

# Resources review

*Edited by Tom Hain*

## Information and involvement

---

### H. Thornton

Saionara, 31 Regent Street, Rowhedge, Colchester, COEA57, UK

### Abstract

This article discusses the beliefs that provision of good quality information is the key to (a) successful and satisfying involvement of patients in their own decision-making and (b) involvement of lay people in the research process, in debate and other involvement in wider health issues. Education of children, health professionals, the public and the media is advocated, enabling critical appraisal skills and good quality health information to lead to improved involvement of citizens in health-care decisions of all kinds, both individual and societal. Examples of individual, group and specific group involvement through research projects, debates about screening, Citizens' Juries, etc. are used to illustrate benefits to patients and to health provision in general.

### Introduction

The lack of adequate, good quality information is the most frequent complaint of consumers.<sup>1-4</sup> It was lack of information that led to my involvement as a 'consumer' in the medical world.

In my own case, the first example of poor information provision was an inadequate patient information sheet from the UK Randomised Trial for the Management of Screen-detected Ductal Carcinoma in Situ (DCIS) of the Breast.

This led to me refusing to join the trial and to writing a paper describing my reaction to the invitation.<sup>5</sup> I offered a viewpoint to voice what many other women in the same plight may feel.

The second example of poor information, although chronologically first, was the invitation I received from the NHS Breast Screening Programme, to attend for screening.

Since that experience (in August 1991), I have become increasingly convinced that the following themes are central to good provision of health-care to all citizens: proper information provision to the general public, appropriate public involvement in debate and research activity, and cultivation of critical appraisal skills (including appreciation of risk and probability).

### Patient involvement in decision-making, debates

In the UK, we are all privileged to be stakeholders in a National Health Service.<sup>6</sup> We need the tools, not only for individual or shared decision-making, but so that we might play a proper part and fulfil our duties by participating in wider debates about such costly initiatives as screening.

It astonishes me that the Breast Screening Programme should have been funded when its introduction clearly contravened several of the 'Principles of Screening' formulated by Wilson and Junger (1968) for the World Health Organization.<sup>7</sup> Recent overview findings<sup>8</sup> and the enormous controversy it raised in the media and medical journals<sup>9</sup> suggest that wider debate and less haste before introduction as well as

more honest motives might have been beneficial. I have since come to appreciate the role of political and commercial pressures, where justice in terms of resource use takes a very poor second place to courting popularity with a poorly informed and gullible public.<sup>10</sup> Frank Dobson's pronouncement in 1999 that inoculation for Meningitis C at a cost of unknown millions to save 150 lives per annum is another illustration of an emotive illness being responded to by an expensive strategy.

### Patient involvement in research

I described my vision of 'The patient's role in research' at *The Lancet* 'Challenge of Breast Cancer' conference in Brugges in April 1994.<sup>11</sup> My experience with the UK DCIS Trial led me to suggest that there would be enormous benefit in involving patients at the design stage of trials so that hypotheses and protocols would reflect patients' desires for outcomes relevant to their needs. Such trial protocols would not only seek data on therapies' effects on survival, but also consider quality of life.

A further benefit of patient involvement would be that patient information sheets could develop to give *adequate* information in a *clear, understandable* manner, explaining the need for addressing the uncertainties about the *relative merits of different therapies*. Ideally, the tone of these information sheets would indicate that research was 'everyone's business!', where speed of progress depended not only on committed clinician/trialists but also on enthusiastic patient participation.

Following delivery of this paper, I was invited by Professor Michael Baum to chair the Consumers' Advisory Group for Clinical Trials (CAG-CT). The Group met for the first time in September 1994 and immediately began work on a feasibility study examining the use of HRT in women with early breast cancer. This study formed the basis for our project, funded by the NHS R & D Cancer Programme,<sup>12</sup> 'Using a consumers advisory group to increase accrual into trials', which helped shape and inform the current multicentre National Randomised Trial

of HRT in Women with Early Stage Breast Cancer.<sup>13</sup>

The CAG-CT is a small working group of health professionals and consumers who see themselves as facilitators for progress in research. Its aims are to educate the public about research and to work with the profession in attempting to improve the quality of research. It is not only a consumer advocacy group representing a membership, but also a working group intent on seizing opportunities for involvement in consideration of research issues; active participation in research projects from initial formulation of hypothesis onwards. This is achieved through writing, presenting papers; through comment and review of papers (research applications, guidelines, systematic reviews, research protocols, etc.); through joint conferences (with Marie Curie Cancer Care, MCCC), working groups and meetings.

Liaison, iteration and activity with groups and organizations such as the United Kingdom Co-ordinating Committee on Cancer Research (UKCCCR), the Medical Research Council (MRC), MCCC, CancerBACUP, are extremely important. We also support and endorse the work of the Cochrane Collaboration in its work of preparing, maintaining and disseminating systematic reviews of the effects of health-care, where consumer involvement is acknowledged as essential throughout.

### Discussion and conclusions

The benefits of a small mixed group of committed lay and health professionals working together are considerable, particularly when one of the main aims is to increase public understanding of difficult concepts. When meetings occur in a well-regulated atmosphere of tolerance and anticipation of increased mutual understanding and education, the possibilities are exciting. Lay or professionals' misconceptions can quickly be identified and discussed, then used as a means of improving information and methodologies. Barriers to achieving true integration can be identified and considered within intimate dialogues which seek more

clearly to identify and rectify unforeseen problems arising from this new working relationship where actuality does not always match up to expectation for both parties. The reality of the intense commitment brought by involved consumers is sometimes a shock to health professionals when it impinges on areas hitherto believed to be sacrosanct to the medical profession. These areas are now being increasingly broached with advantage: joint platforms, publications, steering committees and such like. This is a bumpy road requiring people of maturity, vision, sensitivity, humility and tenacity able to stay the course.

