

WOMEN AS HEALTH CONSUMERS: THE BREAST CANCER EXPERIENCE

This paper provides an overview of women's emerging role within the consumer movement in health, using the Breast Cancer Network Australia (BCNA) as a case study. There is extensive research literature on consumer involvement in health care. However, most research is limited to surveying consumer views of services and facilities that they have used but not on consumer input at a policy level¹.

The emerging role of women as health consumers in Australia is well-illustrated by the BCNA. The BCNA experience of consumer participation provides a useful model of consumer involvement at a policy level, working with a health system that has become more receptive to involving those affected by decisions in the decision-making process.

Women's participation in the health consumer movement can be described as consumer involvement, that is the *process by which those who are affected by decisions contribute towards reaching those decisions*.

Women's role in the health consumer movement emerged out of the women's movement more generally. It also developed in reaction to a belief that the medical profession was one more arena in which men could dominate and control women and their bodies². The movement set about empowering women to question their health care³ and to change the view that women were inherently sick⁴. This activism more recently has extended to gender-specific health issues such as reproductive health and breast cancer.

The Australian breast cancer consumer movement has gathered momentum and achieved substantial results in a relatively short period of time⁵. The BCNA is a peak consumer representative body that has developed a successful model of consumer representation, working in partnership with the medical and scientific communities, government, business and the general community to reduce the impact of breast cancer in Australia.

The social context in which women began participating in health consumer activism followed a long history of women's exclusion from health care development. For example, the absence of women from many drug trials⁶ largely attributed to the assumption that a woman's experience of a drug could be generalised from a man's experience.

In advocating for women's involvement in health care decision making, the women's health movement also had a significant influence over the health consumer movement more generally⁷. As a result of health consumer activism, health systems are considered to be more open to the concept of consumer involvement, with attitudinal change among medical professionals and bureaucrats, and the development of large scale government consumer strategies.

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To receive Focus on Women
please contact:

Communications Section
Commonwealth Office of
the Status of Women
Department of the Prime
Minister and Cabinet

3-5 National Circuit
BARTON ACT 2600

tel: 02 6271 5788

fax: 02 6271 5751

e-mail: jason.mills@pmc.gov.au

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WOMEN'S HEALTH: THE SOCIAL CONTEXT

Society has historically viewed women as dependent, emotional, illogical and irrational⁸. On the other hand, men were viewed as possessing direct opposite characteristics, that is, men were independent, logical and rational. In medical terms these views placed women firmly in the position of the consumers of health care services and men as the providers⁹, as this social perception of women meant that they were not suitable for roles that bestowed any power or authority upon them.¹⁰ Medical professionals needed to display masculine characteristics such as decisiveness and rationality, while being a patient carried with it historically feminine traits, such as dependence and passivity¹¹.

For much of the history of biological medicine, women have had little influence over the development of health services, yet they utilise health services more than men.

With the advent of the women's movement, many of the health care services that were developed for women by men in the medical profession were regarded as inappropriate, particularly for conditions that were gender specific. Some treatments were thought of as too harsh or radical and sometimes completely unnecessary. Women rarely had access to female doctors¹², and instead were treated by male doctors who commonly held paternalistic, hierarchical views regarding their position¹³. This considered, it is not difficult to see why women began to question medical orthodoxies¹⁴ and demand more appropriate services¹⁵.

THE BIRTH OF THE WOMEN'S HEALTH MOVEMENT

The United States of America

Women in the United States have a long history of involvement in social movements, such as the anti-slavery and civil rights movements. The role women played in these movements acted as the inspiration behind the women's liberation movement that developed in the 1960s¹⁶. This movement sought to address many issues relevant to women, particularly women's health¹⁷. The feminists of this time began to alert women about the disadvantages they faced, not only in terms of their health¹⁸ but also in other areas such as employment. Feminists saw the medical profession as a male-dominated 'microcosm of patriarchy'¹⁹. The focus of their attention began with such issues as reproductive and sexual health²⁰.

One of the first organised groups to form specifically around women's health issues was the Boston Women's Health Collective, established in 1969. This group rejected the societal views of women of the time and sought to develop a broader definition of health that took into consideration social, economic and environmental factors. In addition, they believed that women should participate in the development of health care services, not merely consume them²¹, displaying the first signs of the demand for consumer involvement in health care development. Full participation, however, was difficult due to the inaccessibility of medical knowledge²². However, this in time would change.

Australia

The women's health movement quickly spread to both Britain and Australia where women also sought to reform their reproductive and sexual health rights²³. It is the Australian women's health movement, however, that is most well known for its success in achieving broad health system reforms and particularly for the lobbying that resulted in the family planning services network that is now long established²⁴. This network of services is considered unique²⁵ and was the beginning of a powerful women's health advocacy network²⁶.

