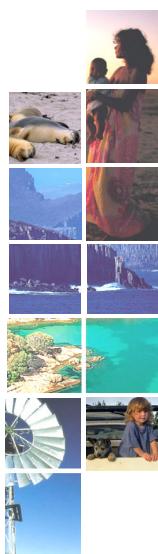


The challenge of developing and evaluating local programs in breast cancer care: the Strengthening Support for Women with Breast Cancer program

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AIM

This paper aims to describe the process of developing and evaluating a range of programs for enhancing breast cancer care in diverse local health jurisdictions. The Commonwealth Department of Health and Ageing has funded the Strengthening Support for Women with Breast Cancer (SSWBC) program over four years to improve supportive care for women with breast cancer, particularly those living in rural and remote areas. State and territory organisations have received funding to develop and implement programs for women and health professionals that are relevant and applicable to the needs of local jurisdictions. The National Breast Cancer Centre (the Centre) is responsible for conducting a national evaluation of the program. This paper will describe some of the challenges associated with developing strategies for enhancing supportive care to suit local health care services. It will also discuss the challenges associated with designing a national evaluation to effectively address locally diverse approaches to health care.



PART I: DEVELOPING STRATEGIES TO SUIT LOCAL HEALTH CARE SERVICES

Background

It is estimated that one in 11 women will develop breast cancer if they live to 75 years of age.¹ Incidence of and mortality from breast cancer does not differ between women living in urban, rural and remote parts of Australia.²

There is a considerable amount of information available about the diagnosis, treatment and supportive care needs of women diagnosed with breast cancer who are living in rural and remote Australia. Most aspects of breast cancer treatment are similar for women in rural and urban areas. For instance, data from a national “patterns of care” study indicate that women living in rural areas are just as likely as urban women to have their breast cancer diagnosed by the screening program, and to receive the same investigations.³ However, some differences are apparent; compared with women from metropolitan areas, rural women are less likely to be treated by surgeons who have a high breast cancer caseload, and may be more likely to have mastectomy rather than breast conserving surgery.³ Furthermore, the *National Survey of Women with Early Breast Cancer*, a population based survey of more than 500 women diagnosed with



early breast cancer, indicated that many rural women have to travel long distances and spend time away from home for breast cancer treatment. The survey found that substantial numbers of rural women travelled more than 100 kilometres for: surgery (32 per cent); radiation therapy (63 per cent of those who received radiation therapy); and chemotherapy (36 per cent of those who received chemotherapy).⁴ Rural women treated with radiation therapy spent an average of 43 days away from home, while those treated with chemotherapy were away for an average of 20 days. It should be noted that rural women in this study did not attribute their treatment decisions to the need to travel or otherwise.⁵

The literature suggests that there are few differences in the provision of information and supportive care to women living in rural and urban areas. There was no evidence in the *National Survey of Women* to suggest that rural women felt that they had poorer access to information about treatment or were less involved in decision making about their treatment than their urban counterparts.⁵ An earlier study of 229 women diagnosed with breast cancer also reported similar levels among rural and urban women of unmet needs related to information and psychological issues.⁶

There is evidence that rural women with breast cancer do experience specific problems as a result of living in rural locations. Eighty nine per cent of participants in a needs analysis of rural and remote women reported experiencing practical and social difficulties as a result of travelling for treatment.⁷ Similarly, one third of rural women in the *National Survey of Women* believed that living outside a major city had limited their access to information or services.⁴ Qualitative research has also highlighted rural women's concerns about issues including how their families cope during their absences for treatment, the burden on the family of having to cope with running a property or farm alone, and added financial strain brought about by the costs associated with travel for treatment.⁸ The *National Survey of Women* found that less than half of the women who travelled for treatment received financial assistance and, of those who did not receive financial assistance, one quarter were unaware of its availability.⁴

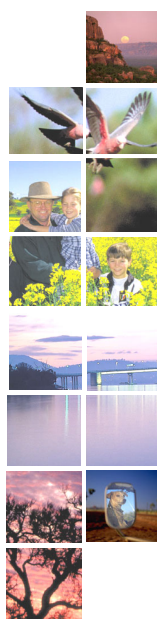
The difficulties faced by rural and remote women have been recognised by the Commonwealth government. In 1995, a House of Representatives Standing Committee on Community Affairs recommended in its Report on the Management and Treatment of Breast Cancer⁹ that:

Commonwealth and state/territory governments, along with practitioners, professional bodies and all other service providers, give urgent priority to addressing the problems faced by women from rural and remote areas in accessing multidisciplinary teams, adjuvant therapy, clinical trials, counselling, support groups, and information. (p14)

In response to this recommendation, the May 1999 federal budget announced funding of \$4.1 million over four years for the SSWBC program to address the supportive care needs of women with breast cancer, particularly women living in rural and remote areas.

