

What women want from women's reproductive health research: a qualitative study

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Abstract

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Background Researchers are being urged to involve patients in the design and conduct of studies in health care with limited insight at present into their needs, abilities or interests. This is particularly true in the field of reproductive health care where many conditions such as pregnancy, menopause and fertility problems involve women who are otherwise healthy.

Objective To ascertain the feasibility of involving patients and members of the public in research on women's reproductive health care (WRH).

Setting University and tertiary care hospital in north-east Scotland; 37 women aged 18–57.

Method Four focus groups and one individual interview were audio-recorded and verbatim transcripts analysed thematically by two researchers using a grounded theory approach.

Results and discussion Most participants were interested in WRH, but some participated to promote a health issue of special concern to them. Priorities for research reflected women's personal concerns: endometriosis, polycystic ovary syndrome, menopause, fertility risks of delaying parenthood and early post-natal discharge from hospital. Women were initially enthusiastic about getting involved in research on WRH at the design or delivery stage, but after discussion in focus groups, some questioned their ability to do so or the time available to commit to research. None of the respondents expected payment for any involvement, believing that the experience would be rewarding enough in itself.

Conclusions Involving patients and public in research would include different perspectives and priorities; however, recruiting for this purpose would be challenging.

Introduction

The value of lay involvement in health research has been debated¹ in the past but a new political mandate has encouraged it.² Bodies like the Cochrane collaboration,²⁻⁴ the Consumer's health forum of Australia^{2,5} and the UK's National Institute of Health and Clinical excellence have all advocated public involvement.^{2,6} The need for consumer involvement in the UK can be traced back to the 'Griffiths Report' in 1983 which highlighted the failure of the National Health Service to recognize and respond to the needs of the consumer.² Health research driven solely by professional and academic interest is being questioned, and democratic accountability is being sought by the funding bodies relying on the public purse.² In the UK, this has led the NHS Research Governance Framework to state that the development of a quality research culture should involve the active involvement of service users and carers.⁷ The ethics of lay involvement would embody 'notions of individual rights, community responsibility, social justice and accountability'.^{2,8} Various authors have defined lay/consumer involvement as including patients, service users, potential service users, consumer advocates, community participation and consumer organizations and support groups.^{1,2}

It is believed that the consumer perspective would complement that of the researcher and provide a holistic interpretation of health as envisioned by the World Health Organisation,^{2,9} 'amalgamating the consumer's perspective on illness with the clinician's understanding of disease'.² Consumer groups like the National Childbirth Trust (NCT) have challenged the paternalism underlying the presumed superiority of professional knowledge over experiences of women using the maternity services with regards to interventions based on limited clinical evidence.^{2,10-12}

It has been suggested that lay involvement would include different perspectives and priorities for research and make it relevant to the needs of the patient.^{1,2,13,14} It would improve

targeting of money and resources and identification of outcomes of greater relevance.² Additionally it is argued that patient and public involvement (PPI) will improve recruitment to studies, dissemination of results and implementation of changes.¹⁵ A national advisory group INVOLVE has been established to support and promote PPI and improve the way that research is prioritized, commissioned, undertaken, communicated and used.¹⁶

Consumers can be involved at the level of individual care (providing information about their experiences), service delivery (being part of a consultation group) or setting up of research agenda and questions, and executing research projects (in partnership with professionals).^{2,14,17-19} An HTA systematic review of consumer involvement in identifying and prioritizing possible topics for research and development found that 91 of 286 relevant documents considered were merely general discussions involving literature reviews or theoretical analysis.¹⁹ A total of 160 reported efforts to involve consumers in studies and a further 51 reported consumers identifying priorities in other contexts.¹⁹ The framework used in this review distinguished degrees of consumer involvement (consultation, collaboration or consumer control) and fora for communication (committees, surveys, focus groups) and recommended engaging consumer groups directly and repeatedly.¹⁹

Consumer advocates from community health councils have been involved in the national research priority setting for nursing and midwifery research.¹⁸ Consumers have been involved in various facets of cancer research,²⁰ low back pain research,²¹ to prioritize asthma and COPD research areas²² and chronic kidney disease research²³ and in setting up research bids to examine parental experience of a having preterm baby.²⁴ Groups like the NCT have been actively involved in conducting research,¹⁰ but there is limited literature on direct attempts to involve consumers in research prioritization, conduct or implementation in the area of WRH. A qualitative study by some of the current authors regarding patients' and staff's

willingness to be involved in a randomized controlled trial of single embryo transfer revealed patients' inherent antipathy to the notion of randomization based largely on a hitherto unexamined notion of fairness.²⁵

