

Senate inquiry into the operation and effectiveness of Patient Assisted Travel Schemes - submission from The Cancer Council Australia and the Clinical Oncological Society of Australia

May 2007

The Cancer Council Australia is Australia's peak non-government national cancer control organisation. Its member bodies are the eight state and territory cancer councils, whose views and priorities it represents on a national level.



The Clinical Oncological Society of Australia is the peak multidisciplinary society for health professionals working in cancer research or the treatment, rehabilitation or palliation of cancer patients.



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Endorsed by the National Rural Health Alliance and by the Cancer Nurses Association of Australia



Overview

The Cancer Council Australia and the Clinical Oncological Society of Australia (COSA) commend the Senate for conducting this inquiry.

The Senate's interest in this important matter has the potential to make a real difference to thousands of Australians living through extraordinary hardship, particularly if the subsequent report encourages national leadership and inter-jurisdictional co-operation to lift the funding and efficiency of patient travel and accommodation assistance to standards commensurate with need.

The Cancer Council Australia and COSA would be grateful for the opportunity to nominate witnesses to appear at public hearings as part of this inquiry. Our organisations have representatives in all jurisdictions.

Core problems

Literature on patient travel and accommodation assistance schemes documents myriad systemic problems, all of which can be summarised in two core areas:

- Assistance is under-funded when measured against demonstrated need; and
- The absence of national minimum standards and a national framework has, over 20 years, led to an inequitable, fragmented, and inefficiently administered collection of schemes operating in isolation within jurisdictions.

Core solutions

The Cancer Council Australia and COSA propose that the most effective way to ensure cancer patient travel and accommodation assistance meets demonstrated need is to fund the program through a robust national framework. Options may include:

- An inter-jurisdictional funding pool, administered through Medicare (e.g. funded through the Extended Safety Net);
- A national funding agreement involving all jurisdictions and negotiated through the Australian Health Care Agreements; or
- A national accreditation system developed under the auspices of the Australian Health Ministers' Advisory Committee and endorsed by the Australian Health Ministers' Conference.

Advantages of a robust national framework include:

- Agreement on minimum standards;
- Streamlined administration;
- Equitable assistance across borders.

The framework would require a “highest common denominator” approach, ensuring that patients in all jurisdictions would be better off in terms of overall benefit paid and that no patient would be worse off in terms of distance eligibility and other criteria.

From the available evidence, national leadership is the only way to deliver a system that is equitable, efficient and provides a level of financial assistance commensurate with need.

Context: cancer and geographic isolation

The case for significantly improving the effectiveness and accessibility of cancer patient travel and accommodation assistance schemes is reflected in some key statistics:

- Approximately 30% of Australian cancer patients are estimated to live outside a major population centre where tertiary care is available;¹
- Evidence shows that those who live furthest from a large treatment centre are at the highest risk of a comparatively poor cancer treatment outcome;²
- A report published in the *Medical Journal of Australia* in 2004 showed that people with cancer in regional NSW were 35% more likely to die within five years of diagnosis than patients in cities. Mortality rates increased with remoteness. For some cancers, remote patients were up to 300% more likely to die within five years of diagnosis.³

Moreover, as the barriers to care associated with distance widen the gap in cancer treatment outcomes between rural and metropolitan Australia, paradoxically the regions continue to make a disproportionately high contribution to the economy that sustains the public health system nationally. For example, exporter numbers in regional areas are growing at 18% per annum compared with only 6% in cities.⁴ Meanwhile, poor health outcomes and reduced access to healthcare services threaten the viability of rural and remote communities.

Providing real increases in financial assistance for cancer patients in the bush and streamlining the complex, inequitable systems that process such payments would be a responsible, measurable and much needed use of taxpayer dollars.

