Breast Cancer Network Australia (BCNA)
Submission to the Senate Community Affairs Committee
Inquiry into the Operation and Effectiveness of Patient Assisted Travel Schemes (PATS)

May 2007

About Breast Cancer Network Australia

Breast Cancer Network Australia (BCNA) is the peak national breast cancer consumer organisation, representing over 180 member groups and more than 22,000 individuals in each state and territory. Around 41% of BCNA's membership comprises those who reside outside a major city, with 13% in areas that can be described as outer regional, remote and very remote.[1]

BCNA's role is to empower, inform, represent and link together Australians personally affected by breast cancer. It is driven by women who have themselves experienced breast cancer. It influences key decision makers to ensure that the needs and issues of people affected by breast cancer are raised and addressed.

BCNA has significant experience in capturing the issues and concerns of Australians affected by breast cancer through:

- day-to-day contact with individual members via a national 1800 freecall enquiries line, email etc
- consultation with State Representatives, Consumer Representatives, and members more broadly
- two national conferences (1998 and 2004)
- Working Parties such as the Rural and Remote Working Party, currently comprised of nine members across rural and remote Australia.

BCNA welcomes the opportunity to provide a submission to the Senate Community Affairs Committee Inquiry into the Operation and Effectiveness of Patient Assisted Travel Schemes (PATS). This submission draws on BCNA's expertise in both representing and speaking out for Australians affected by breast cancer.

Breast cancer treatment

> *I had my operation (breast conserving surgery) in hospital. I then had three months of chemotherapy, six weeks off, and eight weeks of radiotherapy. During the treatment I developed lymphoedema and struggled with feelings of depression, loneliness, disbelief and stress – all of which needed to be managed. I felt I was healthy only a short time ago and now I was so sick and out of control of my body.*

A breast cancer diagnosis is devastating. Treatment for the disease is complex, involving multiple practitioners and specialised technologies mostly located in major cities. For women diagnosed with early breast cancer, treatment typically involves surgery in combination with radiotherapy, systemic therapies (eg hormone and chemotherapy) and targeted therapies – depending on the characteristics of the cancer. Treatment also includes appropriate psychosocial support from counsellors, social workers, psychologists and others to help

manage feelings and emotions. Other professionals, such as physiotherapists, may be involved in follow-up care to manage the physical side-effects of treatment, such as lymphoedema.

For women who develop secondary breast cancer, treatment may stretch over several years and involve systemic therapies to help control the size and spread of the cancer. There may be specific treatments depending on where the cancer has spread; for example, radiotherapy and pain relief if the cancer is in the bones, or surgery to reduce fluid in the pleural cavity if the cancer is in the lungs. Women with advanced disease may require support from specialist palliative care services. Psychosocial support is also an integral part of treatment for women with secondary breast cancer.

For many who live beyond the outskirts of a major city, extensive travel is a key part of the treatment experience and follow-up care described above. Breast cancer treatment is complex and demanding enough on women. Travelling for treatment because local options are simply not available provides an additional burden. Apart from the actual travel required, many women also need to find support away from home – whether from relatives or others. A robust and effective financial assistance scheme to meet the costs of travel and accommodation is critical to minimise the disadvantages faced by women who travel for treatment because of the concentration of expertise and services in major city locations.

Summary of BCNA's submission

Whilst women from rural and remote areas appreciate assistance with their travel and accommodation costs, the current PATS system contains anomalies that diminish its capacity to adequately support those travelling to major cities for breast cancer treatment.

BCNA believes that the PATS system fails to provide adequate assistance for rural and remote women who:

- choose to re-locate to major cities to attend daily radiotherapy for five to six weeks (even if the return journey can be physically completed within one day)
- are accompanied by support persons (for reasons other than 'medical')
- are travelling with dependent children
- choose to travel to specialist centres best suited to treating their breast cancer and meeting their needs, irrespective of state or territory borders
- travel for treatment provided by a multidisciplinary team of specialists of their choice
- receive specialist allied health assessments and treatments.

In addition, women's experiences of PATS are less than ideal. Women find that:

- the process for referral is unnecessarily complex, adding an additional layer of burden to their treatment experience
- there is insufficient information about the schemes
- the amount of paperwork is often daunting.

BCNA seeks a unified system that can better meet the needs of women travelling for breast cancer treatment, with streamlined processes that minimise the complexity of the system experienced by women. BCNA has developed ten recommendations, as follows.

