# Answering back: the role of respondents in women's health research

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## Answering back The role of respondents in women's health research

Helen Roberts

Well quite honestly, I said, I hope this research is worth it. I said to my mum, I've got this lady coming to see me this morning. She said, 'What about?' I said, I hope it's not a load of old rubbish. Because there's been so much research on such rubbishy things I feel money's been wasted. So she said, 'Oh it probably is . . .' Well, it's a bit indulgent isn't it, really, just talking about yourself all the time?

(Oakley 1979: 309)

I would just like to thank everyone involved in this questionnaire because it has made me realise a lot of my feelings and help do something about them.

(Questionnaire 2: 0610, Pritchard and Teo, forthcoming)

From randomized clinical trials to the 'softest' of social research on women's health, the respondent, participant, or 'subject' of the research is crucial to the enterprise. Research on women's health cannot be carried out without women participating, knowingly or not, in the research process. They may be relatively passive participants, taking a particular drug, or having a particular procedure carried out, with the results simply being observed; there may be no real part played by the main players, the patients, other than taking the drugs and recovering or not. Or they may have their opinions actively sought about the desirability of a particular service such as family planning or well women's clinics; they may be questioned on their willingness or otherwise to participate in breast or cervical screening or they may be asked to describe their experience of maternity care. In the finished research 'product', however, the respondents are normally curiously absent. The absence of the respondents from many

finished research projects is indicative of their objectification throughout the research. They are there right up until the last moment, and then they are excluded. They are made mere objects from the beginning, and the human material for the research is frequently relegated to the position of inhabitants of a different world from that of the observer.

In reports of clinical trials or case reports in the medical literature for instance, doctors referring patients to a particular trial, or drawing a colleague's attention to an 'interesting case', are frequently acknowledged while the patients themselves may go entirely unacknowledged. An issue of the British Journal of Obstetrics and Gynaecology (1990), chosen at random, contained a mix of case-studies, trials and other studies, as well as commentaries and research reports. Some of the articles described studies which required no active co-operation from women. Their tissue was examined, or they were entered into a study, and the outcome reported required no conscious input from the women. Other studies required varying degrees of time, effort or discomfort. (One, which required thirty-six women to agree to an extra venesection at delivery, is confusingly entitled 'Determinants of fetal and maternal atrial natiuretic peptide concentrations at delivery in man' (my emphasis) (Voto et al. 1990: 1123).) As well as blood tests, women who provided the raw data for the articles in this journal also provided urine, tissue, diary cards and symptom questionnaires (in one case completed on 7 occasions by a set of respondents). Table 10.1 shows the pattern of acknowledgements in the fourteen articles which comprised this issue of the journal.

Table 10.1 Acknowledgements appearing in obstetrics and gynaecology journal

Acknowledgements to:		
No one	3	
Funders	8	
Colleagues	5	
Clinic staff	1	
Computing help	1	
Preparation of the manuscript	4	
Total no. of articles:	14	

While no paper acknowledged the patients, one acknowledged

the assistance of a nurse in 'the management of patients' and others acknowledged colleagues for 'access to the clinical records of patients under their care'. That it is possible to extend the courtesy of acknowledgement to the women who participate in research in a scientific article may be seen in the acknowledgements to the scholarly report on the Canadian multi-centre trial of chorion villus sampling and amniocentesis; in it the participants are thanked before the funders: 'We thank the women who, generously and altruistically, took part in this study . . .' (Canadian collaborative CVS-amniocentesis clinical trial group 1989: 6)

Frankly acknowledging and drawing on the special part played in research by respondents in the way which Ann Oakley did in her study Becoming a Mother quoted above is rare. This chapter looks at some of the literature on the role of research respondents, discusses in a preliminary way the costs and benefits to respondents of participation in research, and describes a number of ethical issues involved in the participation of live human subjects in research. Finally, using as an example the final page of a questionnaire of a Scottish study, 'Women's experiences during pregnancy', which is being conducted by Colin Pritchard and Philip Teo, this chapter looks at respondents' views as a largely untapped area of expertise on women's health.