Hence, we conducted a study to determine the feasibility of involving patients and members of the public in research on WRH. Our research questions were as follows:

1. How should patients and members of the public be recruited (as researchers rather than participants)?
2. What are their priorities for research in WRH?
3. How do they wish to contribute to research (prioritizing of topics, planning and executing research)?
4. What do they expect to get out of this experience?

Methods

This study used qualitative methods – focus groups and individual interview – to ascertain the views of¹ members of the public and² patients about being actively involved in research. Two groups were planned with members of the public and two with patients, and approval was obtained from the North of Scotland Research ethics committee (Ref. No. 10/SO802/47). Members of the public were recruited by means of information and posters sent to 28 general practices in Aberdeen city and suburbs and five libraries and community centres. The University of Aberdeen issued a press release about the study, and an item appeared in the local press and on the University web page. This publicity resulted in more than 30 enquiries over a period of 4 months, and a preliminary questionnaire on availability was completed by most of them. Some of these enquiries came from women working or studying within the health sector, six whom were convened into one focus group held to test out the interview schedule. The women were not asked how they had heard about this study in the availability questionnaire, so it

was not known to the researchers how many women were recruited through which channel. It was also not possible to say how many women heard about the study and did not respond.

Despite widespread interest in the study, the focus groups involving the general public were relatively small (nine and five members).

We had intended recruiting both post-natal and gynaecology patients. Invitation letters from the Clinical Director for Obstetrics and Gynaecology, Aberdeen Maternity Hospital were sent to 70 women who had had babies in Aberdeen in the past year, but no responses were received. The NCT was also contacted and publicized the study on their local website. As a further mail shot yielded no results, midwives approached women on post-natal wards individually and invited them to participate. As a result, eight post-natal patients completed availability questionnaires, and one was recruited via NCT. Of those who responded, only four attended the maternity focus group. Non-attendees included an individual who had a caesarean section and could not drive, another who could not get childcare organized and a third who was not keen to attend. The remaining two could not be contacted. Because it had taken so long to recruit the post-natal patients, and involving a patient organization had not improved recruitment, we decided to just have one focus group with current patients.

Three focus groups involved non-patient members of the general public and discussed participants' perceptions and experience of research and their views of what topics should be researched within women's reproductive health (WRH). The fourth focus group was convened to discuss more specifically how women who had recently been patients might approach involvement and what they might get out of it. All were held on University premises with times varied to reach as many women as possible; a morning group accommodated young babies and toddlers. An evening group was attended by nine women and an afternoon group by five. (Another two women came to

the afternoon session but were unable to park during that busy time.) Although others were willing to be interviewed individually, time only permitted one such interview to be included.

Each focus group session was led by both researchers and lasted 1–1.5 h. The individual interview lasted 1.5 h. They were audio-recorded and transcribed verbatim. The transcripts were then analysed using framework analysis²⁶ by two of the three researchers. This involves developing codes for the substantive topics discussed during interviews and identifying overarching themes whilst coding the data. A high degree of agreement was reached in the coding of transcripts, and there were no discrepancies which needed to be discussed.

The focus group schedule covered participant's views on what constituted research, how medical research differed from other types of research, views on recruitment, motivation, views on the use of routinely collected data, future research topics including sensitive areas, concerns regarding research regulation and funding and views on public and patient participation in conducting research.

Findings

Background information

Thirty-seven women completed an availability questionnaire on which they also provided some demographic details. Their age ranged from 18 to 57 with an average of 36.7 years.

There was no difference in the mean ages of women in the first three focus groups. However, the women in the post-natal group were younger with a mean age of 33.8 years. All the groups were similar with regards to educational status. Twenty four of them worked outside the home at the time of study. Those able to attend focus groups and be in the study were no different from those unable to do so in this respect. Women also indicated their willingness to be interviewed as an alternative to attending a focus group, and all were willing although this proved largely unnecessary (Table 1).