Other disease groups

This submission focuses specifically on travel and accommodation assistance schemes in the context of cancer, for three principal reasons:

- As dedicated cancer control organisations, reducing the impact of cancer is our core goal and people with cancer are our most important stakeholders;
- Cancer patients in isolated areas, their families and the health professionals who support them identify travel and accommodation assistance as a critical issue; and

- Cancer is Australia's biggest disease burden⁵ and is associated with high levels of personal distress in patients and their families, as well as loss of income, and is the most significant disease group in the context of the schemes in terms of prevalence, morbidity and mortality.

We would enthusiastically support the benefits of the schemes' expansion and streamlined administration as proposed in this submission being made available to people with a wide range of diseases, provided eligibility was based on relative need. Priority would need to be assigned to illnesses causing the greatest risk of death, morbidity and personal distress. On that basis, a cancer diagnosis (excluding non-melanoma skin cancer) would automatically qualify a patient for eligibility. The option of building travel and accommodation assistance into the Medicare agreements would ensure that medical reasons are directly related to eligibility.

Summary

All Australians should be entitled to minimum standards of healthcare support, regardless of the state/territory in which they reside. While there are multiple barriers to uniform administration across the breadth of Australia's complex, two-tier healthcare system, patient travel and accommodation assistance could be streamlined through a national framework, as this submission aims to demonstrate.

Government assistance should, where possible, be commensurate with the needs of its recipients. Cancer patients living in rural and remote areas are clearly in need of improved financial assistance, through a scheme that measurably reduces the distress of coping with a life-threatening illness.

Recommendations

- Build cancer patient travel and accommodation assistance into a robust federal/state-territory funding framework. Options might include:
 - An inter-jurisdictional funding pool, administered through Medicare (e.g. the Medicare Safety Net);
 - A national funding agreement involving all jurisdictions and negotiated through the Australian Health Care Agreements; or
 - A national accreditation system developed under the auspices of the Australian Health Ministers' Advisory Committee and endorsed by the Australian Health Ministers' Conference.
- Form a taskforce of cancer care professionals with experience in remote communities, care coordinators, consumers and federal/state program administrators to develop service standards and an administrative system;
- Extend eligibility for travel and accommodation assistance to include isolated patients' participation in authorised cancer clinical trials;
- Extend eligibility for patient escorts;
- Raise subsidies to rates comparable with Australian Taxation Office guidelines;
- Waive administration fees for patients residing in very remote or isolated communities, those on a low income or Health Care Card holders;
- Introduce a sliding scale for distance eligibility to ensure that patients living within current cut-off points but who still live significant distances from cancer treatment centres have access to some level of support;
- Explore options for subsidising assistance for people at high genetic risk of familial cancer to undergo surveillance; and
- Explore options for patients to be subsidised to attend a treatment centre on the basis of immediacy of treatment as well as proximity.

Addressing the terms of reference...

On 28 March 2007 the Senate agreed that the following matter be referred to the Community Affairs Committee for inquiry and report by 20 September 2007.

The operation and effectiveness of Patient Assisted Travel Schemes including:

- a. the need for greater national consistency and uniformity of Patient Assisted Travel Schemes across jurisdictions, especially the procedures used to determine eligibility for travel schemes covering patients, their carers, escorts and families; the level and forms of assistance provided; and reciprocal arrangements for inter-state patients and their carers;

Procedures/eligibility

Current position

Government-funded travel and accommodation assistance for cancer patients living in isolated areas has been available in Australia since 1978. In 1987 the Commonwealth handed responsibility for patient travel and accommodation assistance to the states and territories.⁶

Since that time, assistance programs have become increasingly divergent between states and territories, in terms of eligibility criteria, subsidy rates and administrative procedures.

For example, the minimum distance a patient has to travel for treatment before being eligible for assistance varies markedly across states – 50km in Queensland; 75km in Tasmania; 100km in South Australia and Western Australia; 100km in NSW; and 200km in the Northern Territory.⁷ (Note that the starting point for eligibility in Queensland is the nearest public hospital, not the patient's home, meaning that many Queensland patients are significantly more disadvantaged than those in other jurisdictions.)