1. BCNA suggests that frequency of travel for treatment is included as part of eligibility criteria for travel and accommodation assistance, not just kilometres covered per individual travel episode. This would contribute to alleviating the burden that women experience when they attend daily radiotherapy for five to six weeks.
2. BCNA supports a system that provides assistance to those deemed necessary to accompany women. However, the definition of 'necessity' must be broad enough to encompass *all* aspects of support – medical, physical, practical and emotional.
3. Schemes must recognise and assist the needs of women travelling with dependent children.
4. A unified system that wherever possible directly covers expenses incurred without leaving patients 'out-of-pocket' is preferred, particularly for those experiencing financial hardship at initial outlay.
5. BCNA seeks a unified system with standard guidelines that will enable patients to discuss with their doctors the specialist centres best suited to treating their breast cancer *and* meeting their needs, irrespective of state or territory borders.
6. BCNA seeks a national committee/body that will monitor and review the effectiveness of PATS across states and territories and ensure that cross-border issues do not disadvantage women travelling to the specialist treatment centres of their choice. BCNA supports the inclusion of consumer representatives in this monitoring and review committee.
7. BCNA supports a system that includes effective promotion of schemes through a range of health providers including GPs, breast care nurses and medical specialists.

8. BCNA seeks processes that are effectively monitored to minimise the ‘paperwork burden’ often experienced by women and make it easier for women to obtain their referrals to assistance schemes.
9. BCNA seeks a system that will support women travelling for treatment (including clinical trials) provided by a multidisciplinary team of specialists of their choice.
10. BCNA seeks a system that provides travel assistance to women attending specialist allied health assessments and treatments such as those provided by counsellors, psychologists, physiotherapists and lymphoedema specialists.

Responses to individual terms of reference

a) The need for greater national consistency and uniformity of PATS across jurisdictions, especially the need to determine eligibility for travel schemes covering patients, their carers, escorts and families; the level and forms of assistance provided; and reciprocal arrangements for interstate patients and their carers.

There is considerable variation in the administration of PATS by state and territory governments, particularly concerning the eligibility criteria and the manner in which assistance is provided. BCNA is concerned that some schemes work less well than others thereby compromising access to treatments.

I tried to get financial assistance to help cover the cost of petrol but was told I wasn't eligible because the distance travelled wasn't enough.

All schemes require a minimum (one-way) distance travelled before assistance can be claimed – usually 100km or 200km depending on the jurisdiction. Issues experienced by women have less to do with the differences across jurisdictions than the way the minimum distance rule is applied within them. BCNA hears from women who have travelled just short of the minimum in their state/territory and who are ineligible to claim for travel assistance as a result. Women travelling 90km to a major city, for example, have similar needs to those travelling 110km, and yet only the latter would be eligible for travel assistance under schemes with the 100km minimum. Women travelling 90 km many times over a few weeks (as they would for radiotherapy) are seriously disadvantaged compared to women travelling greater distances but less frequently.

I didn't want to drive all that way for my appointment and stay in the city on my own. I was upset and scared, and felt that the journey would be too long and lonely (even dangerous) without someone with me.

Whilst the accommodation needs of women are covered by hospitals during treatment as inpatients (eg surgery), the same cannot be said of support persons accompanying women who travel. There is provision in schemes to assist support persons, although schemes require that their 'necessity' be proven through a statement by a referring practitioner. There is little consistency in the definition of 'necessity'. In most jurisdictions, it is defined as medical only; in some, it covers physical, practical and emotional support. Many women who need the emotional support of a loved one during their trip miss out on financial assistance under most current schemes.

The distance to radiotherapy made it hard. It would have been many hours to drive there and back in one day. So we decided to live in the city for the six weeks. But we were lucky to be able to do this. I know of others who have had mastectomies (when lumpectomies were recommended) because the drive to and from radiotherapy would have been too much and they couldn't afford to move.

In the case of outpatient treatment (eg radiotherapy) there is provision in schemes for accommodation assistance if the return journey cannot be made in one day. Despite the availability of assistance for those who can make the round trip in a single day, many go on to endure significant out-of-pocket accommodation expenses especially when receiving radiotherapy. This form of treatment requires a greater number of attendances than others – typically everyday for five to six weeks – thereby intensifying the physical and emotional impact of treatment on women. Women often choose to re-locate to major cities for the

duration of their treatment rather than trying to make the return journey each day. Under the rules of current schemes, they are not eligible for accommodation assistance.

