

The Secretary  
Senate Community Affairs Committee  
PO Box 6100  
Parliament House  
Canberra ACT 2600

Dear Sir

Bosom Buddies NT Inc is a breast cancer peer support, advocacy and awareness group based in Alice Springs. Our activities bring us in contact with cancer survivors, including those who have experienced breast, bowel, gynaecological, and other cancers in the region of Central Australia. Living in a remote locality means that there are many issues in common, such as the necessity to travel long distances to access specialist care and treatment options in capital cities, separation from family, the emotional and financial stress, and lack of some services at a local level, eg psychological support. We also network with service providers whose resources are more thinly stretched, the more remote their location. The members of Bosom Buddies NT Inc welcome the opportunity to lodge a submission to the Senate Community Affairs Committee Inquiry into the Operation and Effectiveness of Patient Assisted Travel Schemes (PATS):

The population of the Northern Territory now exceeds 200,000, with about half living in Darwin, approximately 27,000 in Alice Springs, 11,000 in Katherine, 4,000 in Tennant Creek. The remainder, over a quarter of the total population, are sparsely distributed in remote communities, pastoral properties, mining sites, etc. The more densely populated northern zone has a well developed network of air travel, while in Central Australia, travel over dirt roads, often of many hundreds of kilometres may be necessary to access medical and other services in Alice Springs. This includes people from the cross border regions of WA and SA. The region of Central Australia encompasses in total a million square kilometres, with one bitumen road, the Stuart Highway, running north-south, the second -Lasseter Highway, from the Stuart Highway to Uluru, and the third, eastwards from near Tennant Creek to the Queensland border.

The current PATS scheme in the NT has, as one of its main strengths, the provision for travel and accommodation at hostels for indigenous patients to be pre-booked by the Patient Travel Clerk. However, often an escort is not provided for, and a family member may find themselves looking at \$80 - \$120 per night accommodation costs in Alice Springs or Darwin .

For non-indigenous patients, the situation can be dire. **Apart from a small basic shared accommodation facility in the vicinity of the Royal Darwin Hospital, there is no dedicated patient accommodation facility within the NT.** Commercial accommodation in Darwin and Alice Springs can be very expensive – there are no nearby towns to provide other options. Cost and availability of accommodation can be exacerbated in the tourist season. In common with indigenous patients, escorts/carers for patients are frequently not considered eligible for PATS. If a patient has no family or friends in the

town where they have to access treatment, then financial pressures may substantially add to the stress already being experienced through illness, and from being away from home.

Patients have to obtain a referral from a GP for travel to the treatment centre of Alice Springs. This is the first of their costs. Then they have to transport themselves by road. In the case of Tennant Creek, which has no air service, this is a round trip of 1,000 kilometres. Then find accommodation while the patient undergoes treatment. Patients have reported having to wait for 2 months for reimbursement of PATS claims. Often they may be due for another cycle of treatment before the refund arrives. If they have insufficient funds to enable another trip, then their treatment is compromised. *Hospital budgets should be adequate to cover Patient travel costs, and not simply be responsive, in times of budget shortfall, to how persistent a patient may be in trying to recover reimbursement*

**In areas where there are no dedicated patient accommodation units, and where patients may experience financial difficulty in initial outlay, a prepayment system should be implemented – whether this be a voucher system, (including fuel costs), or via a tender to commercial accommodation facilities in the town.**

**Greater flexibility should also be considered for carers to escort patients – not only in cases of physical need, but also to provide emotional and practical support. Appropriate carers need to be identified for indigenous patients who may need to be away for extended periods of time from their homelands, from their family and cultural environment.**

Northern Territory patients referred to Adelaide for treatment will have their travel pre-booked, but frequently have to book accommodation themselves – depending on the helpfulness of the incumbent travel clerk. If fortunate enough to get into Greenhill Lodge, accommodation costs are met. The direct system of payment in this instance greatly alleviates the financial stress on the patient and family.

Otherwise, patients are forced to seek commercial accommodation – or in the case of one individual recently, sleep in his car for a week. **The current rates of \$33 per day towards costs in commercial accommodation, or \$10 a day if staying with friends/family, are totally inadequate towards meeting food, transport and accommodation when away from home.** In the case of patients with young families who are being cared for back at home, there is the cost of sustaining two households basically.

Within 2 years, it is expected that a radiotherapy unit will be built in Darwin. For patients who live in Central Australia, it is of great concern that the provision of this unit, while of great benefit for patients in northern Australia, will deprive Central Australians of the option to go south for treatment. Once there is a radiotherapy facility operational in the NT, the current stated policy of the NT government is that NT patients needing radiotherapy will only be PATS supported to travel to Darwin. This effectively deprives Central Australian patients of choice. The nearest capital cities, Darwin or Adelaide, are both 1500 kilometres distant.

