

dual level (ranging from women using the maternity services to the undersecretary of state for health in the House of Lords) and as groups (ranging from local branches of the National Childbirth Trust to the health committee of the House of Commons).

The many lay contributions to research in pregnancy and childbirth encourage me to believe that there should be greater lay involvement in research more generally. No one—and certainly not researchers—can claim a monopoly of relevant wisdom in discussions about what deserves attention in health research. Lay people can draw on kinds of knowledge and perspectives that differ from those of professional researchers.

“Researchers cannot assume that their own values and priorities apply to others who do not share their world.”

—Hilda Bastian, consumer advocate

Greater lay involvement in setting the research agenda would almost certainly lead to greater open mindedness about which questions are worth addressing, which forms of health care merit assessment, and which treatment outcomes matter. It should also help to counter the perverse incentives that lead researchers to do trivial and sometimes frankly unnecessary research, such as placebo controlled trials within classes of drugs in which existing preparations are already known to be effective (for example, prophylactic antibiotics for many forms of surgery).

If health researchers are to respond positively to the opportunities that exist for exploring how lay people might become more involved in research, some changes in attitude will be required. Researchers sometimes betray fundamentally disrespectful attitudes towards the public. Medical researchers would do well to follow the example set by the British Psychological Society. After noting that “psychologists owe a debt to those who agree to take part in their

studies,” who therefore deserved to be treated “with the highest standards of consideration and respect,” the society recommended that the term subject should be abandoned and replaced by participant.² Researchers sometimes reveal cavalier attitudes to the public in other ways. For example, it remains rare for researchers to offer to send people who have participated in research a summary of the results of the work to which they have contributed, and to ensure that the results of research are published.

As far as I am aware, my belief that the public might be served more effectively by research and researchers if there was greater lay involvement at all stages of the research process cannot be supported by formal evidence, and there is certainly scope for research to address this issue. At its simplest, this research might consist of an exploration of the feasibility of lay involvement in conducting and commenting on descriptive studies of past and current patterns of research activity in particular fields or localities. Controlled intervention studies should be feasible as well, perhaps using research ethics committees as experimental units.

Many people, however, may feel that greater lay involvement in a pattern of research decision making which has been dominated by professional researchers is justified on the basis of existing informal experience, common sense, and justice. Greater lay involvement in research would also seem likely to result in the development of a lobby of well informed lay people to press for the resources needed to address a more substantial proportion of the many unanswered questions relevant to promoting and protecting health.

This paper is based on a talk given at the Harveian Society of London in January 1994. I am grateful for comments on earlier drafts from Hilda Bastian, Thurstan Brewin, Andrew Chivers, Ruth Evans, Claire Foster, Paul Garner, Gillian Gyte, Andrew Herzheimer, Richard Lilford, Stephen Lock, Sandra Oliver, David Sackett, William Silverman, Jane Smith, and Hazel Thornton. It should not be assumed that they endorse all of my views.

1 Oliver SR. How can health service users contribute to the NHS research and development programme? *BMJ* 1995;310:1318-20.

2 British Psychological Society. *Code of conduct and ethical principles*. London: BPS, 1991:5.

How can health service users contribute to the NHS research and development programme?

Sandra R Oliver

See p 1315 and editorial by Goodacre

The National Childbirth Trust, along with other groups of health service users, is working with health professionals and researchers in planning clinical trials, setting priorities for research, systematically reviewing research reports, and getting research findings into practice. User groups may bridge the gap between the public and researchers by explaining research issues to a wide audience, presenting the needs and views of health service users to the research community, and suggesting how members of the public may be approached for their views directly. Service users recognise their need for training and support, and they call for development and evaluation of this work.

Background

The NHS research and development programme is trying to reflect the concerns of consumers throughout its work.¹ This implies inviting input from health

service users at all stages, from setting the research agenda to the planning and execution of projects, and reporting their findings.

While the NHS has been developing its research and development strategy the National Childbirth Trust has been raising awareness of research issues among its 56 000 members and consulting them, as well as representing health service users in research projects or programmes. Writing as a member of the National Childbirth Trust's Research and Information Group, I shall discuss the difficulties we have met in making such contributions.