Women indicated their reasons for participating in the research project. Of those who applied to attend the general focus groups, most described themselves as 'interested in research' or in the topic of women's health, but some had issues of their own which prompted them to come. The reasons for volunteering included chronic ill health, specific conditions pertaining to reproductive health and a need to be informed.

Experience of research as participants

During the focus groups, it became apparent that some women had considerably more personal experience of research participation than had others. Their experience ranged from none or market research lasting a few minutes, to participation in a longitudinal study of growing up in the north-east lasting many years. Several participants had direct experience of working

Table 1 Characteristics of respondents

	All women responding <i>n</i> = 37	Group 1 <i>n</i> = 7*	Group 2 participants <i>n</i> = 9	Group 3 <i>n</i> = 5	Group 4 <i>n</i> = 4
Age range	18–57	28–46	23–55	27–57	32–35
Av. Age	36.7	39.0	36.6	40.8	33.8
Currently working	24	6	7	3	3
Motivation					
1. Wanting to help	16	3	5	1	3
2. Being interested	13	3	3	4	1
3. Own issues e.g illness, Rx	8	1	1		

*Includes individual interviewee to ensure anonymity.

with researchers or funding organizations and expressed concerns about the situation in the current economic climate. They all were very supportive of research in general and research on WRH in particular. Most of them felt that medical research was more valid than most other types of research but a few expressed concerns about the way such work is reported, suggesting that the media tended to highlight sensational aspects and not to consider the implications of research findings. They felt that research helped doctors provide a better service, to take on board patients' opinions and to advance treatment technologies. They believed that doctors undertook research to answer scientific questions of concern to them and also to further their careers. None had any doubts that adequate ethical safeguards are in place in the UK, and many felt that the rules are too stringent, making it difficult to fund or complete good research. However, some in the maternity focus group were unaware of the safeguards. Few had considered the issue of who funds research prior to coming to the focus group. There was no significant difference in the views expressed by women with previous research experience when compared to those with limited or no past research experience.

Views on recruitment

Discussing how people should be approached and involved in research, a personal approach by a health worker or researcher was seen as good, as was a parent group such as the NCT sending out an email. Participants suggested that focus groups might be useful for obtaining opinions and to make research more accessible to ordinary people. If the topic were relevant and local, it was easier to be involved. Respondents felt that those who volunteered for research often had specific personal reasons such as having an illness themselves or becoming aware of health issues because of a sick relative or friend or were active members of support groups (Box 1).

Box 1 Views on recruitment

FG2: If people have a vested interest in it, whether it is experience themselves or experience of a family member they are more likely to {participate}.

FG4: The people that are interested in it are the ones maybe that are more cautious on things.

FG4: People are more likely to participate in something you feel more strongly about. ... if it is relevant then yeah I am more inclined to participate.

FG4: {of phone calls}... it could be like cold calling, it is intrusive.

FG4: I was invited through the NCT. I got the e mail through; So that was a good point of call as well. They have lots of lunch brunch and bumps to babies so they get the post- and the antenatal mums going to the same group.

Almost all had objections to being recruited by personal call or visit, but they had few concerns about receiving a letter providing that they knew how their name was obtained. Initially, they felt that asking women to recruit other women was unacceptable, but after discussion in two of the groups, they realized that this was a tried and tested method, used for example, in the nationwide Breakthrough Breast Cancer Study. Some women became enthusiastic about this method of recruitment, believing that it would result in a wider and more representative sample. Most found the idea of non-responders being followed up as intrusive and unacceptable. Most also felt that an ethics committee should not dictate who could and could not be recruited into a study.

Priorities for research

A number of respondents came specifically to mention medical conditions they believed needed investigation, usually because of being sufferers themselves or knowing of someone affected. These included endometriosis, polycystic ovary syndrome and ectopic pregnancy. Some women raised issues about inequalities in service delivery, for example postcode lottery for fertility treatment, differences in provision between England and Scotland. In two of the general public groups, women mentioned that

the menopause was the only condition which affected all women and that there was widespread ignorance about its effects and management. In all but the post-natal group and the individual interview, the question of forewarning women about the risks of delaying parenthood and prolonged pill use came up. This was partly because several women had experienced difficulties conceiving which they had not anticipated. In one group, there was a feeling that women lacked information on many aspects of reproductive health, especially hereditary influences, which would help them make informed decisions (Box 2).