Objective of the SSWBC program

The objective of the program was to develop a framework for effectively improving supportive care for rural women with breast cancer, taking into consideration the unique difficulties facing women in rural and remote areas of Australia. To support



the initiative, the Centre prepared a paper that summarised the available data about the needs of rural women with breast cancer and the effectiveness of different strategies for improving support.¹⁰ Specific factors to be taken into account in developing the framework included:

- the range of rural and remote contexts across the country;
- the diverse range of health services and health delivery structures in each state and territory;
- the finite (four-year) funding period; and
- the availability of human and other resources to implement the program in rural areas.

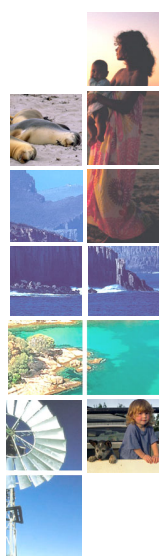
Methods: the SSWBC program

In November 1999 the Centre convened a workshop involving key stakeholders from across the country, including representatives from Commonwealth, state and territory health departments, cancer organisations, clinical and consumer groups, and rural health professionals. The aims of the workshop were to:

- review existing data about rural women and breast cancer and their supportive care needs
- canvas the views of key stakeholders about options for strengthening supportive care services
- reach a consensus about optimal approaches to strengthening supportive care services for rural women with breast cancer within the context of the funding announced in the federal budget.

During the workshop, stakeholders participated in interactive small group work to consider potential models for implementing the project. Stakeholders were asked to focus on the merits of various models and issues associated with implementing and evaluating each model in the rural context.¹¹ Of key importance was the need for the project to result in feasible and **sustainable** improvements in supportive care for rural women, as funds would not be available beyond the end of the four year funding period. Based on stakeholder consultations at the workshop and existing local and international evidence about strategies that are effective in improving supportive care, systematically reviewed in the Centre's *Psychosocial Clinical Practice Guidelines*,¹² four models for implementing the project were proposed:

- **Establishment of new specialist breast nurse / cancer supportive care co-ordinator roles:** There is considerable evidence from international randomised trials that specialist breast nurses can improve many aspects of supportive care for women with breast cancer.^{13,14,15,16,17,18} There are also some Australian data to show that breast nurse positions are acceptable to women and health care workers, effectively provide emotional and practical support, and maintain continuity of care for women with breast cancer.¹⁹



- **Upgrading existing services through audit, training, co-ordination and promotion:** Most rural and remote areas have existing professional services that provide support for women with breast cancer. Upgrading the skills and resources of these professionals may help ensure that the best care is provided in a co-ordinated manner. This model also assists health professionals in accessing continuing education.
- **Extending the role of an existing health care worker to include the tasks of a specialist breast nurse:** As it may be difficult to establish dedicated breast nurse positions in rural areas, it may be possible to include the core tasks within the job description of an existing health care worker position. This offers the opportunity to make good use of scarce expertise in rural areas.
- **Strengthening access to tertiary referral support services:** While psychological distress can be a significant problem associated with the diagnosis of breast cancer,²⁰ access to specialist psychological or psychiatric services in rural and remote areas is often limited. Strategies for enhancing access to tertiary support services might include the development of a framework for creating tertiary referral links to existing services, the implementation of satellite clinics, or the provision of psychiatric services via tele-health.

Funding to develop and implement the program was distributed by the Commonwealth to health departments or Cancer Councils in each state and territory, who selected models for implementing the program. States and territories were encouraged to combine models or explore variants of different models to suit local circumstances. Collaboration within and between states, territories, and other organisations was also encouraged. The models selected by each state and territory are described in Figure 1.

A case study of Tasmania has been included in this paper to illustrate some of the challenges associated with developing and implementing strategies for enhancing supportive care to suit local health care services.

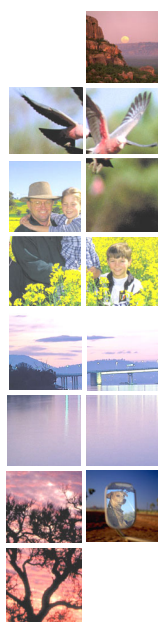
Case study: Tasmania

Background

Of all Australian states, Tasmania has the largest proportion of its population living outside major metropolitan areas. In 2000, 263 women living in Tasmania were diagnosed with breast cancer.²¹ Women can access services in several areas of the state or may travel to other states such as Victoria for treatment.