We have found that “too often what women have to say about their experiences is either ignored, forgotten or dismissed. . . . [Their] views must be publicised and specifically drawn to the attention of health professionals, policy makers and researchers, and the implications which flow from them for the care of women during pregnancy and childbirth should be emphasised.”² With this in mind the trust has under-

Research and Information Group, National Childbirth Trust, London W3 6NH
Sandra R Oliver, antenatal teacher

Correspondence to:
Dr S R Oliver, The White Cottage, Crampshaw Lane, Ashted, Surrey KT21 2UD.

BMJ 1995;310:1318-20

Policy statement: the importance of evaluation in maternity care

The National Childbirth Trust aims to enable every parent to make informed choices. We are concerned that important aspects of maternity care have not always been thoroughly evaluated and therefore choice is often based on incomplete or inaccurate information.

The NCT recommends that all new procedures and treatments are introduced as research studies which are subjected to rigorous evaluation before being adopted more widely. Current forms of care which have not been adequately investigated for their benefits, risks, and side effects should, where possible, be subjected to equally stringent evaluation and open debate.

While parents may be guided by research evidence, individuals making decisions will be influenced by their own beliefs, wishes and priorities.

taken surveys on women's experiences of epidurals, postnatal infection, rupture of membranes in labour, and the perineum in childbirth.³⁻⁶ All of these have focused on women's personal experiences and views of their care.

Recently we have been finding more opportunities for making women's views known to health professionals, policy makers, and researchers. Our efforts have not been evaluated formally, but our experience may be useful to others.

Research policies

The Health Select Committee report on maternity services (the Winterton report),⁷ criticised the lack of evaluation and audit in maternity care and concluded that "too many fashionable interventions" in care during childbirth had been introduced without sufficient evaluation. The National Childbirth Trust responded by developing a policy statement on the importance of evaluation in maternity care (box) and making a commitment to encouraging and supporting research in pregnancy, childbirth, and early parenthood (box).

Recognising the benefits of reliable evidence about the effects of health care, the National Childbirth Trust and other consumer groups were quick to adopt *Effective Care in Pregnancy and Childbirth*, a collection of systematic reviews of published and unpublished research projects from 1950 onwards, and its accompanying summary paperback.⁸⁻¹⁰ The Cochrane Collaboration, which produces and updates these and other reviews, invites constructive criticism to improve its working practices and final products and encourages input from health service users.¹¹ The National Childbirth Trust has offered ideas for making the reviews more relevant and accessible to lay readers.^{12,13}

Supporting clinical trials

Lay support of clinical trials in pregnancy and childbirth was led by the Association for Improvements in Maternity Services in 1985 when, with other organisations, it supported the Medical Research Council's proposal to compare chorionic villus sampling with amniocentesis in a randomised controlled trial.¹⁴ The National Childbirth Trust's council debated whether public endorsement would unduly influence individual women invited to enter the trial rather than encouraging them to make an informed decision alone. It decided that "to press for randomised controlled trials without openly acknowledging the need for participation in those trials is not a tenable position."¹⁵

Since then the trust has supported controlled trials on the use of low dose aspirin in pregnancy and treatments for inverted and non-protractile nipples,^{16,17} and it is currently supporting trials of the use of antibiotics for threatened preterm labour, of extra-corporeal membrane oxygenation, and of management of the perineum at delivery.

Before committing the trust to supporting a trial we scrutinise published reports of research and the protocol to decide whether the investigation is likely to address questions which we consider important and whether we have any reservations about the ethics of the study, including its source of funding. Questions that have arisen include the implications of relying on scarce resources and the efforts of lay volunteers publicly to support trials; the legal responsibilities of lay members of advisory groups or steering committees; and whether the indemnity offered to NHS staff should be extended to cover lay members.

Research issues

A wave of consultation exercises on research issues began with a request for suggestions from the task force developing a strategy for research in nursing, midwifery, and health visiting. It found that "many effectively organised user and consumer groups have structures to identify research priorities and concerns. As public knowledge and interest in health matters has grown, patients demand more information and are less prepared to accept professional judgments without explanation or consultation. Their expertise should be an integral part of the process."¹⁸

Naturally we were delighted that the efforts of consumer groups were welcomed, but representing consumer perspectives is not easy and not always satisfactory. To elicit the views of our members we raised research issues in our quarterly journal, *New Generation*, at the National Childbirth Trust's

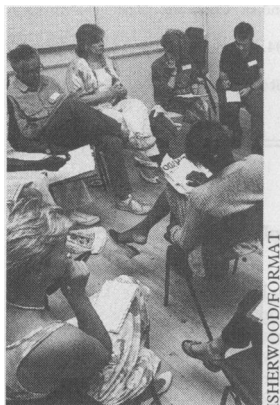
Summary of policy paper, March 1993

The National Childbirth Trust should:

- subscribe to the Cochrane Pregnancy and Childbirth Database
- recognise rigorous research as an integral part of the maternity services and increase awareness of research among health service users
- publicise and debate research in *New Generation* and other journals, both popular and professional
- cooperate with clinical trial collaborators in the development of a strategy for informing and supporting those who will be invited to participate in a trial
- represent maternity service users through research planning committees, ethics committees, and research steering committees
- call for research which aims to enhance short and long term physical, social, and emotional good health
- promote its policy statement on the importance of evaluation in maternity care
- present evaluative research for maternity care practices to health service users so they have sound evidence on which to base their decisions in personal maternity care and requests for policy changes
- encourage health service users to consider seriously invitations to enter clinical trials

The National Childbirth Trust should encourage health professionals:

- to recognise rigorous research as an integral part of the maternity services
- to evaluate the quality of information they offer their clients, differentiating between information based on uncontrolled experimentation and information based on controlled, evaluative research
- to undertake rigorous research
- to consult lay representatives, including the NCT, when planning, conducting, and reporting research and implementing the findings
- to implement or discontinue practices in line with the findings of well designed research



ISHERWOOD/FORMAT

Consumers and researchers can carry out consultation exercises...

members' conference, and in a mailing to the 350 branches of the trust, asking them to discuss which subjects they would like to see investigated more thoroughly. Topics recommended for further research included a wide range of issues: some high technology practices, some established practices, some new ideas, and many variations on the theme of patient information and support.

We restricted this wide ranging list to five "burning issues" for a national study to establish priorities for research in midwifery.¹⁹ Suggestions were scored by a panel of 10 National Childbirth Trust members, half of whom had a particular interest in research. Our final choices were: methods for effective communication and support to meet individual needs; methods for preserving an intact perineum; attitudes of midwives to breast feeding; midwifery training on breast feeding; and withholding food and drink in labour.

Since then, enthusiasm for consulting consumers has grown. In quick succession we have been asked to identify priorities for research in care at the primary-secondary care interface, health technology assessment (in the acute sector, for population screening, and in primary and community care), maternity care, and systematic reviews. Each task needs thinking time, discussion time, library resources, and administrative support—all of which diverts energy and resources away from our primary purpose of offering information and support to the public.

Canvassing opinion on health care research is a serious challenge, even with an established communication network reaching a nationwide membership.²⁰ Other consumer groups may fare better if they depend less heavily on volunteers or have previous experience of effective canvassing methods. They may fare worse if they lack library resources or administrative support.

More satisfactory for consumers are consultation exercises that allow discussion of the issues both among consumers and with health professionals or researchers. But involving service users does not guarantee their voice being heard.

Training and support

The Greater London Association of Community Health Councils is planning to strengthen the voice of maternity services by supporting lay members of maternity service liaison committees, funded by the Department of Health's Development Fund for Changing Childbirth. Consumer involvement in research could also be strengthened by relevant training and support. The getting research into practice (GRiP) project,²¹ which has developed critical appraisal workshops to help purchasers make use of reliable research, has already adapted workshops for National Childbirth Trust members such as antenatal teachers and breast feeding counsellors.

Consulting public opinion may be more effective if consumer groups are able to work with those more experienced in canvassing methods. Access to specialist libraries and support for health service users wishing to express their views in professional journals would open the debate about research issues much wider.

Getting research into practice

Gathering and publishing reliable evidence does not ensure that health service users are offered optimal care.⁹ The trust's latest survey report, *The Perineum in Childbirth*, found discrepancies between some midwifery practices and research findings.⁶ This inspired the trust's strategy for putting research into practice²² and gave us experience to offer the North Thames Research Implementation Group and the

advisory group to the Central Research and Development Committee on priorities for research in implementation.

Conclusions

Consumer groups are well placed to bridge the gap between the public and researchers by explaining research issues to a wide audience, by presenting the needs and views of health service users to the research community, and by suggesting how members of the public may be approached for their views directly. Funding, practical support, and training for consumer groups could help in the development and evaluation of this work.

We have found that the most fruitful partnerships result when time is allowed for health service users to understand the history, organisation, and aims of the research and for researchers to understand the experiences, organisation, and aims of health service user groups. Working together, we can look for better ways to share information, opinions, decision making, and responsibility.