In some large-scale studies, research respondents may be at several removes from a piece of research, particularly where secondary analyses are concerned. The General Household Survey (GHS) for instance, on which some of the data in Jennie Popay's chapter are based, collects data from a very large number of households, and respondents are, of course, aware that this is part of a research enterprise. The detailed analyses of GHS data to look at, for instance, sex differences in sickness absence and care of the elderly (Arber 1990) or differences in health and health status between men and women may not have been foreseen by the original research respondents, but it is difficult to foresee any undesirable consequences for those who participated in the survey. This is not always the case. In some clinical research, women may not always be aware that as well as receiving treatment, they are also the subjects of research. A patient who found herself in two randomized clinical trials without her knowledge or consent subsequently wrote, 'Withholding information about the trials may have invalidated them. It was forgotten that patients, unlike laboratory animals, can move around and communicate with each other. Treatments are discussed and unexplained differences discovered . . . the stress produced may be the very factors which

affect health and well being' (Thomas 1988). Meanwhile, some doctors argue that it is wrong to inform patients with life-threatening illnesses that one treatment or another means that they are entered into one arm or another of a clinical trial, since this may be an added source of stress: 'If protection of the subject is the reason for obtaining informed consent, the possibility of iatrogenic harm to the subject as a direct result of the consent ritual must be considered' (Loftus and Fries 1979: 11). As Ann Oakley points out, the term 'ritual', used in a derogatory sense, gives a view of how these investigators regard the task of informing people what is being done to them (Oakley 1990). The research design described in this collection by Rona McCandlish and Mary Renfrew is, of course, at the extreme other end of the spectrum of information and consent, which brings its own problems.

Research published in 1990 in The Lancet compared the survival of a group of women with breast cancer undergoing only conventional treatment with a group who supplemented conventional treatment with the more holistic therapies of the Bristol Cancer Help Centre (Bagenal et al. 1990). Early results, which were the subject of a press conference and therefore attracted wide publicity outside the medical press, indicated a reduced survival period in the group who had attended the Bristol Cancer Help Centre. Within a few weeks, attention had been drawn to a number of serious methodological flaws in the study (Hayes et al. 1990; Heyse-Moor 1990; Munro and Payne 1990). The director of research of one the funding organizations involved wrote, 'Our own evaluation is that the study's results can be explained by the fact that women going to Bristol had more severe disease than control women' (Bodmer 1990: 1188).

Less prominence was given in the national press to criticisms of the study. While many research subjects are not in a position to be aware of, let alone comment on, research to which they have contributed, the wide publicity given to this study meant that few of the women who had participated could have been unaware of the initial findings. Thus, late entries to the public debate over this study were some of the research subjects themselves. In a letter to a national newspaper, one wrote, 'As one of the women surveyed in the ill-fated Lancet study, I . . . am at a turning point. Serious issues arise for patients who are used in such surveys. A support group is being formed to share experiences and to consider what action should be taken' (Goodare 1990: 16).

### The role of research respondents in women's health research

Those who are researched, as others have noted, are more likely to be the powerless than the powerful: patients are more likely to come under scrutiny than hospital consultants or general managers in the National Health Service and are less likely to have the opportunity to comment on such scrutiny.

A great deal of research on health depends on the good will, participation and time of women, although the choice of women as respondents is not always dictated by an overwhelming desire to explore women's needs and experiences as such. Women may become research respondents because they are less willing to slam the door on the researcher, more likely than are men to be socialized to want to be helpful, and because they are perceived as being more flexible in relation to demands on their time, a misconception discussed in Jennie Popay's chapter in this collection.

George Brown and Tirril Harris, whose work on depression among women is a classic, frankly admitted,

We needed as many people as possible to agree to co-operate in what we knew would be a lengthy interview. Such an interviewing programme is expensive and one way to reduce its cost was to study women only, as they probably suffer from depression more than men. It also seemed likely that women, who are more often at home during the day, would be more willing to agree to see us for several hours.