Evidence suggests that Australian women are by no means passive when it comes to the health care they receive²⁷ and have continued to question health practitioner advice²⁸, while playing a large role in setting up self-help and consumer advocacy groups, and not just for health care issues specific to women²⁹. With this history of questioning established medical practice³⁰, Australian women continue to play a crucial role in the health consumer movement³¹. Women's higher usage of health care services for their own health and reproductive needs, and on behalf of those they care for - such as partners, parents and their children - has led them to seek an extensive understanding of their health and the health care system.

THE WOMEN'S HEALTH MOVEMENT'S INFLUENCE ON THE CONSUMER HEALTH MOVEMENT

Prior to the women's health movement there had been few instances in Australia where the general public had the opportunity to be involved in decision making processes in health care development³².

The women's health movement has not only contributed to the changing social status of women but it has also changed medical practice, reshaped health care institutions and influenced health care policy.

Health consumers have become more empowered. They now have access to health information, through such tools as the Internet, that in the past was only available to members of the medical profession. Access to this information is crucial if consumers are to contribute equally in decisions regarding their health.³³ Health consumers in general are now more likely to question their medical care³⁴. The status of the medical profession has also diminished in recent years and doctors as a group are no longer viewed or universally accepted as 'heroes in white coats'.³⁵

The medical fraternity in Australia has begun to recognise the need to respond to these changes. For instance, most medical schools throughout Australia have now implemented changes in both the entry requirements of students and the structure of their courses to focus more on the needs of the consumer³⁶. This shift in thinking was illustrated when the University of Newcastle Dean of Medicine and Health Sciences, in respect of entry criteria for medical students, stated:

"...if you believe both technical competence and the 'care dimension' are important, then you should select for both – ability to acquire and regurgitate information in set formats, but also the ability to work and talk with people".³⁷

Changes are also reflected in evolving course structures, such as that described by Stephen Leeder, Dean of the Faculty of Medicine at the University of Sydney:

"We've organised students' learning not according to disciplines but according to four themes – basic and clinical science, community and doctor, patient and doctor and personal and professional development".³⁸

As consumer participation requires some form of power redistribution between the medical profession, governments and consumers³⁹, there are many attitudinal obstacles to the truly effective engagement of consumers.

Both governments and the medical profession have undergone and supported significant attitudinal shifts in that both have taken substantial steps in implementing strategies that recognise consumers as a crucial component in the provision of more effective services and treatments. These steps may partly be a result of the increasing concern about public accountability in an arena where needs are high and funds are scarce⁴⁰. But overall there has been a realisation that by empowering consumers to participate in the development of health care services, it will result in more cost effective and appropriate services.⁴¹

ATTITUDINAL CHANGES AMONGST MEDICAL PROFESSIONALS

“...at any one time there is potential for harmony as well as for discord in patient-professional clinical and working relationships. But patients’ definitions of their own interests and health professionals’ acceptance of those definitions both call for protracted effort: and both can experience anger or anguish. Consumer advocates feel their task is unending; health professionals feel under constant threat of criticism, however conscientious their practice.”⁴²

The medical profession, however, has begun to understand that it is this very potential for discord which makes consumer participation so valuable⁴³. This is reflected in the increasing numbers of patient liaison groups in medical colleges and patient participation groups in general practice. Consumers are being asked to participate in everything from clinical audit groups, research groups designing study protocols, to groups developing clinical guidelines⁴⁴.

Ms Lyn Swinburne, National Coordinator of the BCNA, provided a specific example of this attitudinal change when she discussed the role consumers played in the Leura International Breast Cancer Conference, which was first held in 1994:

“I remember Marcia O’Keefe an early breast cancer activist attending that Conference and this being considered a major move forward. In 1996 and 1998 a few more ‘consumers’ were allowed to attend, but in 2000 there was a major shift when I was asked to be the Opening Speaker and launch the Conference. This, to my mind, was a huge indication that we are now accepted as having a rightful place in the breast cancer arena. The feedback from my speech was outstandingly positive and there was a real sense that we were working together as true collaborators.”⁴⁵

While the medical profession is sometimes criticised for merely trying to keep up with the move toward increased consumer participation rather than leading the way⁴⁶, the benefits of an increase in consumer participation are sought by governments and consumers alike.

