury of 'tools', a potential level to change service provision and make things better for future parents of pre-term babies. The support group also planned to use feedback systems and service reviews in addition to raising the profile of prematurity among national charities and Government agencies.

Developing ideas

The support group started by discussing very general ideas which became more refined as the process gathered momentum. The researcher started to collect literature around the themes of parents' experiences of having a pre-term baby and it became clear that this was a widely

researched topic, with many studies examining different aspects of parents' experiences. This was fed back and discussed with the group and the NCT policy research department. There was consensus that a specific focus was required with a precise research question. Ideally, members of the group would have read and commented on papers that the researcher identified, but this was difficult in practice because members had limited time and small children or babies to look after. Instead research-based issues were summarized and presented by the researcher at group meetings, with parents commenting on these issues. The potential differences that might exist between developing research questions based on gaps in the literature compared with the developing questions based on parents' experiences was openly discussed with users and it was agreed to keep discussions open and to reflect on potential areas of difference as they arose. While users obviously recognized the value of their own experiences, through these discussions they became more aware of the need to consider research-based justifications. More specific research issues such as generalizability or transferability of findings were not discussed in detail at this stage, as time was limited and the priority was developing the focus of the study. It became apparent that while there was extensive literature on parental experiences, there was no recent synthesis to provide direction for future service development and to influence the development of parent-centred services.

The advisory group

The development of a specialist advisory group became increasingly important as the bid developed. The support group discussed the different types of specialist who should be included in the advisory group and identified clinicians, midwives and researchers, in addition to representatives from the support group and the project team. While the advisory group provided vital input, one of the key challenges was how to ensure that the support groups' ideas

remained a central focus of the bid, while acknowledging the importance of research-based justifications and rationales which the advisory group were likely to focus on.

Developing questions

As the bid developed, more specific research questions gradually emerged. Three main stages of question development are identified in Table 1. Each of these stages took a number of months to develop as the lead researcher only worked part-time on the bid, alongside other research studies.

During stage 1 the idea for the project remained relatively vague, with a broad topic outlined. By stages 2 and 3, a more focused set of research questions were evolving, with input from the support group who challenged the relevance of studies they viewed as less relevant, for example, more clinically orientated studies concerned with prematurity. The parents thought their clinical care had been good and so viewed clinical studies as less relevant; they wanted to focus on studies of more interpersonal aspects of care such as communication, information and support. While parents recognized that these two areas are obviously interconnected, they also saw them as distinctly different.

Table 1 Key stages in the development of the research question

Stages	Timescale	General description of the study
Version 1	Months 0–7	A study focusing on parents general experiences – identified by the group
Version 2	Months 7–12	A more specific study focusing on information, communication and support – refined by advisory group based on their expertise and by the Support group
Version 3	Months 12–14	An even more specific study focusing on the identification of effective interventions to help parents with pre-term babies, in relation to information, communication and support. Refined by the advisory group and endorsed by the Support group

The role of the advisory group strengthened towards stage 3, as they helped to refine study aims, emphasized the importance of relating the project specifically to other research, policy and service development, and ensured there were practical outputs for the dissemination phase. The support group were aware of the rationale behind these refinements and were fully supportive. If they had not been supportive, a reappraisal of the focus of the study would have been required. Any researcher or user refining a research question would need to consider the extent to which they would accept changes to the original idea and decide how to negotiate areas of disagreement. In total, the development of the bid with the support group took around 14 months, with two formal opportunities for comment from the advisory group, as well as significant individual input from advisory group members and from the charities involved in the bid, including the NCT and BLISS.

Funding sources

Funding sources were considered early in bid development. The lead researcher along and the support group tried to locate a responsive funding source that did not have a pre-set agenda but would be interested in a study with significant user input. Having considered a number of sources, the Big Lottery was identified as the most suitable source, although those applying for funds need to have charitable status which immediately excluded the support group from applying as the main applicant. Instead the support group joined forces with the NCT, to whom the group was already affiliated. A meeting arranged with the head of policy of NCT UK to discuss the project. At this meeting the overall research area was presented and the possibility of collaboration discussed. As a user-led organization, the NCT was well placed to devolve such collaborations to local groups and local users. This user-led approach was one of the main reasons why the support group wanted the project to be affiliated to the UK office of the NCT. The support group also wanted to link up with other organizations working in this area.