Subsidy rates for petrol and accommodation, as well as being well below the Australian Taxation Office benchmarks (see page 10), vary between jurisdictions. The maximum petrol allowance is 16c per kilometre in South Australia; the minimum is 10c per kilometre in Queensland. Most jurisdictions pay \$30 per night for accommodation, although eligibility and subsidy levels vary markedly on the basis of Healthcare Card holder status.⁸

Administrative processes for reimbursement also vary significantly between jurisdictions, in key areas including: subsidisation for petrol, other transport costs and accommodation costs (in addition to the inconsistencies in overall eligibility on the basis of distance between home and treatment centre); eligibility for subsidising an escort to accompany a patient in transit; and variations in assistance between Healthcare Card holders and non-Healthcare Card holders. Administrative irregularities are also evident within individual jurisdictions.

For example, a 1999 study showed that up to nine different job titles were assigned to administrators of one state's patient travel assistance scheme.⁹ In a number of jurisdictions, reimbursement rates vary markedly depending on concession card holder status. Clerical arrangements also vary markedly across and within jurisdictions. In Queensland the scheme is administered by the patient's local hospital, with each hospital interpreting the scheme differently. In South Australia, billing arrangements vary depending on the length of stay, with short-term patients reimbursed directly and long-term patients subsidised through a bulk-billing system that first bills the scheme.

No jurisdiction provides a subsidy for isolated patients to be involved in cancer clinical trials, despite clinical trials presenting significant benefits for participating patients.¹⁰

There is inconsistency in the level of assistance provided to escorts, with very limited subsidy paid across jurisdictions.

Impact

In order to measure the impact on cancer patients of under-funded and inconsistently administered travel and accommodation assistance schemes, it is important to first consider the overall impact of a cancer diagnosis. There is ample evidence that in the majority of cases a cancer diagnosis causes significant physical and emotional distress (including distress for family members), loss of income and substantial out-of-pocket expenses.¹¹ A recent Access Economics study, commissioned by The Cancer Council NSW, showed the average cancer patient in NSW faces almost \$9000 in out-of-pocket expenses.¹²

There is also growing evidence showing that the personal costs of cancer are significantly higher for people who live beyond major urban centres. Travel and accommodation assistance schemes fall well short of addressing the stark inequities in treatment access and support across the metropolitan/rural divide.

An important result of cross-border inconsistencies in travel and accommodation scheme administration is that Australians diagnosed with cancer may be subject to an inherent disadvantage on the basis of not only their geographic isolation, but also the jurisdiction in which they reside.

There are also complications for patients who reside in regions where the nearest tertiary treatment centre is interstate. A recent example featured cancer patients from Broken Hill, whose nearest treatment centre was Adelaide, reporting that they received lower reimbursement than patients at the same centre who reside in South Australia. Numerous similar examples appear in the literature or are reported anecdotally.

The impact in terms of treatment outcomes is discussed in more detail under term of reference e). An informative example of the impact of distance on treatment outcomes is a report showing that some women in isolated areas with breast cancer choose mastectomy rather than lumpectomy with radiotherapy, when either option would be equally effective, because the radiotherapy involved travel and accommodation that may be too disruptive or unaffordable. In effect, these patients are declining breast conservation because of the difficulties of distance.¹³

Clinical trials

Cancer clinical trials deliver a range of benefits to participating patients. For example, patients trialling successful new modalities are at the cutting edge of new treatment technology, while patients on a trials control arm also benefit from the rigorous standards of care and monitoring applied in a trial. Patients also report a sense of heightened care quality from their experience of a trial's disciplined and structured environment.⁹

In the absence of any eligibility for travel and accommodation subsidy linked to cancer clinical trials, isolated patients can only become involved in such cutting-edge treatment programs if they are able to fund their own participation. This presents a clear disadvantage for isolated patients in terms of the potential for optimal treatment outcomes.

Escorts

There is very limited assistance available for patient escorts, despite the important contribution escorts make in helping patients to manage stress and treatment side-effects such as pain, nausea, vomiting and fatigue.