> *I decided to have all my treatment in the city as this meant I could have all my treatment in one place. The next hurdle was to find accommodation for me and my son who needed me to cope with his autism. The most important thing was that we remained together. But the accommodation options proved to be limiting. We would have preferred private accommodation for a more 'homely' feel but this wouldn't have been supported by the scheme (public accommodation only).*

BCNA hears from women who have the additional stress of caring for dependent children during their treatment. Some are unable (or do not wish) to leave children in the care of others, and are faced with extra travel and accommodation needs. None of the schemes currently recognise the needs of women with dependent children who may be travelling with them.

> *My mind was boggled with many things, and I kept thinking 'Where's all the money going to come from?' I knew I had to travel for treatment and that it was going to cost money. It was a real concern.*

The circumstances within which women with breast cancer find themselves vary enormously. BCNA hears from rural and remote women who experience significant difficulties over initial outlay of travel and accommodation expenses. Some schemes cover expenses directly through hospital-based patient services staff who make arrangements for patients. Others reimburse patients after travel has concluded. Women experiencing financial difficulties need to seek special approval to have their expenses covered in advance (an added burden for them).

Recommendations

1. BCNA suggests that frequency of travel for treatment is included as part of eligibility criteria for travel and accommodation assistance, not just kilometres covered per individual travel episode. This would contribute to alleviating the burden that women experience when they attend daily radiotherapy for five to six weeks.
2. BCNA supports a system that provides assistance to those deemed necessary to accompany women. However, the definition of 'necessity' must be broad enough to encompass *all* aspects of support – medical, physical, practical and emotional.
3. Schemes must recognise and assist the needs of women travelling with dependent children.
4. A unified system that wherever possible directly covers expenses incurred without leaving patients 'out-of-pocket' is preferred, particularly for those experiencing financial hardship at initial outlay.

c) The extent to which local and cross-border issues are compromising the effectiveness of existing PATS in Australia in terms of patient and health system outcomes.

> *If you don't give us specialists out here, then at least respect our choices to have our treatment where we want to have it – and help us get there! I live on a state border and it's much easier and closer for me to go interstate for treatment than to see specialists within my own state.*

> *My sister lives in Adelaide so I wanted to go there for my treatment rather than Melbourne. I was so scared and didn't want to be in a big city where I didn't know anyone.*

PATS schemes provide assistance for planned clinical treatment involving intrastate travel to the nearest medical specialists, although some schemes cover interstate travel if services are not available within their state/territory. PATS guidelines do not include provision for patients to choose the specialists they prefer.

BCNA hears from many women who prefer to travel interstate for treatment, either because they have family and friends there or it is actually closer than travelling to a scheme's nominated treatment centre. If these women were to exercise their choice, they would not eligible for financial assistance under current schemes. State and territory governments have long recognised that patients residing outside of major cities do not share the same level of access to services afforded to their urban counterparts. Whilst the PATS system seeks to improve rural patient access to services and address this equity issue, state/territory issues mean that schemes are, in reality, inflexible with respect to patient choice.

Recommendations

5. BCNA seeks a unified system with standard guidelines that will enable patients to discuss with their doctors the specialist centres best suited to treating their breast cancer *and* meeting their needs, irrespective of state or territory borders.
6. BCNA seeks a national committee/body that will monitor and review the effectiveness of PATS across the states and territories and ensure that cross-border issues do not disadvantage women travelling to the specialist treatment centres of their choice. BCNA supports the inclusion of consumer representatives in this monitoring and review committee.

d) *The current level of utilisation of schemes and identification of mechanisms to ensure that schemes are effectively marketed to all eligible patients and monitored to inform continuous improvement.*

We live in outback Queensland and I was not advised of travel and accommodation assistance until months after my diagnosis. It is meant to be in place to help us but no one was very helpful in letting me know about the scheme or telling me about the receipts I needed to keep.

I was referred to the assistance scheme. I know every little bit helps, but I sometimes felt the contribution received was not worth the amount of paperwork and forms!

A study exploring the needs of 80 rural and remote women travelling to major cities for breast cancer treatment found that only 39% received financial assistance whilst 19% experienced difficulties in claiming expenses they were eligible for.[2] Promotion of schemes to women travelling for treatment is critical to ensure access and reduce stress associated with travelling for treatment. Yet, patient referral to PATS is often dependent on GPs' knowledge of schemes and their understanding of patient eligibility. Some jurisdictions have appointed hospital-based patient services staff responsible for the day-to-day administration of schemes, including their promotion.[3] This could be a promising model for a unified national PATS system.