FEDERAL GOVERNMENT INITIATIVES FOR INCREASED CONSUMER PARTICIPATION

Federal Governments, via the Commonwealth Department of Health and Ageing (DoHA) have implemented a range of strategies over the past 20 years that promote consumer involvement in health care development, including:

- funding of the Consumers’ Health Forum, a national peak consumer body
- funding of research into consumer participation and its benefits for health care
- establishment of a national complaints project, which involved the development of a national data framework
- funding and development of accreditation programs
- establishment of the Taskforce on Quality in Australian Health Care and the National Expert Advisory Group on Safety and Quality in Australian Health Care (the latter aiming to take forward the recommendations of the former)
- funding of the National Resource Centre for Consumer Participation in Health
- establishment of the Consumer Focus Collaboration in order to further the Commonwealth’s goal of enhancing quality and safety in the health system through increasing its consumer focus⁴⁷
- funds of the ‘Improving Health Services Through Consumer Participation Conference’, held in May 2001.⁴⁸

These initiatives were developed or funded with the specific aim of promoting, integrating and disseminating information and increasing consumer involvement in health service planning, delivery, monitoring and evaluation.⁴⁹

In addition to specific work in increasing awareness of the benefits and levels of consumer participation, there are also many other projects that DoHA administer or fund which involve the promotion of consumer involvement and participation in health care. For example, the Cochrane Collaboration is an international organisation set up to facilitate the preparation and maintenance of systematic clinical reviews of health treatments and services.⁵⁰ It maintains a Consumer Network, whose role is to support and develop consumer participation and help make the information produced available to consumers.⁵¹

Consumers also hold positions on many committees throughout DoHA, such as the Cancer Strategies Group⁵², and the National Advisory Committee for BreastScreen Australia⁵³. In addition, consumer organisations are frequently consulted through bodies such as the Australian Council for Quality and Safety in Health Care⁵⁴. HealthInSite is another initiative funded by the Federal Government, which aims to “bridge the gap between the increasing potential for consumers to access health information via the Internet, and the absence of quality control of web information”.⁵⁵

A particular initiative for women as consumers, funded by the Commonwealth, is the BCNA ‘A Seat at the Table’ project. The Cancer Control Section of DoHA funded BCNA to record their process for identifying, recruiting, appointing and supporting women to be consumer representatives in the field of breast cancer⁵⁶. This process will be discussed in more detail in a later section.

THE BREAST CANCER EXAMPLE OF CONSUMER PARTICIPATION: A MODEL FOR CHANGE

The increasing activity in female specific health issues, such as breast cancer, is “inseparable from the rise of the women’s health movement and with it, the empowerment of women to control their own bodies, as a first step to controlling their lives”⁵⁷.

In the past much of the responsibility for breast cancer policy development lay with health planners, doctors, researchers and politicians. The priorities for breast cancer established by these parties were often very different from those held by women experiencing the disease.⁵⁸

THE BIRTH OF THE BREAST CANCER MOVEMENT

The breast cancer movement has achieved success through lobbying the right people, by learning where decisions are made, identifying champions in influential places, and recognising the importance of a united voice.

Breast cancer first achieved significant coverage in Australia in 1993 when the disease was found to be the most common cause of cancer death in Australian women and the risk of developing the disease stood between one in 11 and one in 16⁵⁹. As a result an inquiry into the treatment and management of breast cancer was referred to a House of Representatives Standing Committee on Community Affairs⁶⁰. In 1995, the Standing Committee released its report, containing numerous recommendations aimed at improving the treatment and management of breast cancer in Australia.

The National Breast Cancer Centre was then established with Federal Government funding in response to community concerns about the human costs of the disease. The NBCC’s aims were to improve breast cancer control by:

- analysing research and making it readily available to women and health professionals
- developing, disseminating and encouraging the adoption of clinical guidelines to improve the diagnosis, treatment and support of women with breast cancer
- providing accurate and accessible information to well women, women with breast cancer, primary care providers and breast cancer specialists
- developing a national monitoring system to provide information about all aspects of breast cancer.⁶¹

THE ESTABLISHMENT OF A NATIONAL VOICE FOR BREAST CANCER CONSUMERS

The momentum continued to gather, and in 1998 Australia held its first 'National Breast Cancer Conference for Women' at Parliament House in Canberra. This was an opportunity for women who were affected by the disease to join together, discuss their experiences and share their views on the priorities for breast cancer policy development. Government officials, researchers, health care workers and clinicians also attended.⁶²

Prior to the conference it became evident that there was a need for a collective consumer voice for those affected by the disease. As a result BCNA was officially launched on the lawns in front of Parliament House in Canberra following the conference⁶³.