One of the most important charities working in the field of prematurity is BLISS, the premature baby charity, who offer parental information and support. BLISS were contacted and discussions about the project started. The support group were therefore instrumental in deciding on and directing the selection of collaborators for the project.

Users' contribution

In addition to developing aims and selecting collaborators the support group advised on the methods and on ethical issues. While they felt interviews and focus groups were appropriate methods for the study, they were concerned about timing. The support group felt very strongly that parents should not be interviewed or participate in a focus group while their baby is still in hospital, because it would take away from time with their baby during a very difficult period. The group felt that the researchers might not glean as much information from parents about their experiences very soon after the birth, compared with later participation. Such insights were helpful in developing the methods section and in considering the ethical implications of when parents should be contacted. The possibility for support group members to be involved in interviewing the parents was also discussed and provision was made in the budget for this possibility.

The researchers' role

Researchers usually work as specialists developing research bids using published research evidence and their own expertise. However, working with users means a potential change to this model with the researcher adopting a more facilitative approach. In this study, the facilitation occurred between the different collaborators. The views of the advisory group was sought by the researcher and then weighed up and discussed with the support group. The views of the support group were also sought by the researcher and then discussed with members of the advisory group. The researcher tried to ensure

the transparency and openness of this process. The advisory group and the support group could not meet as childcare and travel were difficult for the Group, and there was no funding available at this point to cover such expenses. However, this did not cause difficulties and both users and advisory group members were positive about each others' contributions and about the role of the researcher as facilitator. The facilitation of the process was lengthy and time-consuming, with each issue requiring adequate time to be discussed and resolved. Researchers using this model would need to recognize that adopting a facilitative style of working might involve putting their research priorities and agendas to one side which may be difficult. The time-consuming nature of this type of collaboration means it may be unachievable for many bids that have relatively short turn-around times, unless collaboration was pre-formed and a clear research focus already established.

Writing the bid

Ideally, the support group would have contributed substantially to the writing of the bid, but this was difficult for a number of reasons. First, finding the time was difficult, particularly with small children to care for, as the project had no research monies at that point to pay for childcare. Secondly, despite the focus on user involvement, many funding bodies still require research bids to be written in an academic style that can be peer-reviewed by relevant experts. As a result the lead researcher wrote bid, meeting regularly to discuss progress with the group. While the research aims were discussed with the group, some aspects of the methods section were more difficult, such as the minutiae of systematic review methods. While these discussions should form an important part of any collaborative approach, in reality time was limited because the support group met in the evening and used the meetings to discuss a variety of issues, in addition to the research bid, reflecting their broader agenda around raising the profile of parents' experiences of having pre-term baby.

The final bid

As the bid development became more refined, it developed into a four-stage study, with four main aims. Table 2 presents the final study aims, the selected methods and notes the main originators or influencers who helped develop each idea. It also illustrates how the research questions contained within one bid can originate or be influenced by different sources, without necessarily leading to an inconsistent set of questions. The final research questions complement each other and address parental experiences from different perspectives. The support group also had an important input into planning the dissemination of the study. In addition to the usual academic routes, the involvement of the support group and the charities ensured that the dissemination strategy tries to reach out to a range of health-care professionals and parents through a range of methods including publications and workshops. The possibility of the bid failing to attract funding was also discussed with users. It might be helpful for researchers and users to plan a strategy which includes a number of sources of funding, so that an initial rejection does not dishearten the team, but if possible, is viewed in a positive way, for example, by being seen as the source of useful comments that can help to improve the bid before it is re-submitted elsewhere. The bid was submitted in February 2004 and successfully funded by the Big Lottery in August 2004.

Discussion

User involvement has become an integral part of health-care research, with an increasing number of studies contributing to the developing evidence base in this area.^{16-19,25-31} This study represents one of the few examples of projects where researchers have involved service users in the design of a research bid. This study describes this process and highlights some of the impacts of user involvement, in addition to the barriers that hinder and the enablers that helped.