Box 2 Priorities for WRH research

FG2: Probably for me the hereditary conditions (murmurs of agreement) not just cancer.
 FG2: Or early menopause.
 FG2: I think things like, tied into that recurrent miscarriage and stillbirth as well although it is very emotive it would be... So often there isn't a reason for it.
 FG2: fertility and again the discrepancy in different areas about being eligible for IVF treatment.
 FG4: Probably the six hour discharge. Do you know what kind of experience people have? Do you know, is it a good thing? Is it a bad thing?
 FG2: I think it might also be useful to have more... forecasting when you are going to go through the menopause or if you are going to have fertility problems.

Pre-eclampsia, blood loss, preconception health, Crohn's disease in pregnancy and the six hour turnaround of maternity patients came up as potential research topics in the maternity focus group. Respondents also questioned information available on time to conceive and the value of breast-feeding. The full list of topics mentioned is shown in Table 2.

Practical involvement in research

In most groups, women were initially enthusiastic about getting involved in research on WRH at the design or later stages, feeling that their personal experiences meant they had a lot

Table 2 Topics in WRHC which should be studied

	Group 1	Group 2	Group 3	Group 4
Age and fertility relationship, infertility	X	X	X	
Menopause and psychological effects		X	X	
Early pregnancy screening		X		
Women's knowledge/info needs		X	X	
Endometriosis, PCOS, period problems	X	X	X	
Early discharge after birth	X			X
HPV vaccination	X			
EDD determination, Induction and post-term delivery				X

to offer. They felt that 'nuggets of valuable experience' tend to be missed because they are not brought to the attention of researchers designing studies. Further discussion, often dominated by women with more research experience or understanding, led some of them to question their abilities to be involved in the process other than recruiting patients or disseminating results (Box 3).

Box 3 Views on active participation

FG4: If you do research with us, it has got to be what can fit into our schedules.
 FG4: Also full time people, the general working population specially again with children, ... you are really struggling for time you know to sit down sometimes and eat, let alone participate in {research}.
 FG4: If it is lengthy I would probably give up half way through the first page. It has got to be brief; it has got to be very clear because I am not very academically minded.

The need for training was mentioned in view of concerns about confidentiality and partiality.

Participants of the maternity focus group felt that training was unnecessary and that listening to people's experiences was a form of research. However, those in this group were less favourable to actually being involved in setting up studies or assisting in doing them as the demands on their time and the level of commitment needed were seen as too great as they had a young family. The maximum commitment they could realistically contemplate was meeting on a one-off basis – such as the current focus group – and perhaps looking over a questionnaire to check its relevance and readability.

As far as disseminating results were concerned, the groups were divided. Some felt that health professionals were more likely to be believed than friends or mothers, whilst others felt women's groups were good sources of information and promulgation. Involvement of post-natal groups, toddler and breast-feeding groups was considered appropriate not only for disseminating relevant results but also recruiting women to undertake studies; however, one participant had reservations because such groups often do not include the whole spectrum of women.

Expected rewards

Asked what they thought people would get out of being involved in research in a lay/unpaid capacity, most believed the experience would be rewarding and interesting enough in itself. Significantly, only those employed in the health professions thought that women would need to be paid in order to participate. Most did not feel that people would use the opportunity to further their own career although they might gain personal gratification from involvement with health experts. Two participants worked with volunteers in other contexts and believed that motivating them to be involved in quite difficult research tasks would not be a problem. Two women appealed to a common experience of being a woman which would make them wish to participate. None of the respondents felt they would want to be paid for their involvement, and none sought expenses for coming to the focus groups.

Discussion

Key findings

It is evident from this small study that obtaining a representative sample of patients or members of the public willing actively to participate in the research process may not be easy. As far as priorities for research were concerned, women tended to focus on service delivery matters of particular relevance to them or their friends such as the postcode lottery for fertility treatment, lack of information about delaying childbearing and the 6 h discharge from maternity care. As far as direct involvement was concerned, post-natal mothers were happy with the limited amount of involvement required of them, whereas those in the other groups often seemed to be looking for more. None of the women thought it was appropriate to be paid for contributing to the research process, and none sought recompense for parking or bus fares to attend focus groups.