The report commissioned by the NT Government “Options for Radiation Oncology Services in the NT” July 2004, prepared by Professors Michael Barton and Michael Frommer, recognises that “people in Central Australia appear to have a more natural affinity with Adelaide”. There is a long standing and well established referral pathway between the Alice Springs Hospital and the Royal Adelaide. Patients receive excellent multi-disciplinary assessment, and can avail themselves of the support services, both within the RAH, while undergoing radiotherapy, and the additional support offered by the Cancer Council of SA. This includes the dedicated accommodation facilities of Greenhill, Seaview and Flinders Lodges. In addition, many residents of Central Australia have strong family ties in South Australia, and this offers significant emotional and practical support during their period of treatment and being away from home. For many, having no choice but to have treatment in Darwin, would mean they would be further removed from family and emotional support. (3,000 kilometres distant). It is recognised that as well as the surgical and medical aspects of treatment, the psycho-social dimension is also crucial in the recovery process.

Both consumers and health professionals in Central Australia, as well as health professionals in the Top End recognise and support the need for patients in the southern half of the NT to have choice in their treatment options. **Recommendation 6 of the Report states: “Northern Territory cancer patients from Central Australia should retain the right to choose whether they receive radiotherapy in Darwin or Adelaide.”**

**A more equitable solution would be for national minimum standards of PATS guidelines to enable cancer patients to exercise choice, regardless of state/ territory borders, to the specialist centre most suited to their treatment and family support needs.**

The Northern Territory is a jurisdiction where there is limited access to specialist services, allied health services, dental services, etc. For instance, Darwin has an Oncologist, while Alice Springs is visited by an Adelaide oncologist once every three months. There is no cardiologist in the NT

There is a high turnover of allied health staff- nurses, physiotherapists, speech pathologists, etc. Consumers have difficulty in having assessment undertaken, - the process can take up to two years, as well as accessing the required therapy after diagnosis. As well, there is a chronic shortage of GP’s both in town, and in remote areas.

**The Patient Travel Scheme in the NT should be extended to include all treatments listed on the Medical Benefits Schedule, and to enable allied health professionals providing care for remote area patients to authorise PATS eligibility for such patients to centres of treatment when necessary.**

**Additionally, where waiting time for patient is beyond what is acceptable, then patient should be PATS supported to where assessment/treatment can be provided.**

On occasion, in the NT, patients are told there is a waiting period of so many months – unbeknowns to them, it is often a case that the position has not been filled for some time.

Finally, there is a serious issue regarding **lack of equity for women from remote areas being able to access BreastScreening services**. Technically, this is not Patient Assisted Travel. However, a form of funding needs to be identified to enable women from remote areas of the NT to travel to the towns where BreastScreen operates periodically - Alice Springs, (3 x 3 week blocks annually,) Tennant Creek, (1 week per year,) Katherine and Nhulunbuy, as well as a fulltime service in Darwin. Windows of opportunity for women in regional areas to access BreastScreen are narrow, and bookings through Darwin can only be made in the 2 weeks prior to screening.

BreastScreenNT's participation rates were as low as 44.7% in 2001-2002, much lower than the national participation rate of 57.1% at the time. While participation rates would be much more favourable in urban centres such as Darwin and Alice Springs, it is much more difficult for women in remote areas to participate. Mammography units cannot travel off the bitumen, so it is necessary for women to travel often many hundreds of kilometres on dirt roads to access screening. In some cases, this may mean a 3 day round trip. Costs of travel and accommodation, as well as distance, can prevent from women accessing the screening service, which could identify early breast cancers.

Detection of early breast cancer while it is still small and confined to the breast provides the best chance of effective treatment for women with the disease. Benefits of early detection include increased survival, increased treatment options and improved quality of life. Mammography is one of the most effective tools in early detection in women who have reached the appropriate age. With early detection comes decreased cost both socially and financially, as well as a lesser burden of treatment cost on the health system.

**We respectfully request that the members of the Senate Community Affairs Committee give consideration to a suitable form of travel funding to enable women from remote areas to access screening mammography.**

Thank you for your consideration of our submission

Yours faithfully

Liz Locke, Lesley Reilly, Wave Hayden, Joy White, Jeannie Lewis

Bosom Buddies NT Inc,  
PO Box 9099  
Alice Springs NT 0871

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