I brought my travel assistance forms to my GP appointment. But my GP was not prepared to sign them because there were so many to fill in!

I have to visit my GP every 12 months for a referral to PATS. I find this incredibly time-consuming and inconvenient – and something that itself requires a bit of travel time! Surely there's an easier way for me?

Most schemes require that patients are referred by their general practitioner or a nurse in some (but not all) remote areas. BCNA hears from women who experience difficulties in obtaining referrals to PATS. Making an appointment with a GP for referral to schemes can lead to further travel costs. Sometimes even getting an appointment with a GP is difficult.

Recommendations

7. BCNA supports a system that includes effective promotion of schemes through a range of health providers including GPs, breast care nurses and medical specialists.
8. BCNA seeks processes that are effectively monitored to minimise the 'paperwork burden' often experienced by women and make it easier for women to obtain their referrals to assistance schemes.

f) The benefit to patients in having access to a specialist who has the support of a multidisciplinary team and the option to seek a second opinion.

A multidisciplinary team, all liaising together, gave me confidence in knowing there was a great deal of expertise around me.

The National Breast Cancer Centre (NBCC) has several clinical practice guidelines for the management of breast cancer, all of which indicate the benefits of multidisciplinary care in patient outcomes.[4] For breast cancer, the multidisciplinary team includes a surgeon, medical oncologist, radiation oncologist, pathologist, radiologist and breast care nurse. BCNA believes that it should also include at least one person with psychosocial skills and expertise. Other members may include a physiotherapist, gynaecologist, plastic surgeon or other health professionals.

The concentration of specialists and services in major cities makes multidisciplinary care in rural and remote Australia difficult to achieve. The main barrier is the lack of infrastructure resources (both human and technological) to overcome difficulties in communication between members of the treatment team who are often located in different urban and rural centres over large geographical distances.

Recommendation

9. BCNA seeks a system that will support women travelling for treatment (including clinical trials) provided by a multidisciplinary team of specialists of their choice.

h) The feasibility and desirability of extending PATS to all treatments listed on the Medicare Benefits Schedule Enhanced Primary Care items such as allied health.

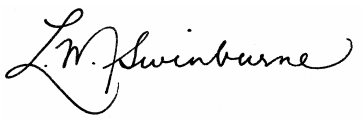
> *Counselling really helped me deal with the emotional side to breast cancer. I had to travel a fair way to see my counsellor because we don't have one in our area. But it was such an important part of my treatment.*

BCNA believes that access to timely and appropriate allied health care is an essential requirement for all women receiving breast cancer treatment. There is evidence that good supportive and follow-up care to help manage the effects of treatment leads to improved health outcomes. Allied health care is a core part of breast cancer treatment, not an optional extra. Yet, expenses incurred by those travelling for services delivered by allied health practitioners are currently not covered by PATS.

Recommendation

10. BCNA seeks a system that provides travel assistance to women attending specialist allied health assessments and treatments such as those provided by counsellors, psychologists, physiotherapists and lymphoedema specialists.

BCNA looks forward to the results of this Senate Community Affairs Committee Inquiry into the Operation and Effectiveness of Patient Assisted Travel and would be most willing to speak further to the issues identified in our submission.



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ENDNOTES

[1] Breast Cancer Network Australia (2007) *2006 BCNA Member Survey Analysis and Report* (unpublished), p. 6.
[2] Davis C, Girgis A, Williams P, Beeney L (1998) 'Needs Assessment of Rural and Remote Women Travelling to the City for Breast Cancer Treatment' in *Australian and New Zealand Journal of Public Health*, vol. 22, pp. 525-7 as cited in Cancer Council Australia (2004) *State and Territory Travel and Accommodation Subsidy Schemes: Position Statement*.
[3] National Rural Health Alliance Inc. (2005) *Transport and Accommodation Assistance for Health Patients from Rural and* Remote Areas: Position Paper, p. 5.
[4] The relevant clinical practice guidelines are *The Management of Early Breast Cancer*, *The Management of Advanced Breast Cancer, The Management and Support of Younger Women with Breast Cancer,* and *The Psychosocial Clinical Practice Guidelines.* See also National Breast Cancer Centre (2005) *Multidisciplinary Cancer Care in Australia.*