As Henry G. Sigerist said in 1941, 'The people's health is the concern of the people themselves....'.<sup>15</sup> Since that time, constantly developing technological advances and specialization have caused particularly difficult and complex shared-decision making scenarios.<sup>6</sup> It has, nevertheless, been demonstrated that perfectly ordinary members of the public are well able to become involved in Health Services decision-making through the medium of Citizens' Juries, as demonstrated by the Citizens' Jury on Genetic Testing for Common Disorders Recommendations, produced under the auspices of the Welsh Institute for Health and Social Care's<sup>15</sup> initiative, and jointly taken forward to help shape policy.

Such methods as *Citizens' Juries* or *Citizens' Deliberations* enable consideration of all aspects of problems of public health provision to be considered.<sup>16-18</sup> This is achieved by ensuring accurate information on all relevant matters around the topic is provided to the jurors – with opportunity for questioning – so that they may make a balanced, reasoned appraisal under the direction of a moderator. Ground rules have to be set out at the beginning. Accountability, both to the commissioning body and to the public, is served by the process being open to observers, including the media.

Education of the public and provision of good quality information by every means and at every level is vital.<sup>4</sup> In addition, particular attention should be paid to how best to educate people – children, health professionals, the public and the

media – about explaining and understanding risk and probability. It forms a part of very many shared health decisions – both individual and public. Contingent decisions can be amongst the most difficult to make. Development of graphic tools and stratagems to assist in this difficult area will be of great benefit and should be encouraged.<sup>19-21</sup>

## References

- 1 National Cancer Alliance. Patient-centred services? What patients say. National Cancer Alliance, 1996.
- 2 Audit Commission. *What Seems to Be the Matter: Communication Between Hospitals and Patients*. HMSO. London, 1993.
- 3 Meredith C, Symonds P, Webster L *et al*. Information needs of cancer patients in the West of Scotland: cross-sectional survey of patients' views. *British Medical Journal*, 1996; **313**: 724–726.
- 4 Thomas R, Thornton H, Mackay J. Patient Information Materials in Oncology: Are they Needed and do they Work? Review Article in. *Clinical Oncology*, 1999; **11**: 225–231.
- 5 Thornton HM. Breast cancer trials: a patient's viewpoint. *Lancet*, 1992; **339**: 44–45.
- 6 Thornton H. Today's patient: passive or involved? *Lancet*, 1999; **354**: Supplement 4, 2.
- 7 Wilson JMG, Jungner G. *Principles and practice of screening for disease*. Paper 34. Geneva: World Health Organisation, 1968.
- 8 Gotzsche Olsen O. Is screening for breast cancer with mammography justifiable? *Lancet*, 2000; **355**: 129–133.
- 9 Letters. Screening mammography re-evaluated. *Lancet*, 2000; **355**: 747–752.
- 10 Currie Edwina. *Lifelines. Politics and Health 1986–88*. London: Pan Books, in association with Sidgwick & Jackson, 1989.
- 11 Thornton H. The patient's role in research. In: *Health Committee Third Report on Breast Cancer Services, Vol. II*. London: HMSO, 1995.
- 12 Project NCP/D18. *Using a Consumers' Advisory Group to Increase Accrual into Trials*. NHS R & D Cancer programme. 1995–6.
- 13 Marsden J, Whitehead M, A'Hern R, Baum M, Sacks N. Are randomized trials of hormone replacement therapy in symptomatic women with breast cancer feasible? *Fertility and Sterility*, 2000; **73** (2): 292–299.
- 14 Sigerist HE. Quoted in Silverman W.A. *Human Experimentation. A Guided Step Into the Unknown*. Oxford: Oxford University Press, 1985: 161.
- 15 Welsh Institute for Health and Social Care. *What conditions should be fulfilled before genetic testing for*

- susceptibility to common diseases becomes widely available on the NHS?* Cardiff: Citizens' Jury on Genetic Testing for common Disorders: Recommendations, 1997.
- 16 Thornton H, Baum M. Should a mammographic screening programme carry the warning. 'Screening can damage your health!?' *British Journal of Cancer*, 1999; **5/6**: 691–692.
- 17 McIver S. *Independent Evaluation of Citizens' Juries in Health Authority Settings*. London: King's Fund Publishing, 1998.
- 18 Davies S, Sang B. *Where should women with Gynaecological Cancer who live in Brighton, Hove and East Sussex be offered treatment?* East Sussex, Brighton and Hove Health Authority Citizens' Jury Report. King's Fund Citizens' Jury Programme. 1997.
- 19 Edwards A, Elwyn G. *Health in Partnership Research Initiative, DOH. funded project: The use of shared decision-making skills and risk communication tools in common therapeutic decisions: a primary care trial*. London: Department of Health, 1999.
- 20 Lilford RJ, Pauker SG, Braunholz DA, Chard J. Decision analysis and the implementation of research findings. *British Medical Journal*, 1998; **317**: 405–409.
- 21 Straus SE, McQuay H, Moore RA, Sackett DLA. *Proposed Patient-Centred Method of Delivering Information About The Risks and Benefits of Therapy. The Likelihood of Being Helped Versus Harmed*. 2nd Symposium on Systematic Reviews: Beyond the Basics. Recent Advances, New Challenges, Effective Dissemination. Oxford: St. Catherine's College, January, 1999.