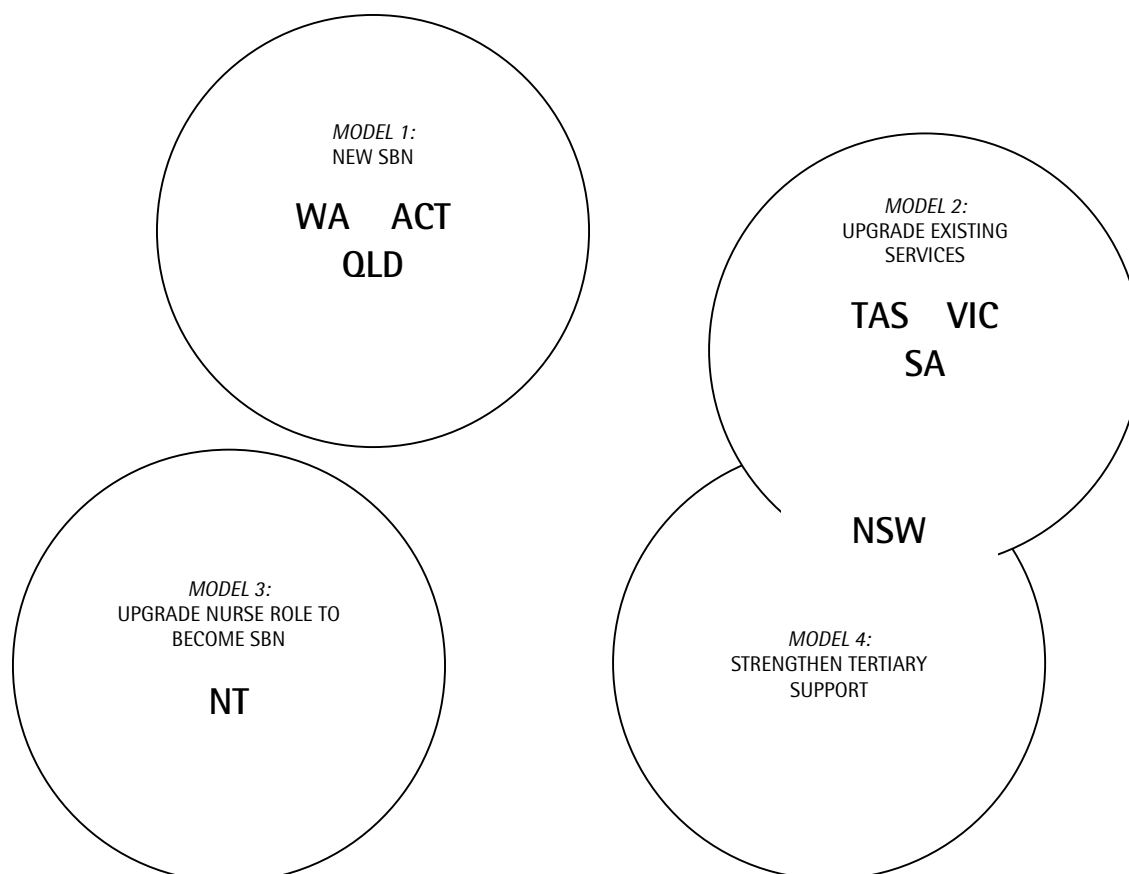
Model selection

In Tasmania the project was tendered to The Cancer Council Tasmania, who formed a project team. From the outset, the team recognised that a model to upgrade existing services would be most applicable in Tasmania, given the small and broadly distributed population of women with breast cancer. Historically, there had been reservation about the applicability of the specialist breast nurse role in Tasmania; clinicians, health professionals and health administrators had voiced concerns about the sustainability of these specialist positions in resource-stretched areas, despite strong consumer support for the breast nurse model. On the other hand, a broad range of support services already existed for Tasmanian women with breast cancer,



including local breast cancer support groups and professional networks. These services were, however, often poorly co-ordinated; for instance, there were inconsistent approaches across the state to the distribution of information about breast cancer for consumers and health professionals. Furthermore, many support services were under-utilised, indicating a need to raise awareness of clinicians and consumers about existing services.

Figure 1 Overview of models chosen by states and territories



The project team proposed to develop the model in three phases: audit of current service provision, development and implementation of strategies to improve service provision, and project evaluation. It was anticipated that this model would have a number of benefits. First, the process of conducting an audit would enable the identification of needs **specific to Tasmania**, at both state-wide and regional levels. This process of determining and addressing local issues would in turn encourage buy-in from local stakeholders. Second, the emphasis on developing and improving **existing** rural resources and infrastructure would enhance the long term sustainability of the project in the absence of ongoing funding. Third, the successful implementation of the nominated strategies would enhance the potential for expansion into other cancer or health areas following the project.