(Brown and Harris 1978: 22)

Women's willingness to act as respondents is a compelling reason to use them as such. The time after the birth of a child is unlikely to be the most leisured period in a woman's life, yet surveys conducted to explore women's experiences of childbirth can expect responses of at least 75 per cent (Mason 1989: 1) which compares very favourably with responses to research enquiries from medical practitioners.

Given the importance of human subjects to research on health, it is perhaps surprising that the role of women as participants in research has received little more attention than the role of the rats in the physiology department animal house (and perhaps rather less, since the interest taken in the latter by the Animal Liberation Front). With the exception of Hilary Graham's (1983, 1984) work, such literature as there is tends to concentrate on ethical matters. The questions of whether researchers are doing right by their respondents; whether they are benefiting or harming them; whether respondents are active participants in research or unwitting 'subjects', are important and deserve the serious attention they have received. Marina Barnard's chapter in this collection represents a contribution to this genre. From a feminist perspective, Ann Oakley's article on interviewing women (Oakley 1981) and Janet Finch's discussion of the ethics and politics of interviewing women (Finch 1984) are classics.

Other aspects of the role of respondents have been less thoroughly explored. In an early research project in which I was involved, looking at variations in consultation rates in middle-aged women at the general practitioner's surgery (Roberts 1981), I became uncomfortably aware that research respondents may have an agenda of their own, quite at variance with that which interests the researcher. Just as a doctor taking a history may discard those symptoms which seem important to the patient, but which don't fit a particular 'story' or disease pattern, so researchers may prefer to frame their questions so as to induce the minimum of 'interference' from respondents. It is clearly simpler, more convenient, and will lead to less equivocal research results to ask a woman to rate the discomfort from her episiotomy on a scale of 1 to 5 than to ask her a more general question about her experience of childbirth. General or so-called 'open' questions may be difficult for respondents to answer, are untidy and time-consuming at the analysis stage, and at the end of the day may be difficult to use. There is an understandable tendency in research reports where responses to open questions are used, to concentrate examples on those women providing witty, unusual or otherwise colourful responses. Val Mason, whose survey manual provides an excellent guide to those wishing to carry out a survey into women's experiences of maternity care, suggests:

[Open questions] are less likely to be answered fully, for example by groups such as those with no educational qualifications and those for whom English is not their first language. . . . [Responses] can provide useful illustrative material in a survey report. Indeed they can bring to life for the reader the experiences behind the necessarily more standardised answers printed in the questionnaire.

(Mason 1989: 17)

#### Respondents' voices

As an example of the sorts of things respondents may contribute to a study when given a free rein, I refer below to one aspect of a Glasgow study currently in progress exploring women's experiences during pregnancy (Pritchard and Teo, forthcoming). The study is designed to assess the stressfulness of daily social roles. The emphasis is on the persistent and continuing problems and difficulties encountered by pregnant women in the course of their daily lives and the extent to which these are translated into the experience of stress. The study consists of two antenatal self-completed questionnaires at 20 and 30 weeks gestation and data on the course, management and outcome of pregnancy from case-note abstraction. In common with other well-planned surveys, the response rate to this one has been high (in excess of 70 per cent), and a formidable range of data have been collected and are in the process of analysis. The questionnaires were well designed, easing the respondent through a fairly lengthy series of questions, helping her to bypass those questions irrelevant to her situation and providing appropriate guidance to secure optimal response. As one respondent wrote,

I'm very pleased with the lay-out of this booklet . . . and I think if it can help others, well good enough.

(Questionnaire 1: 0054)

The A4-sized questionnaire was put together in a booklet format, a design which apparently had some bearing on the way in which it was perceived by respondents. Booklets received during pregnancy tend to be aimed at providing something: information, advice or help of some kind, and a number of respondents clearly viewed the questionnaire in this light:

Having books like this makes me feel confident about my pregnancy to know that there is research being done to help people through pregnancy.

(Questionnaire 1: 0052)

I think this booklet is very good as it can help a lot of people. It's a very good idea. And thank you for giving me the chance to let you know how I feel as it's very hard for me this time.