Breast Cancer Network Australia was formed based upon the strong belief that those affected by the disease needed to play a part in decisions made about policy and services that would affect them and that there was a need to link advocacy groups that were quickly evolving around Australia. BCNA now links up to 90 member organisations and has approximately 7,000 individual members⁶⁴ and is considered the national peak body for women personally affected by breast cancer⁶⁵.

It also carries out a number of functions with the primary goal of supporting those affected by breast cancer. These include such activities as the quarterly publication of The Beacon consumer newsletter; coordination of the national Field of Women; sponsorship of the Dragons Abreast dragon boat team; and production of the *My Journey* folders⁶⁶. BCNA also put forward consumer representatives to sit on government and non-government committees in the field of breast cancer through their 'A Seat at the Table' project.

BARRIERS TO EFFECTIVE CONSUMER PARTICIPATION

Evidence suggests that there are three main barriers to effective consumer involvement.

1. There tends to be an imbalance of power between professionals and consumers.
2. Consumers historically lack ties with local support networks in health care institutions and organisations, thereby having less ability to influence health care issues.
3. Consumers tend to lack access to information and skills necessary for making decisions related to health policy planning and hence undermining their success in participation.⁶⁷

The BCNA has addressed these barriers as follows:

1. Imbalance of power between professionals and consumers

There is extensive evidence describing the difficulties that consumer representatives face when part of a professional committee and the tactics that can be used to "reduce the effectiveness of their contribution".⁶⁸

"Taking a person out of the community and setting her or him down in, for example, a committee with a bunch of influential doctors ideally affects the doctors, but it is even more certain that it will affect the consumer."⁶⁹

A breast cancer committee is likely to face the barrier of an imbalance of power as consumers are almost always women and medical specialists are almost always men.

In the Australian context, however, from an experienced breast cancer consumer representative point of view, there are more status barriers at play in the breast cancer policy development arena than there are gender barriers and these are not always between the clinicians and consumers.⁷⁰

“Although some of the status barriers have been reduced, there is still a sense of the GP for example having less status than the specialist. There are times when GPs and nurses are not included in policy setting; but there are usually several surgeons.”⁷¹

There were some instances, prior to the establishment of the NBCC when “...there was a real mentality of the clinicians ruling, and other people being very much poorer relations. Consumers had no place at all in policy-making! However, through years of working together a sense of mutual respect has developed.”⁷²

2. The lack of ties with local support networks in health care institutions and organisations

Through their ‘A Seat at the Table’ project supported by the Federal Government, BCNA has developed strong relationships with both the Federal Government and the National Breast Cancer Council. The NBCC also has a commitment to consumer involvement in the development of breast cancer policy, illustrated through the development of the ‘Consumers and the NBCC’ policy.⁷³

Through this policy the NBCC provide a dedicated staff member who works closely with BCNA on consumer issues;⁷⁴ and a formal fee for service agreement with BCNA to engage a consumer representative on all advisory groups formed for specific projects, whether they be clinical, administrative, policy or research orientated.⁷⁵ BCNA consumers have contributed to the development of many clinical practice guidelines and the complementary consumer guides produced by the NBCC, such as the *Psychosocial Clinical Practice Guidelines: Information, Support and Counselling for Women with Breast Cancer*, the *Clinical Practice Guidelines for the Management of Advanced Breast Cancer* and its complementary consumer guide, *A Guide for Women with Metastatic Breast Cancer*. Their role is emphasised in the following statement by BCNA National Coordinator, Ms Lyn Swinburne:

“We have been crucial to the establishment of guidelines, both clinical versions and consumer versions. The Psychosocial Guidelines clearly display the consumer fingerprint, with the supportive care of the individual highlighted at the start and the more clinical aspects to follow. These Guidelines are now forming the basis for more generic guidelines for use with patients with a range of cancers.”⁷⁶

Australia, and more specifically the breast cancer sector, appears to be quite innovative in its involvement of consumer representatives in guideline development as compared to other countries, where guideline development processes, which may on the surface seem to advocate consumer participation, are more often merely targets in the dissemination of the recommendations made in the guidelines themselves.⁷⁷

In addition to these initiatives, the NBCC also invites BCNA, as the peak breast cancer consumer organisation, to provide input into setting its yearly work program, via two dedicated positions on its Program Implementation Advisory Committee.⁷⁸

3. The lack of access to information and skills necessary for making decisions

BCNA believes that “for consumer representatives to be effective and influential on science, medical and other committees, they need more than a personal experience with breast cancer.”⁷⁹ This belief supports the notion of “information is power”⁸⁰. In response to the historical monopoly the medical profession have held over medical and health system knowledge, BCNA encourage their potential consumer representatives to complete the Consumer Advocacy and Science Training Program.⁸¹

This program provides training in skills such as consumer advocacy, lobbying government, understanding the health system, using the media, running campaigns, communication skills, how to identify major stakeholders in the breast cancer community, the science of breast cancer diagnosis and treatment and interpreting breast cancer scientific research⁸².

