

AUSTRALIAN NEW ZEALAND BREAST CANCER TRIALS GROUP: IMPACT - IMPROVING PARTICIPATION AND ADVOCACY FOR CLINICAL TRIALS



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Clinical trials research

We are now in the most exciting and productive time ever in breast cancer research. The genetics of breast cancer are being unravelled, new treatments are being tested and greater understanding of the controls of cell growth and mechanisms of development of breast cancer are being explored.

The most significant obstacles to new research are low recruitment to clinical trials and lack of infrastructure funding. Relying on the generosity of the community and industry does not allow for long-term commitment. Lack of ongoing infrastructure funding makes it difficult for health professionals to make a commitment to research and the number of institutions which offer clinical trials is limited.

Community education about clinical trials research is very important if participation rates are to increase. Not only is the general community ill-informed about clinical trials research, but so are many health professionals who are in a position to advise people diagnosed with cancer.

People diagnosed with cancer should be given as many opportunities as possible to participate in cancer clinical trials research. The involvement of partners, families and friends is also important in the decision of whether to participate in a clinical trial. Therefore, the whole community needs to be informed so appropriate enquiries can be made at the time of diagnosis.

There are still many myths of how trials are conducted. Perceived uncertainty or the "guinea pig" mentality is still very prominent.

Because of these misconceptions, many people still feel that by participating in a clinical trial they will be giving over their treatment to chance. People who are eligible to participate in a trial are reliant on good communication and full explanations about the trials they may be considering.

Positive community education is vital to influence decision-makers, politicians, health professionals and people in the general community who may face a diagnosis in the future. The myths surrounding cancer clinical trials research need to be openly refuted.

Consumer involvement in clinical trials research

Hanley et al¹ recently made the following points about consumer involvement in research.

"The consumers helped convince researchers and funders that the trial was possible and ethical."

"They were important in helping to refine questions."

"More relevant and clearer questions were... asked."

"They helped make a complex trial comprehensive to most patients."

"They provided insights into issues important to the community and patients."

"Their participation led to improved recruitment."

Australian New Zealand Breast Cancer Trials Group (ANZ BCTG)

Established in 1978 to create a national collaborative approach to breast cancer research through clinical trials, the ANZ BCTG collaborates with over 500 researchers in 60 leading medical and research institutions in Australia and New Zealand and with 15 countries internationally.

The ANZ BCTG initiated the inclusion of consumer representation to research planning in 1994 when a breast cancer survivor and a breast nurse counsellor were invited to become members of their Scientific Advisory Committee. They were invited both because of their own life experiences with breast cancer, and their academic expertise. They have contributed to the scientific discussion and have been responsible for reviewing and commenting on new trial protocols and participant information sheets. They also represent consumers' perspectives on various external committees and present consumers' viewpoints to the media, at conferences and at symposia.

Australian New Zealand Breast Cancer Trials Group Consumer Advisory Panel

In 1998, the ANZ BCTG extended consumer involvement in its research planning by establishing its own Consumer Advisory Panel (CAP). All CAP members are committed to clinical trials research and, as consumer advocates, aim to:

- become effective partners with researchers and health providers to increase nationally the number of women participating in breast cancer clinical trials;
- provide a voice for women who may be participating in breast cancer clinical trials;
- raise awareness and understanding about breast cancer clinical trials and breast cancer issues generally; and
- provide advice to researchers of the ANZ BCTG from the perspective of women who have had breast cancer and who are currently or have been clinical trial participants.

IMPACT – Improving Participation and Advocacy for Clinical Trials

IMPACT was established to further enhance consumer involvement. IMPACT aims to provide a positive voice in the community about breast cancer clinical trials research. The aims of IMPACT are to:

- recognise the important contributions made by women to breast cancer clinical trials research of the ANZ BCTG;
- increase participation to ANZ BCTG breast cancer clinical trials research;
- lobby for increased infrastructure funding for breast cancer clinical trials research;

- enhance links between health professionals with women who have participated in clinical trials research;
- provide reliable up-to-date information on breast cancer clinical trials research;
- educate women about the science of breast cancer and the processes of clinical trials research so they can become effective advocates for clinical trials research; and
- educate the wider community about clinical trials research.

The strategies for achieving the IMPACT program's aims include:

- 1 IMPACT Newsletter
- 2 Information sessions
- 3 IMPACT Education Program

The first aim, of recognising the important contributions made by women to breast cancer clinical trials research, is the most important aspect of IMPACT. High quality breast cancer trials are impossible without the participation of women with breast cancer.

The opportunity to network in a non-clinical environment and to meet with others who have had similar experiences reinforces how important and empowering each woman's contribution is and how much it is valued.

The ANZ BCTG wants to help consumers become more effective as advocates so that they can take a greater role in research development and planning. The information and education provided through IMPACT is designed to do this.

The IMPACT Newsletter is distributed regularly and provides information on research issues and educates readers about the research process. It also provides a vehicle for members to have a say and maintain a connection.

Information sessions are being scheduled nationwide. A brief overview of the IMPACT program and current research updates are presented. Most importantly, however, these sessions provide an opportunity for the ANZ BCTG to acknowledge the contributions of participating women to its

research programs, and for participating women to meet others with similar experiences.

The IMPACT Education Program is offered to members who continue to show a commitment to the clinical trials process and an interest in learning the concepts of basic science, breast cancer research and policy issues.

The Education Program runs over three to four days. Presentations are made on subjects specifically designed to give the participants an understanding of:

- the biology of breast cancer;
- genetics;
- study design, statistics and interpretation;
- diagnosis and treatment;
- conducting clinical trials; and
- advocacy and communication skills.

IMPACT allows its members to make choices. However they choose to contribute, their participation is constructive, valued and they can continue to provide a broader consumer perspective.

What sets IMPACT apart is that it specifically aims to address issues relating to clinical trials research.

Inevitably, the positive messages about breast cancer trials will carry over to the benefit of other clinical trials research. This is another positive attribute of IMPACT. There is still a long way to go to eradicate breast cancer. Advocates cooperating and striving for a common cause can help achieve this sooner. IMPACT members will continue to make their contributions to the research process count.

Reference

- 1 B Hanley, A Truesdale, A King, D Elbourne and I Chalmers. "Involving consumers in designing, conducting and interpreting randomised controlled trials questionnaire survey." *BMJ*, 322 (2001): 519-23.