(Ouestionnaire 1: 0060)

The results of this study will be reported elsewhere (Pritchard and Teo forthcoming), and the aspect which I discuss below relates to only one page of two lengthy questionnaires. At the end of each questionnaire, an A4-sized page was left blank, apart from the following invitation:

Now that you have answered all our questions, it would help us if you have any comments that you would like to make. We would be specially interested if you have anything to say about this booklet or about your pregnancy and the care you are getting. Please use the space below to write anything you want to say.

Although an invitation to respondents to comment on research is not unique, it is not standard practice. It is, however, good practice, and the invitation above allowed respondents to comment both on the questionnaire and on areas of their pregnancy or their care which were not addressed in the questions asked. It is perhaps testimony to women's desire to contribute to research in this area that over half the respondents took the opportunity to comment. It should be remembered that the women doing so were in the last few months of pregnancy, all had another child to care for, some were in addition in paid employment and all had domestic responsibilities. It was clear from handwriting and spelling (for which women frequently and needlessly apologized) that the comments were by no means restricted to women who had had the benefit of further and higher education.

I hope I have been able to help you with your questionnaire. I am sorry for any mistakes I have made and hope you understand my answers.

(Questionnaire 1: 228)

As in Oakley's (1979) work and other studies, the comments revealed a desire to help other women in the same situation as an important motivation in completing the questionnaire:

I ... like to take part in research work. I think it's good that people take an interest in research work specially about pregnant people.

(Questionnaire 2: 441)

The extent to which respondents, who had donated their time to the research, thanked the researchers for 'listening' was striking, and has been remarked upon in other studies (Oakley, McPherson and Roberts 1990).

Thank you for letting me help you.

(Questionnaire 2: 0060)

Ann Oakley's chapter in this collection refers to the therapeutic potential of research, and a number of respondents to this study tend to confirm her view:

The booklet is very good as it makes you sit down and think about yourself for a change. As I usually spend so much of my time thinking about other people's problems I am apt to have no time to think of my own like the fact I do get depressed but try not to show it or even admit it to myself.

(Ouestionnaire 2: 0563)

I like the booklet very much. You can tell someone your problems without facing them.

(Questionnaire 2: 0352)

I feel this booklet has helped me cope with my pregnancy. It's good to know you are not the only one who is feeling down and unwell. (Questionnaire 1: 0637)

One respondent described in some detail her physical and emotional problems during the pregnancy and wrote,

I would be interested in your opinion about my feelings put down in this booklet. Anything that helps women during pregnancy has got to be worthwhile . . . . I really appreciate getting the chance to tell someone about this. I only hope you find some use for the information.

(Questionnaire 1: 201)

She was not the only respondent who was concerned about the outcome of the study. One respondent asked,

Why do you want to know all this for? and what will the outcome be? I know it's to improve the health care system, but it's not that you have to improve. It's the waiting to be seen.

(Questionnaire 1: 9476)

Women had helpful comments to make on both the design of the research, and factors which they felt might influence the findings. In this respect, respondents were conscientious in their concern to draw the researchers' attention to what they felt might be problems in interpreting their replies. A particular concern which a number of women pointed out was that strains and stresses varied from day to day. One woman was sent the second questionnaire twice, as her first response was lost in the post. She was good enough to complete it again and wrote.

I have already completed and returned to you this questionnairemust have got lost in Christmas post. I think that I have answered some questions differently since a few weeks ago, but this is mainly due to the fact that I am no longer working and therefore have more free time.

(Questionnaire 2: 0446)

Respondents also drew the researchers' attention to the fact that the questions might have been answered very differently in a first pregnancy. In fact both these points had been addressed in the design of the research. Women who already had a child had been chosen in order to avoid as far as possible the confounding effect of marriage and the transition to motherhood in first pregnancies. The questionnaires were administered at 20 and 30 weeks in order to explore differences in response, though some women were clearly puzzled by the similarities in questions asked on the two occasions.

A concern which neatly encapsulates some of the issues which Hilary Graham discusses in her essay 'Do her answers fit his questions? Women and the survey method' (Graham 1983) was raised by one respondent:

I frequently felt that the answers I gave were not a true reflection of my attitude because the questions themselves did not fit my experience. . . . Not enough attention is paid to the psychological problems a woman, especially a working woman, can face.