Escorts are particularly important for people of non-English speaking background and for Indigenous people, many of whom live in Australia's most remote locations and face language barriers and complex cultural needs such as the presence of a traditional healer. Indigenous communities report that traditional healers provide an important cultural interface for Aboriginal patients from remote communities referred for treatment in larger centres, yet there is very little scope for healers to attend as escorts.

Healthcare professionals

A number of studies have shown that the complexity of current patient travel and accommodation schemes is a significant problem even for dedicated staff directly responsible for their administration, with a survey in one jurisdiction reporting that up to 80% of staff experienced some degree of difficulty working through the procedures.¹⁴

More generally, clinical professionals report that the paperwork is complex and onerous, with social workers performing an unofficial clerical role to help reduce the bureaucratic burden.¹⁵ A report published by COSA in 2006 and editorialised in the *Medical Journal of Australia*¹⁶ surveyed healthcare professionals in all regional Australian hospitals that provide chemotherapy, with 65% of respondents reporting that travel and accommodation assistance schemes were a barrier to improving cancer care provision in isolated areas.

The widely reported impact of this complex administrative burden on professionals is ultimately felt more acutely by patients. Patients and social workers report a number of cases where bureaucratic delays, attributed to procedural inefficiencies, cause patients to wait for more than three months for reimbursement – at a time when they are already likely to be financially disadvantaged and distressed by their cancer experience.⁷

Recommended solutions

Evidence and expert opinion indicate that pivotal to improving patient travel and accommodation assistance is a national framework, negotiated and endorsed by the federal and state/territory governments, that includes minimum standards and a uniform, streamlined administrative system.

Established structures for inter-jurisdictional funding and administration are the Medicare Agreements; the Australian Health Care Agreements; and the Australian Health Ministers' Conference.

While it is a matter for government to determine which mechanism is most suitable, The Cancer Council Australia and the Clinical Oncological Society of Australia strongly contend that such a joint approach is the only way to make a measurable difference to the effectiveness of patient travel and accommodation assistance nationwide.

It would be essential that eligibility criteria be benchmarked to improve, rather than reduce, the level of assistance, and that some flexibilities remained. A "highest common denominator" model would need to apply to ensure that patients in all jurisdictions would be better off in terms of the overall amount of benefit paid, and that no patient was worse off in terms of distance eligibility.

The framework would need to achieve a significant increase in assistance, the establishment of national standards, and streamlined administrative processes in order to reduce the disadvantages faced by isolated cancer patients.

Summary recommendations:

- Build cancer patient travel and accommodation assistance into a robust federal/state-territory funding framework, such as the Medicare Agreements (administered through the Safety Net); the Australian Health Care Agreements; or an accreditation system endorsed by the Australian Health Ministers' Conference;
- Form a taskforce of cancer care professionals with experience in remote communities, care coordinators, consumers and federal/state program administrators, to develop service standards and an administrative system;
- Extend eligibility for travel and accommodation assistance to include isolated patients' participation in authorised cancer clinical trials;
- Extend eligibility for escorts;
- Waive administration fees for patients residing in very remote or isolated communities, those on a low income or Health Care Card holders; and

Level/form of assistance

Current position

In 2006, cancer overtook cardiovascular disease as Australia's largest disease burden.⁵ Cancer is diagnosed in between one in three and one in four Australians by the age of 75.¹⁷ Around 30% of Australia's cancer patients are estimated to be living outside a major population centre.¹

Despite cancer's predominant impact, the disease accounts for only 5.8% of healthcare expenditure in Australia (\$2.9 billion).¹⁸ Of that amount, it is estimated that less than 2% is spent on patient travel and accommodation assistance. So, while governments clearly have a fiscal responsibility to minimise taxpayer burden, on a healthcare expenditure/overall disease burden ratio, cancer care remains significantly under-funded across jurisdictions in Australia. There is a major disconnect between the impact cancer has on our community and the amount of money we invest in reducing that impact.