Table 2 Final study aims

Study aims	Methods	Main originators/ influencers
To identify what works: To identify effective interventions for communicating with, supporting and providing information for parents of pre-term babies	Systematic review carried out by RCNI	Support group, advisory group, NCT, BLISS, researcher (SS)
To identify what is currently provided: To establish which interventions neonatal units currently provide for parents of pre-term babies, in relation to communication, information and support	National survey of neonatal units carried out by RCNI	NCT, BLISS
To identify what works for parents: To identify which communication, support and information interventions are effective, appropriate and acceptable from the parent's perspective	Focus groups and interviews with a range of parents varying in age, minority ethnic background carried out by RCNI	Support group, researcher (SS)
To disseminate the findings as widely as possible: To disseminate the study findings to parents, voluntary organizations, health-care professionals and the NHS, and to the general public	A comprehensive dissemination strategy led by NCT and BLISS	Support group, NCT, BLISS, researcher (SS)

Demonstrating the impacts of involvement will become increasingly important, as involvement activities compete for finite research resources.

User involvement in the development of a research bid can represent a key pivotal moment in any research study, as it provides probably the best opportunity to influence a study. Once the bid has been written it becomes harder for user to influence key aspects. In this study, use involvement had a clear impact on the research aims, methods, ethical issues and dissemination plans. As a result we would argue that their contributions have resulted in a bid that is more firmly rooted in the reality of parental experience, has more relevant research questions, uses appropriate and sensitive methods and has a strong dissemination strategy to reach out to health-care professionals.

Users' motivations to get involved in research may differ from researchers. In this study, parents' poor experiences meant they were motivated by a desire to improve services, to make things better for future parents and for themselves, if they had another baby. This differed from the researchers more general motivation of developing an understanding of peoples' experiences and contributing to the development of an evidence base, which would ultimately improve services. While the parents and the researchers' motivations may have differed, they overlapped enough to allow collaborative working. However, there may be situations where the motivations of users differ so significantly from researchers that collaborative working would be very difficult and would require extensive discussions at the start of bid

development to see if they could be reconciled. These possible differences reflect an implicit agenda around empowerment vs. consumerism,³² where people become empowered through their participation by gaining some control over public services by influencing them in order to meet their specific needs and ultimately gaining control over their own lives.³¹ It is important that researchers recognize the possibility that becoming involved in research may lead users to feel empowered.

During the development of the bid a number of barriers and enablers were identified. A key enabler was the good working relationship that developed between the researcher and the users. This was based on mutual respect, good communication, support for the aim of the project and the perceived lack of a significant operationalized power structure between users and the researcher. This perception of equality was vital to developing open and honest ways of discussing the research,¹⁷ and was helped by the lead researcher being a member of the NCT who helped at nearly new sales organized by some support group members. This created a more equal power relationship than might traditionally exist in the researcher/user relationship. While it is recognized that this approach may not always be feasible, researchers should consider other ways of developing more equal power relationships with user groups.

Good relationships were important between all the collaborating partners and evolved between the charities, the researchers, the support group and the advisory group during the 14 months it took to develop the bid. This established important groundwork for successful future working. The project also illustrates how local user involvement led to the development of a national project, through the involvement of the NCT and BLISS, which is now drawing on international research evidence. The NCT UK office has a relatively small staff group and small budgets relative to its lobbying, campaigning, information-giving, training, education and support work across the UK. Although committed to the ideal of 'all parents' having 'an experience of pregnancy,

birth and early parenthood that enriches their lives and gives them confidence in being a parent'³² at the time that the bid was first being discussed the NCT was doing a limited amount to support parents of a premature baby. Some mutual support networks and one-to-one support for breast-feeding was available, but little attempt was being made to influence services offered in neonatal units or train health-care professionals in a parent-centred approach. However, staff in the policy research department were committed to responding to the expressed needs and wishes of new parents and saw this as an opportunity to develop a funded project that would be evidence informed and also highly practical in its outputs. BLISS, as the premature baby charity, was interested in developing more support networks and services for parents.