(Questionnaire 1: 0354)

She added, in a letter which expanded on some of her concerns,

I hope your studies lead to at least a degree of improvement in professional attitudes to the psychological problems of pregnancy.

This concern is central to taking seriously the concerns of our respondents, which may sometimes be rather different from our own. Some of the concerns raised by mothers in the Scottish study were frankly practical. Why were waiting times so long at the hospital? Why could that waiting time not be used to better effect? Why was there no crèche? As one mother wrote,

This pregnancy is much more difficult in terms of tiredness and physical problems dealing with another small child e.g. picking them up, going upstairs, unable to get a sleep during the day. I think 2nd time mothers need more help and support, but I think the assumption is that if you've had one normal pregnancy, you should be able to cope without help with the second.

(Questionnaire 2: 0341)

Another referred to the view that second pregnancies are less problematic than first:

I think when you are having your first baby, it is worrying but when it is your second baby, it is more worrying because you know what to expect . . . and you get a little more scared.

(Ouestionnaire 2: 0380)

There were some direct references by respondents to problems they perceived with the research design. One referred to a question on income:

I think the booklet doesn't go deeply enough to get a true reading. Like the money situation, do you mean our partner's money? or what we are given from our partners? My partner earns high wages but he pays the bills and only gives me money for food . . . I hope this will be of help.

(Questionnaire 2: 168)

There was a feeling that some questions were not sufficiently fine grain to reflect the complexity of people's experience (a problem of which the researchers, were, of course, aware):

I hated the questions where you have a choice of agree, disagree etc. I find them a bit limited and always have to read them a few times to make sure I've understood them the way they were meant. (Questionnaire 1: 155)

In quite a few instances, it has been very difficult to match an appropriate answer with my response.

(Ouestionnaire 1: 222)

Some respondents were concerned on the other hand about bias as a result of the length or complexity of the questionnaire:

The questionnaire takes quite a lot of thought to fill in and can be off-putting, hence the time it has taken me to get round to filling it in. I think this will make [it] very selective in who bothers to fill it in - wouldn't it be better to come to the clinic and make use of the time mothers have to sit around. People much prefer talking!

(Questionnaire 1: 0341)

There were a number of ways in which the respondents in the Scottish study used their experience to address research needs. The first and most straightforward way was in responding to the questions framed by the researchers within the terms set for the research. The high response rate and the conscientious way in which respondents drew attention to difficulties indicates the willingness of respondents to take research seriously. The respondents were also taken seriously by the researchers. As one perceptively commented,

About the booklet. I feel you are really grateful for the fact that I have filled in the questions.

and added.

I would like to know really what you are doing with all the information you are gathering.

(Questionnaire 2: 9614)

Occasionally, a respondent would use the comments page to make suggestions about future research. Two women commented on their extraordinarily vivid dreams during pregnancy, and felt that more should be known about this. One had a very specific piece of data which she had brought to the attention of the hospital in the hope that it might help other mothers. Hypothesis formation is not, after all, confined to 'experts':

[During my first pregnancy] my epileptic condition got better and better until the attacks were practically nil. After he was born, I could almost feel some foreign body re-entering and the attacks began again. But although I requested a doctor from the neurological department, no one was informed. Surely if someone had come either myself or someone with the same problem may have benefited . . . If the case is the same this time, I hope someone is informed.

(Questionnaire 1: 9566)

The problem is, how can these experiences be used by researchers in any kind of meaningful way? Mason (1989) suggests a number of alternatives for dealing with the responses to 'open' questions. It might be disappointing to respondents to know that the first option suggested is to carry out no analysis. The second is to simply note whether or not there was a response to the open question, as was done earlier in this chapter. The third option is to list some or all of the open answers with a view to giving the researcher an idea of the range of answers, providing illustrative material for the survey report, and providing the raw material to help develop a coding frame. Such a coding frame involves assigning each answer to a category or a number of categories in order to show the percentages of women giving each category of answer. These are one way forward, but are there other ways in which the richness and diversity of 'free-range' (as opposed to 'battery') data from research respondents might be used?