The imbalance between overall cancer burden and public expenditure on cancer care is particularly acute in terms of the assistance provided to isolated patients, who have demonstrated support needs.⁵ (Given the pervasive impact of cancer, it is the view of The Cancer Council Australia/COSA that the Australian community would welcome additional whole-of-government funding support to relieve the hardship faced by isolated cancer patients.)

Benchmarked against the subsidisation for travel and accommodation paid in the commercial and government sectors,¹⁹ the amount of financial assistance is exceptionally low, as this accommodation comparison demonstrates:

Place*	ATO rate \$	PATS rate \$
Adelaide	136	30
Brisbane	141	30
Canberra	114	30
Darwin	128	30
Hobart	104	30
Melbourne	150	30
Perth	126	35
Sydney	158	33

*Note that a subsidy paid in one state/territory may be for accommodation in another jurisdictions, so direct comparison on the basis of place alone is not always applicable. On average a cancer patient in Australia staying in any city is receiving accommodation assistance that is less than a quarter of that in the Australian Taxation Office guidelines for employee reimbursement.

Petrol subsidy

Petrol allowance subsidy rates are well below Australian Taxation Office recommended rates for employee reimbursement. In some cases rates not been increased since the

schemes were devolved to the states and territories in 1987. Real petrol prices in Australia have increased markedly in that time.

The maximum fuel subsidy is 16c per km in South Australia; the minimum is 10c per km in Queensland. By contrast, Australian Taxation Office rates vary from a maximum of 70c per km to a minimum of 58c per km, depending on vehicle engine size.

Impact

The literature on the cancer journey for people in rural and remote communities is infused with stories of extraordinary personal hardship, exacerbated by loss of income, the distress of relocation for treatment and the insufficiency of, and problematic access to, government support.

There is compelling anecdotal evidence and a growing body of research* showing that insufficient subsidisation for isolated patients' travel and accommodation is a major cause of distress.

Literature showing the insufficiency, inefficiency and under-utilisation of patient travel and accommodation assistance is increasingly suggestive of a link between the schemes' performance and disparities in cancer treatment outcomes across the metropolitan/rural divide.

Epidemiology

There is growing epidemiological evidence that cancer mortality rates increase significantly in step with geographic isolation.²⁰ A study published in the *Medical Journal of Australia* in 2004 showed that people with cancer in regional NSW were 35% more likely to die within five years of diagnosis than patients in cities. Mortality rates increased with remoteness. For some cancers, remote patients were up to 300% more likely to die within five years of diagnosis.²¹

A study published by COSA in 2006 and editorialised in the *Medical Journal of Australia* mapped the provision of rural/remote oncology services across Australia.²² The study was the first national analysis to statistically demonstrate what has long been assumed: that access to essential cancer care in all disciplines decreases nationwide as communities became more isolated.

On the basis that increased cancer mortality in rural/remote populations is linked to service inaccessibility (as well as other factors, such as comparatively late-stage diagnosis), it is reasonable to infer that the under-utilisation of travel and assistance schemes may have some relationship to the poor treatment outcomes experienced by isolated patients.

Or, to put the equation in a positive context, it is reasonable to infer that significant improvements in the funding and administration of the schemes aimed at increasing access and usage rates have the potential to reduce the disparities in cancer treatment outcomes across the rural/metropolitan communities.

* See Appendix 2 – Research by Dr Pam McGrath

Psychosocial impact

There is a growing evidence base showing that sub-optimal psychosocial care can contribute significantly to poorer overall cancer treatment outcomes.

For isolated patients, the distress of a cancer diagnosis is compounded by relocation, separation from family, and additional loss of income and out-of-pocket expenses. A number of studies* indicate that current travel and accommodation schemes fall well short of recognising the psychosocial impact of a cancer diagnosis on a rural/remote patient.

Moreover, distress and relatively poorer access to psychosocial support are likely to compound the effect of other well-documented factors linked to overall reduced cancer survival in rural/remote communities, such as later-stage diagnosis and incompleteness of treatment programs.