Phase 1: Audit of service provision

The aims of the audit were to identify:²²

- issues and concerns of women from rural communities regarding diagnosis and treatment of breast cancer
- existing resources and possible gaps or difficulties in current service provision
- best practice, and ideas that could be transferable to other areas or developed further
- gaps in the current skills base and the potential for training and development.

The Tasmanian project team undertook an extensive consultation process to seek the views and opinions of women and health professionals regarding breast cancer support service provision. Consumer focus groups were held in four rural regions, and additional consultations were held with four cancer support groups. Data were also collected through group discussions with Breast Cancer Support Service volunteers and the Breast Cancer Network Australia (Tasmanian group), and three one-on-one in-depth interviews.

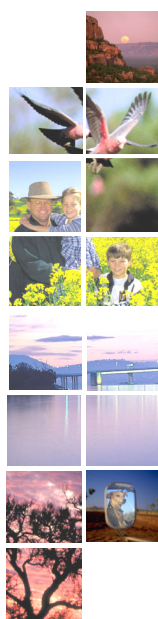
Consultations were also conducted with clinical and organisational stakeholders with an interest in breast cancer, including surgeons, medical and radiation oncologists, physiotherapists, nurses, social workers, community nurses, general practitioners, and breast cancer screening staff. Over twenty local, state and national stakeholder groups were involved in the consultation process.

The perceived benefits of the consultation were numerous for the project team and participants. The information provided by consumers and health professionals was of great value in the development of a description of current service provisions in Tasmania. Furthermore, many women who contributed to the discussion groups had not previously had the opportunity to reflect on their experience and share it with other women. Those who participated described the discussion groups as a positive experience. The project was subsequently actively promoted through consumer and professional networks, and interest, support and active participation in the project were enhanced.

Phase 2: Project development and implementation

The project team used information gathered from the consultation to develop pragmatic and specific suggestions for enhancing supportive care, which were circulated to stakeholder groups for comment. Based on this feedback and input from the Project Reference Group, which was formed following the consultation phase, five key implementation objectives were determined:

- to develop and implement appropriate and readily accessible **information service initiatives** for women with breast cancer, their families and service providers
- to facilitate the further development of **peer and group emotional support services** for women with breast cancer, and for their families and carers
- to establish and or strengthen **communication networks** between service providers and consumers



PART II: IDENTIFYING THE CHALLENGES OF DESIGNING A NATIONAL EVALUATION

The development of a plan to evaluate the SSWBC program at a national level was undertaken by a project team at the Centre using a four-step process:

- clarification of program objectives, goals and outcomes
- development of key evaluation questions and aims
- development of evaluation methods
- preparation of a timeline for evaluation activities.

Program objectives and goals

The first step in the development of a national evaluation plan was to clarify the objectives and anticipated outcomes of the projects in each state and territory. As described above, a range of different projects were being implemented in diverse contexts across the country. Furthermore, while some strategies were targeted at specific sites or regions within a state or territory, others aimed to target women and/or health professionals state-wide, building on existing infrastructure or adding on to previous initiatives.

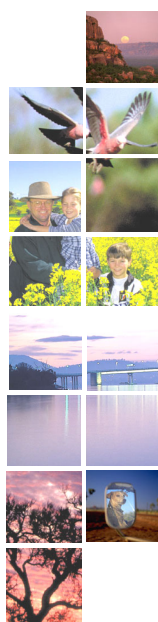
The Centre undertook a process of consultation with states and territories to determine details of the strategies being implemented and anticipated outcomes for each of the SSWBC projects across the country. Despite the diversity of nominated strategies, commonalities between anticipated outcomes of the projects in each state and territory were identified. The outcomes related to five key theme areas:

- health care or supportive care provider needs in relation to training and support
- models that seek to improve approaches to supportive care, such as creating specialist breast nurse positions or multi-disciplinary care
- providing information to women and health care providers
- improving communication between health care providers
- improving continuity of care.

These common theme areas were used to inform the development of questions and methods for conducting the national evaluation.

