

# A CONSUMER-INITIATED SURVEY OF WOMEN'S EXPERIENCES OF BREAST CANCER SERVICES IN NSW

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Advocates of consumers of breast cancer care are increasingly seeking to influence the cancer research agenda, by urging the investigation of those aspects of cancer prevention and treatment that are of most interest to them. Consumer advocates can either influence existing scientific and behavioural research, or they can instigate consumer-driven research themselves. This article describes an example of the latter—a survey of women's experiences of breast cancer services in NSW, initiated and conducted by the cancer advocacy group, Breast Cancer Action Group NSW. While the response to the survey was low (20 per cent), the article presents an analysis of the qualitative questions, which provides insight into both the perceived gaps and deficiencies in services and the areas of satisfaction with services.

## BREAST CANCER SERVICES DEVELOPMENT GROUP

Reorganising breast cancer services, to overcome fragmentation and reduce unacceptable variations in treatment and outcomes, has been recognised nationally as a key priority in cancer control.<sup>1</sup> In March 2000, The Cancer Council NSW established a Breast Cancer Services Development Group with the goal of improving breast cancer services in NSW and encouraging the adoption of multidisciplinary care based on 'best practice'. Membership of the group comprises representatives from The Cancer Council NSW, the NSW Breast Cancer Institute at Westmead, and the Breast Cancer Action Group NSW (BCAG).

As a first step, the Breast Cancer Services Development Group agreed to obtain baseline information about breast cancer services in NSW, by compiling material from a variety of sources and perspectives, including cancer registry data. It proposed to map the breast cancer services provided across the 17 area health services. The BCAG undertook a survey of its members in May 2001, regarding their experiences of the treatment of breast cancer. The main objective of this survey was to provide a consumer perspective on gaps in breast cancer care, and to prioritise issues relating to improving breast cancer services.

## METHODS

The BCAG developed a short eight-item postal questionnaire, in collaboration with The Cancer Council

NSW and the Cancer Education and Research Program (CERP) at the University of Newcastle. The questionnaire included: closed questions concerning each respondent's care—the number and type of clinicians and hospitals involved, and the organisation and coordination of care; and open-ended questions regarding the respondent's personal experience of her treatment, both positive and negative. A convenience sample was taken, as the questionnaire was mailed to the entire BCAG membership in May 2001. In total, 400 questionnaires were sent and participants were asked to respond within three weeks.

Responses to the closed questions were analysed using simple summary statistics. The qualitative, open-ended responses were analysed using a pragmatic, grounded-theory approach; written responses were read a number of times to identify emerging themes. Responses focusing on similar aspects of service delivery were grouped together into categories in order to identify common issues.

## RESULTS

Seventy-nine completed questionnaires were received, giving a response rate of 20 per cent. This response rate is low for a survey of this type and, as such, the quantitative data obtained are of limited value. However, respondents' answers to the open-ended questions appeared thoughtful and detailed and provided a rich source of qualitative information about the women's experiences.

The average age of respondents was 54.3 years (median 54 years), with a range of 32 to 86 years. More than 80 per cent lived in an area of NSW covered by a metropolitan area health service; and over 88 per cent of women received the majority of their care at hospitals located in a metropolitan area health service. Only six women stated that they received the majority of their breast cancer care at a hospital located in a rural area health service.

### Coordination of care

Nearly two-thirds of women (60 per cent) attended more than one hospital for their breast cancer treatment, with 39 respondents mentioning one other hospital besides their main treatment provider, and a further nine women mentioning two additional hospitals involved in their care. Less than half of all respondents (46.8 per cent) perceived their care to be coordinated by a multi-disciplinary team. A further five respondents gave a qualified positive response, indicating that elements of the care pathway had been coordinated, or that efforts towards coordination had been partially successful.

### Positive aspects of breast cancer care

Respondents were asked to highlight three or four elements that went well during their treatment and care for breast cancer. Common aspects of care that were perceived positively by respondents were:

- supportive and caring attitudes of staff throughout various stages of the care pathway;
- role played by support groups, counsellors, friends, and family in meeting the emotional, psychological, and practical needs of women;
- quality and organisation of the clinical care received—many women indicated their general satisfaction with their clinical treatment as a whole, while others highlighted particular elements of care that went well, in particular surgery, radiotherapy, chemotherapy, reconstructive surgery, or follow-up;
- accessibility and availability of certain services, such as community nursing post-discharge and breast reconstruction;
- control or absence of pain, discomfort, or other physical symptoms and side-effects.