How does it relate to the available evidence

The concern regarding difficulty in recruiting patients as researchers has been expressed by various authors in the past^{1,2,27,28} and could be due to a number of reasons in our study.

1. Whilst many women were interested in discussing their views of research in general and the topics they thought should be prioritized by researchers, relatively few attended the focus groups despite a variety of times and days being on offer and the broad-based recruitment approach suggested in some other studies.²⁰ The use of focus groups may have inhibited some women – as all respondents indicated they were willing to be interviewed individually – but this would seem closer to the real experience of research generation.
2. Whilst it is unsurprising that post-natal mothers were too busy to attend a focus group, they clearly had views about their

treatment they wished to express. Other researchers have found that participants are keen to recount their personal experience.²¹ Individual interviews might have been more productive.

3. Those who were happy to take on the role of untrained 'researchers' tended to have a vested interest in a particular condition or to have some other connection to research through work or friendships, highlighting the risk of bias or lack of representativeness.²⁰ Women with conditions such as endometriosis and PCOS expressed willingness to be involved in all aspects of research but seemed most enthusiastic about recruitment and dissemination. Women tended to favour the method of recruitment to the present study which they had experienced, whether this was a personal approach or coming forward themselves via websites and publicity. This is contrary to the approach suggested in other studies where respondents preferred mail or telephone recruitment.²⁷

They were generally well informed about technical aspects of research such as the need to have an unbiased or representative sample and their perceived expertise put off others. This was contrary to observations in some studies that the patients lacked knowledge about research issues and understanding of scientific language.^{22,27} There was a sceptical attitude towards the reporting of research results in the media. On the whole, they thought well of medical research and those engaged in it and had faith in the system of regulation. This was similar to the findings of other such studies.²⁷

Where prioritization of research was concerned, the overriding nature of a few topics does suggest a direction for future research: relationship between delaying and infertility, menstruation and its many problems, early discharge from maternity care.

Financial compensation is one of the areas highlighted in the framework of successful user involvement; however, our participants felt that women would help because they were interested in the topic or wished to help with research

because they had benefited themselves from previous research. They felt that the whole experience would be fulfilling in itself. Although this might seem to apply only to WRH, it has been highlighted by other authors.²

Strengths

The study is the first to investigate perceptions of involving women as researchers in women's reproductive health care. It highlights the problems that can be encountered in such a venture and what women are willing to contribute. The spectrum of women recruited came from different age groups, different walks of life and different nationalities and this strengthens our findings.

Limitation

The main limitation of the study was the difficulty in recruitment and inability to interview individually women who could not be included in focus groups due to time constraint.

Although the results are not widely generalizable, there is evidence that they are in keeping with other studies of attempts to involve patients and public in health-care research.

Conclusion

Framework analysis was used to analyse data. This resulted in identification of certain overarching themes. It was felt that it was easier to get women to come to a general group partly because they often had issues they wanted to discuss because these affected themselves, for example endometriosis, infertility; partly as it also appealed to those interested in research in general/WRHC.

Recent postnatal mothers, however, felt that they were too busy to contribute more than minor help with study, for example checking a questionnaire or attending one-off focus groups. The topics women wanted researched/more information on included relationship between delaying pregnancy and infertility; periods problems but women also tended to be preoccupied

with conditions that affected them or their friends and families. They did not wish to be paid for contributing or even recompensed for parking etc. They were particularly willing to recruit other women to studies if appropriate. Concern was, however, expressed about their lack of expertise and the time commitment which they anticipated would be required. Reservation was expressed about the practical aspects of participation and representativeness of the recruited participants as they felt that more vocal women or those with vested interest would more actively participate. However, most women believed that the experience of participating would be rewarding in itself.

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Details of ethical approval

Ethical approval was obtained from the North of Scotland research ethics committee reference no.: Ref. No. 10/SO802/47.

Contribution to authorship

Dr Shilpi Pandey (SP) contributed to conception and design, conducted the focus groups, contributed to data analysis, performed the literature search and wrote the first draft. Dr Maureen Porter (MP) conceived the idea, obtained funding, conducted the focus groups, contributed to data analysis, provided significant intellectual input in constructing the arguments presented; revised the manuscript and edited the final version. Prof Siladitya Bhattacharya (SB) conceived the original idea, revised all drafts and edited the final version.

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