The other key enabler that aided user involvement in bid development was the permanent core-funded status of the researcher who was employed by the RCN Institute, and so had the time to adopt a collaborative approach. The other key enabler was the existence of a responsive funding source which provided enough flexibility, in terms of research themes, to enable the research aims to be developed with users. The lead researcher facilitated the process of bid development. This role was generally a positive one, but researchers should be aware that it can be quite different from the usual model of working, where a specialist researcher develops a bid in their own area of expertise, which may reflect fixed ideas about the focus of research questions. In some respects, it might help if the lead investigator is a generalist, rather than a subject specialist, and works in collaboration with an expert advisory group and a user group, as the research questions that develop through collaboration may not fit with the specialist researcher's ideas on how a particular area should develop and so could impede collaborative working. However, the time, effort and potential difficulty of undertaking the role of facilitator should not be underestimated and could represent a significant barrier for many researchers.

While some factors enabled the project to develop and progress, a number of barriers were also identified which have the potential to severely limit the nature and extent of involvement in others studies. The two key barriers were time and cost. While user involvement should ideally occur at the start of a project, this is exactly the point at which research monies are usually unavailable. This means that certain activities such as a meeting of the advisory group and the support group could not take place because funding for travel and childcare for the support group was not available. The cost and the time involved in adopting a more collaborative approach to bid development may mean that without the appropriate support, researchers may have no other option than either to rely on user's good will in giving their time freely or adopt a limited approach to user involvement which has less of an opportunity to influence the nature of the research. Ultimately this form of partial involvement will affect the overall nature of the user involvement evidence base and so the extent to which the impact of user involvement can be properly demonstrated.

Another potential barrier to user involvement was the language and methods used by researchers. While user involvement in research is encouraged by many funders and commissioners, they still want researchers to submit bids that reflect the research paradigm. In this study, the researcher tried to meet these requirements whilst trying to encapsulate the users' perspectives, although this process still produced a research-orientated bid rather than one suitable for users. While the support group could have received research methods training to help with writing the bid, it does raise a number of questions around user involvement, for example, should users only be involved when they can readily understand an issue? Should training always be part of involvement and what are the cost implications? Or should we as researchers and funders adopt a more radical perspective and open up the debate more fully by considering how bids could be written in a more user-friendly way. Discussing some specific aspects of the research, such as confidentiality, indemnity

and accountability was not possible in the time available and will be discussed as the project progresses. While this study has focused on peoples' experiences, similar issues exist for more clinical or basic forms of research. For example, the Wellcome Trust supports research and activities to stimulate the public's interest in science.³³ Some of the arguments outlined in this study could also be considered in the context of such clinically-orientated research.

The process used to develop the bid has highlighted the complexity of user involvement and its relatively fluid nature. There was clear evidence of collaboration, consultation and some partial aspects of a user-led approach, according to the INVOLVE classification.¹⁶ There were also evidence of some aspects of the Arnstein ladder¹⁵ present such as partnership, consultation and informing. Attempts were made to ensure users were equal collaborators on many aspects of the bid, such as deciding on the most appropriate methods. With some tasks, such as reading the protocol for the systematic review, users became consultees, commenting on aspects of the research. On occasion there were elements of a more user-led approach, for example, when we focused on users identifying the research questions based on their own experiences. While it is useful to consider involvement in a more traditional hierarchical way, in some respects this constrains the very nature of involvement, which can be much more fluid and evolving. Within one activity there may be evidence of different types or levels of involvement, some aspects being user-led while others are more consultative. This makes it difficult to use an overall description where a study is described as 'collaborative' or 'user-led.' In reality there are probably elements of many of these levels of involvement operating within one study. In many ways this points to the complexity of involvement as a concept as a multidimensional concept, which varies in a number of different ways. Future research needs to continue to develop our understanding of the concept of involvement, the content of its varying dimensions and how involvement should be measured and its impact assessed in order to develop our understanding of the complexity of

involvement. The continuing development and consolidation of this evidence base will help to secure the future of user involvement in research.

Conclusion

User involvement remains high on the international political and research agendas, and the development of research bids represents a key opportunity for users to influence the aims, methods and outcomes of research. This study has highlighted important ways in which user involvement helped to strengthen the bid, making it more relevant for users. However, the barriers to involvement in bid development need to be more fully recognized by funders and commissioners, if the polemic of user involvement in research is to become a reality with the potential for significant future impact and influence.

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