The NBCC developed and initially administered this program and the BCNA now runs it bringing interested women from different areas throughout Australia, including rural and remote, to Melbourne to complete the training.⁸³

Despite BCNA's desire to provide consumer representatives who are well versed in both the views and perspectives of other health consumers and in medical and health system information, this approach does not counteract the criticism that the more 'knowledgeable' a consumer representative – in this case, of the bureaucratic and medical discourse - the less likely they are able to truly represent other consumers⁸⁴. However, BCNA place a strong emphasis on consumers obtaining and maintaining a broad understanding of all issues that women with breast cancer face.⁸⁵

Further, a criticism of earlier consumer movements, particularly around women's health, is that they "encouraged people to make demands but failed to emphasise reciprocal responsibilities".⁸⁶ There has been a shift in the health consumer movement, displayed by BCNA encouraging consumer representatives to obtain higher levels of knowledge, acknowledging that consumers also have a responsibility. That is, if they are to demand that those in decision-making positions, such as government officials and doctors, must listen to and incorporate their views, the consumer representatives also should remain accountable, to both those whom they are representing and those with whom they are working⁸⁷. It is only fair that in a society where the health system and medical knowledge is more accessible to consumers than in times past, that "what is expected of doctors who are members of a working group should apply to every member of the working group"⁸⁸, including consumer representatives.

Other barriers to effective consumer participation

Another barrier to effective consumer participation is difficulty in raising independent funding. This pressure to survive in a difficult climate has led voluntary organisations to seek commercial funding. BCNA have secured corporate support and funding from two commercial entities.⁸⁹

A further barrier that consumer groups have difficulty in overcoming is the lack of organised methods of recruiting potential consumers⁹⁰. In response to this, in 2000-2001 BCNA secured funding from the Commonwealth Office of the Status of Women and DoHA (as part of their Consumer Focus Strategy) to develop and document a model for a disease-specific group to select and support consumer representatives. The objective of the project is to ensure consumer representation on all types of committees, whether clinical, administrative, policy or research, that made decisions about breast cancer⁹¹. The project is also establishing a standard of practice for the BCNA consumer representatives to enhance the outcomes of the committees in which they were involved.⁹²

The project comprises a resource kit for women electing to become a consumer representative, a resource kit for organisations wishing to engage a consumer representative and a database about each woman's diagnosis, treatment, skills and associations with breast cancer related groups. Women are recruited in a number of ways, including through independent or membership interest.⁹³

CONCLUSION

The BCNA experience illustrates how the women's health consumer movement paved the way for disease-specific consumer groups and provides just one example of Australian approaches to health consumer participation.

The National Breast Cancer Centre (NBCC) has already begun to examine how the BCNA model could be applied to assist people with other cancers. The centre recently secured additional DOHA funds to begin work on a similar model of consumer involvement for women with ovarian cancer with the intention to utilise a similar model in terms of consumer involvement as that utilised through their relationship with BCNA.⁹⁴

Although BCNA can claim success in many areas, it has highlighted a need to address the issue of including people who are difficult to reach and represent, particularly women from rural and remote areas, Aboriginal and Torres Strait Islander people and culturally and linguistically diverse women.⁹⁵ Consumer groups using the BCNA model will need to address this issue if they wish to be fully representative

The breast cancer experience provides a positive template for effective consumer participation for continued change.

The development of innovative strategies for effective consumer involvement continues in Australia. These elements for mutually beneficial partnerships between policy makers and consumers are:

- a shared belief that consumers have a right to be involved, and that outcomes are improved by their active involvement;
- a commitment by the policy makers to involving consumers at all levels and providing practical encouragement and support for this to happen;
- the provision of funding for the process of involving the consumers;
- commitment by the consumer organisation to develop and nurture a serious involvement with other organisations requiring their representation;

- establishment by both parties of a standardised, easy to use consumer engagement process, which supplies effective, trained and supported consumer representatives; and
- close working relationships formed on mutual respect between organisations.⁹⁶

The work of breast cancer consumer representatives is a powerful illustration of the valuable role health consumers can play in improving health services; that consumers can provide more than just feedback on services received, they can also be utilised in the planning and implementation of effective and efficient services and provide a model for other disease specific areas.

The BCNA experience of consumer participation provides a useful model of consumer involvement at a policy level, working with a health system that has become more receptive to involving those affected in the decision-making process.

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