### Negative aspects of breast cancer care

Women were also invited to describe three or four areas of their care in which they experienced problems. A small number reported no major problems; however, most women cited at least two or three areas of concern. Some of the key negative experiences described by respondents were:

- poor communication and information provision;
- inappropriate, unsupportive, or uncaring attitudes of health professionals;
- problems with the quality of the clinical care received, including misdiagnosis or delayed diagnosis, poor management of radiotherapy burns, poor infection control, and poor management of other clinical symptoms and conditions, such as depression and lymphoedema;
- problems relating to the organisation and delivery of treatment, including: delays throughout the treatment pathway; limited ongoing follow-up and after care, particularly in primary care; long clinic waiting times; travelling long distances for treatment; follow up and support groups; inconvenient appointment times; and seeing different doctors each time;
- physical and psychological effects of diagnosis and treatment, such as pain, discomfort, swelling, wound infection, scarring, depression and anxiety;
- limited attention paid to women's emotional and psychological needs;
- lack of a coordinating or central focus to treatment; no single point of contact for information, advice, and access to different components of care;

- inadequate, inconsistent coordination and communication between secondary–tertiary cancer services and local health services, including primary care.

### Areas for improvement

Women wanted to see improvements in those areas of treatment and care in which they perceived problems, or reported negative experiences. Some of the key areas for improvement highlighted by respondents were:

- patient communication and information, including the accessibility, timeliness and reliability of information;
- coordination of care and a multidisciplinary team approach, including access to a designated person to coordinate the breast cancer journey and to provide advice and support;
- services and support mechanisms to better meet women's psychological, social, and information needs;
- the attitude of health professionals, and communication between clinicians and patients;
- the availability and accessibility of local services, particularly for women living in rural areas.

### DISCUSSION

The principal value of this survey is in providing qualitative insights into both the positive and the negative aspects of women's experience of breast cancer treatment and care in NSW, and reporting those areas of care in which women would like to see improvement.

As the majority of the respondents to the survey were from metropolitan areas of NSW, the issues and priorities reported here potentially underplay issues of importance to rural women.

The ways in which they are treated and the care and support they receive from breast care services influences women's overall experience of breast cancer. This survey indicates that the presence or absence of a number of key features strongly determines women's negative or positive experiences of the treatment pathway. These features include a multidisciplinary, coordinated approach to care; provision of information and patient–clinician communication; and the availability and accessibility of services, in distance and time, including supportive care services. These fundamental elements of care are widely recognised, and have been incorporated into models and guidelines for best practice in Australia and internationally.<sup>2, 3, 4</sup> The consumer experiences reported here serve to highlight that some women experience a gap between these recommended models of care and on-the-ground service delivery.


The key challenge facing the health system is how to achieve a statewide system of care that is responsive to, and meets the needs of, all women with breast cancer and

also of their families and carers. By undertaking this survey, and disseminating its findings widely, the BCAG hopes that consumers' views will inform service development and quality improvement strategies in breast cancer services across NSW.

## CONCLUSION

This survey also demonstrates that consumer-initiated and designed research can make a contribution to the treatment experiences of people living with cancer. It also provides consumer groups, such as the BCAG, with an evidence-based platform for their advocacy and lobbying activities.

## REFERENCES

1. Cancer Strategies Group. *Priorities for Action in Cancer Control 2001–2003*. Canberra: Commonwealth Department of Health and Ageing, 2001.
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3. Breast Care Implementation Advisory Committee. *Breast Disease Service Redevelopment Strategy 1999–2003*. Melbourne: Victorian Government Publishing Service, 1999.
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## RELEASE OF THE 2002 AREA HEALTH SERVICE REPORTS

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The *2002 Area Health Service Reports* (AHSRs) are the first of a series of annual reports produced to assist the area health services monitor the health status of their population, and to support policy development and service planning at the area level.

The AHSRs present data from the 1997, 1998, and 2002 NSW Health Surveys that is specific to each of the 17 area health services. These surveys were conducted by the Centre for Epidemiology and Research through the NSW Department of Health's Computer Assisted Telephone Interviewing (CATI) Facility. The 2002 NSW Health Survey reports on data collected from approximately 15,000 randomly-selected adults.

The NSW Department of Health, in consultation with the 17 area health services, has identified 15 indicators that will be reported on annually. These are:

### Health Behaviours

- alcohol risk drinking behaviour
- fruit intake
- vegetable intake
- physical activity
- smoking status
- smoke-free households

### Health Status

- self-rated health status
- asthma
- diabetes or high blood sugar
- oral health—no natural teeth missing
- overweight and obesity
- psychological distress

### Health Services

- difficulties getting health care when needing it
- emergency department care rating
- hospital care rating.

These indicators are presented in graphical and tabular form. For each indicator, the AHSRs include line charts of trend by sex (1997, 1998, 2002 data) comparing the area health service with the whole of NSW, and a bar chart of the indicator by age group (2002 Area Health Service data).

Examples of the trend graph for one of the indicators used in the Health Survey Program Area Reports—Smoke-free households by sex for people aged 16 years and over—are shown for an urban area (Central Sydney Area Health Service, Figure 1) and a rural area (New England Area Health Service, Figure 2).

The AHSRs were released during May 2003 and are available via the NSW Department of Health intranet as both PDF and HTML files.