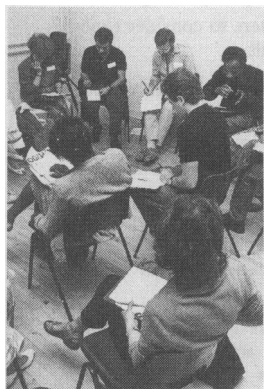
While the views expressed here are my own, I am very grateful to Leonie Allday, Iain Chalmers, Vikki Entwistle, Gill Gyte, and Eileen Hutton for their encouragement and constructive criticism.

- 1 Peckham M. Research and development for the National Health Service. *Lancet* 1991;338:367-71.
- 2 Moran-Ellis J. Rupture of membranes in labour. *J Obstet Gynaecol* 1991; 11 (suppl 1):S6-10.
- 3 Kitzinger S. *Women's experience of epidurals*. London: National Childbirth Trust, 1987.
- 4 Greenshields W. *Postnatal infection survey*. London: National Childbirth Trust, 1988.
- 5 Borton H, Newburn M. *Rupture of membranes in labour survey*. London: National Childbirth Trust, 1989.
- 6 Greenshields W, Hulme H. *The perineum in childbirth*. London: National Childbirth Trust, 1993.
- 7 House of Commons Select Committee on Health. *Report on maternity services*. London: HMSO, 1992. (No 430-I.)
- 8 Stocking B. Implementing the findings of effective care in pregnancy and childbirth in the United Kingdom. *Milbank Quarterly* 1993;71:497-521.
- 9 Chalmers I, Enkin M, Keirse M. *Effective care in pregnancy and childbirth*. Oxford: Oxford University Press, 1989.
- 10 Enkin M, Keirse M, Chalmers I, eds. *A guide to effective care in pregnancy and childbirth*. Oxford: Oxford University Press, 1989.
- 11 Sackett D. Cochrane Collaboration. *BMJ* 1994;309:1514-5.
- 12 Gyte GML. Evaluation of the meta-analyses on the effects, on both mother and baby, of the various components of active management of the third stage of labour. *Midwifery* 1994;10:183-99.
- 13 Enkin M, Keirse MJNC, Renfrew MJ, Neilson JA. *A guide to effective care in pregnancy and childbirth*. 2nd ed. Oxford: Oxford University Press (in press).
- 14 MRC Working Party on the Evaluation of Chorion Villus Sampling. Medical Research Council European Trial of Chorion Villus Sampling. *Lancet* 1991;337:1491-9.
- 15 Somorjay L. [Letter.] *Birth* 1987;14:109.
- 16 CLASP (Collaborative Low-dose Aspirin Study in Pregnancy) Collaborative Group. CLASP: a randomised trial of low-dose aspirin for the prevention and treatment of pre-eclampsia among 9,364 pregnant women. *Lancet* 1994;343:619-29.
- 17 Renfrew MJ, McCandlish R. With women: new steps in research in midwifery. In: Roberts H, ed. *Women's health matters*. London: Routledge, 1992:81-98.
- 18 Taskforce on the Strategy for Research in Nursing, Midwifery and Health Visiting. *Report*. London: Department of Health, 1993.
- 19 Sleep J, Clark E. Major new survey to identify and prioritise research issues for midwifery practice. *Midwives' Chronicle* 1993;106:217-8.
- 20 Oliver S. Creating dialogues: consumer groups. In: Dunning M, Needham G, eds. *But will it work doctor?* London: Consumer Health Information Consortium, 1994:28-31.
- 21 Dunning M, McQuay H, Milne R. 1994. Getting a Grip. *Health Service Journal* 1994;April 28:24-6.
- 22 Gyte G. Putting research into practice in maternity care. *Modern Midwife* 1994;4(8):19-20.

Correction

Vitamin A deficiency and xerophthalmia in the United Kingdom

An authors' error occurred in this Lesson of the Week by Dr N J Watson and others (22 April, pp 1050-1). In case 1 British guidelines on nutritional supplementation had been adhered to, so the fourth sentence in the case report should have read: "This along with recurrent episodes of bacterial overgrowth resulted in nutritional deficiencies, for which he had received intravenous feeding (but not sufficient [rather than no] vitamin A supplementation)."



... to canvas opinion on health care research and discuss the issues