Key evaluation questions and aims

The Centre project team recognised at the outset that the evaluation would not be able to assess the impact on supportive care of the SSWBC program in isolation of other existing strategies aimed at improving outcomes for women with breast cancer. In order to do so, a randomised trial methodology would have been required. The evaluation would also be unable to make comparisons between states and territories, owing to the range of different strategies being employed. It was agreed that the



national evaluation would focus on supportive care delivery structures (process) rather than measurable outcomes such as quality of life or mortality (impact). Specifically, the evaluation would seek to ask:

- How is supportive care provided to rural women with breast cancer in Australia?
- How were strategies for improving supportive care developed and implemented as part of the SSWBC program?
- What changes were there to the provision of supportive care services during the SSWBC program?

The aims of the evaluation were therefore to:

- provide a detailed description of the SSWBC program in each state and territory
- analyse the successes, barriers and enablers of the strategies adopted, including a description of the acceptability of the implemented strategies in each state and territory
- provide a description of supportive care at the outset and at the end of the program relative to the identified set of themes.

Evaluation methods

A range of methods for gathering information were proposed by the Centre, in order to ensure the evaluation resulted in a comprehensive description of the nominated strategies undertaken in each state and territory including the benefits, unanticipated outcomes, successes, and barriers to implementing strategies. The development of the evaluation methodology was a collaborative process, with feedback about the proposed methods sought from states and territories through individual discussions and at regular meetings.

Three-monthly discussions

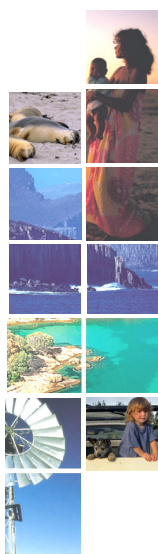
For the duration of the program, regular three-monthly semi-structured discussions are being held between the project co-ordinator in each state and territory and the Centre's project officer to provide a detailed description of progress with each project. These discussions also provide information about successes, barriers and enablers of strategies as the process evolves.

Workshops

Throughout the funding period, regular one-day workshops are held to encourage the sharing of information about state and territory projects and reflective discussions about the successes, barriers and enablers of the strategies over time. The most recent workshop, held in September 2002, was designed to assist states and territories in planning for the sustainability of their projects and evaluating their strategies at the local level.

Time One and Time Two surveys

To provide a description of supportive care at the outset and the end of the program, two rounds of interviews are being held with a range of health professionals at two or



more nominated sites in each state and territory. Structured interviews will be conducted with clinicians, breast or oncology nurses, and supportive care staff about supportive care systems and structures. The common themes that were identified across the states and territories will form the basis of these surveys. Time Two interviews will also include additional items about the acceptability to health professionals of the strategies that were implemented in each state and territory.

State and territory specific evaluation strategies

Finally, states and territories will be undertaking local evaluation of their strategies to a greater or lesser extent. While the national evaluation will contribute to an understanding of common objectives, local evaluations are also important in describing and assessing how a model has worked in the local context. Although the Centre is not directly responsible for these local evaluations, we are able to provide existing resources and support to avoid duplication of effort.

Evaluation timeline

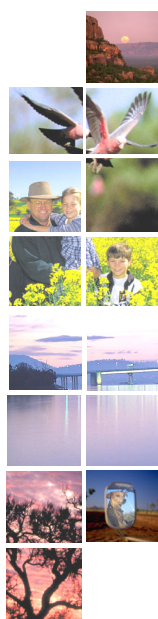
The national evaluation is an ongoing process. By March 2003, five rounds of three-monthly discussions and eight national workshops will have been held. The Time One interviews with health professionals were completed in September 2002, with the Time Two interviews to follow at the end of 2003.

CONCLUSIONS

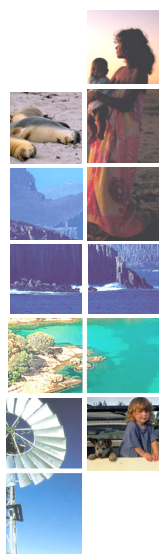
The SSWBC program highlights some of the challenges associated with developing, implementing, and evaluating strategies for improving supportive care that are appropriate for diverse rural contexts and health service delivery structures. Despite finite funding and limited resources in some rural areas, local and national stakeholder knowledge in combination with existing data can inform the development of models for improving care that are both potentially effective in addressing local needs and sustainable in the longer term. The challenges of evaluating diverse models at a national level were met by undertaking a consultative process to identify common thematic outcomes, adopting a process approach with a range of information sources, and encouraging the conduct of local evaluations to describe how strategies worked in the local context. At this early stage in the implementation of the program specific policy recommendations are premature. However, it can be recommended that future initiatives consider the processes undertaken as part of the SSWBC program in developing sustainable health initiatives that meet the local concerns of rural health professionals and consumers.

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PRESENTER

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