In practical terms, the needs of funders, researchers and respondents are unlikely to coincide at every point. In the Scottish study quoted above for instance, the researchers' stated (and worthwhile) objective to provide a descriptive 'epidemiology' of psycho-social stress in pregnancy is unlikely to meet the desire of respondents for crèche facilities at the hospital. It may, however, lead indirectly to the improvement in treatment of some of the emotional and psychological consequences of pregnancy which some of the respondents feel is necessary.

It seems to me that there are a number of positive ways in which respondents' views could be used over and above the cosmetic use of apt quotations to enliven research reports. As well as using open comments in the analysis and discussion of a study where appropriate as a matter of course, funding for the following needs to be built into projects:

- 1 Respondents should receive reports on the findings of the research to which they have contributed, with an invitation to comment.
- 2 Where hospitals or clinics are used to recruit respondents, they should be sent not only the formal research report, but also any comments made, positive or otherwise, on service provision.
- 3 Where respondents make recommendations for future research, these should be brought to the attention of funders by way of an appendix.
- 4 There should be effective dissemination of project findings not simply to academic but also to service providers and wider audiences.

As researchers, we do have particular skills in the collection, analysis and dissemination of research findings (see for example Roberts 1984) but ordinary people use the skills of observation and experience in their everyday lives to make sense of the world in a way which may not be dignified by the lofty term research, but could have similar results. Oakley points out that

Experience does alter the way people (experts and others) behave: this is part of the scientific method that theories should be tested empirically, not just once under artificial conditions, but constantly in the real world. . . . It is from their own experience in this world that most people (who are not scientists) develop their theories, build up their generalisations, become confident about asserting things generally to be true.

(Oakley 1979: 308)

The intention of the current imperative to conduct research into 'consumer satisfaction' is unlikely to be targeted towards the use of these kind of data, however freely given they may be, and however cost effective. But in developing health services truly responsive to patients, clients, customers or consumers, we need to take their views seriously, use them effectively, and draw from and build on their knowledge.

The typical concern of social scientists has been with the unique character of research into human subjects which arises from the humanity of the scholar, from the fact that she is both an observer and a part of the thing being observed. But there is another side. For whilst the scholar is also potentially a subject, the subject is potentially as much a source of interpretation, understanding and criticism as is the observer. In their concern to understand the place of their own feelings and suppositions in the interpretation of the human subjects from which they are only artificially, by the process of scholarship, separated, social scientists have been led to neglect the isolation of the thinking object of their research. If the common humanity of object and subject make it impossible for the social scientist to be treated as simply objective, it makes it to the same extent impossible for respondents in a survey to be treated simply as data or the source of data.

What can be learnt from the responses to the survey quoted above? Some of the answers are self-evident, and are provided by the respondents. These also show that the human material of the social scientist is constantly escaping from or simply ignoring the paths set down for them by the researcher. It is often alleged that the evidence of the social scientist, unlike that of the clinician or historian, which is simply 'given', is in a sense created rather than discovered. But the evidence of respondents confounds this charge.

A further reason for looking afresh at the active role of the human participants in research arises from the aspiration on the part of many social scientists and those who fund them, to make research 'useful', or helpful in the making or refinement of government, health authority or other policies. If research is to be policy relevant, then the conventional separation of observer and subjects is even more inappropriate. For until an objective criterion of needs is established, what other source of policy objectives can there be than the aspirations of policy users?

The objection to the exclusion of human participants from the business of research is therefore both epistemological and has a market and a democratic dimension. For if the human object of research and policy is a customer, then the customer is always right. And if she is a citizen, then the people are sovereign. There is a further reason why the thinking subjects of research ought wherever possible to be employed. A social or governmental policy is not applied to inert matter, but to active human beings. Its success will depend in considerable measure on its relation to their aspirations and aversions. Drawing on the active contribution of citizens to research is a necessary way of ensuring that policies which arise from that research can in a meaningful and effective way be connected with the lives of those towards whom they are directed.

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