Recommended solutions

In order to measurably improve the effectiveness of patient travel and accommodation assistance schemes, there is a demonstrable need to significantly increase the current level of government subsidy.

Funding commensurate with the magnitude of the problem is fundamental to ensuring that the schemes can deliver a meaningful reduction in the well-documented inequities between rural/regional and metropolitan cancer care outcomes in Australia. The extent of personal hardship reported by cancer patients in rural/remote communities,²³ and the increasingly suggestive evidence base linking geographic inaccessibility of treatment and care to cancer mortality, can only be effectively addressed through patient travel and accommodation assistance if the schemes receive a significant funding increase nationwide.

Reciprocal arrangements between jurisdictions

There are no formalised, reciprocal arrangements consistent across jurisdictions. Some informal arrangements are in place where cross-border patient travel may occur frequently. For example, The Cancer Council Australia South Australia, whose jurisdiction has multiple state borders, has informal arrangements with NSW, Victoria and the Northern Territory for billing patients' use of Cancer Council accommodation. The billing arrangements vary widely according to the travel and accommodation scheme procedures in each client jurisdiction, again reflecting the scope for inequity and inconsistency prevalent in other components of the schemes.

A system administered locally by jurisdictions according to national minimum standards set and co-funded by the Australian Government would facilitate more efficient cross-border billing arrangements.

* See Appendix 2 - Research by Dr Pam McGrath

- b. the need for national minimum standards to improve flexibility for rural patient access to specialist health services throughout Australia;

Current position

Currently, there are no minimum standards for patient travel and accommodation assistance, either nationally or within jurisdictions. There are established reimbursement rates and fixed eligibility criteria, but, as outlined against term of reference (a), these are funded well below demonstrated need and subject to complex administrative procedures.

The most significant problem in terms of system inflexibility is the fixed cut-off point for distance eligibility in all jurisdictions, which, in some cases, can mean that a patient living 95km from essential care may be ineligible for assistance, yet a neighbour (5km is a short distance in rural Australia) meets the 100km criteria and is therefore eligible for support.

Inflexibilities also mean patients are funded to attend the nearest treatment centre only, irrespective of the length of waiting lists.

Impact

The literature features a considerable number of testimonials from patients whose distressing cancer experience and loss of income were significantly exacerbated by the knowledge that a few kilometres prevented them from accessing much needed travel and accommodation assistance.

In addition, patients who are subsidised only to visit a centre with long waiting lists may make suboptimal treatment decisions, which they would not have to face if they were given support to attend an alternative centre where appropriate treatment was more readily available.

Moreover, the absence of national minimum standards means inequity in cancer treatment access is instituted, which is unacceptable in a nation where cancer is identified as a national disease priority and is subject to a quality, multi-jurisdictional national service improve framework.

Recommended solution

The simplest way to remove the inherent unfairness of a fixed distance eligibility cut-off is to introduce a sliding scale. If a patient lives within the agreed cut-off zone for full assistance, a reduction in the full fee, based incrementally on the patient's proximity to a recommended treatment centre, could apply. The sliding scale could cease to apply once a patient was located within the borders of a greater metropolitan area. Increases in overall subsidy rates would be integral to ensuring the sliding provides meaningful assistance to patients at the nearer end of the scale.

It is recommended that a nationally agreed and administered scheme could provide a mechanism for meeting minimum standards and the rigour and efficiency to ensure flexibilities could be introduced without a significant administrative burden.

Summary recommendations:

- Raise subsidies to rates comparable with Australian Taxation Office guidelines;
- Introduce a sliding scale for distance eligibility;
- Explore options for patients to be subsidised to attend a treatment centre on the basis of immediacy of treatment as well as proximity; and
- Build a minimum standards/highest common denominator framework into a robust national funding framework.

c. the extent to which local and cross-border issues are compromising the effectiveness of existing Patient Assisted Travel Schemes in Australia, in terms of patient and health system outcomes;

Current position and impact

Local issues

Administration procedures of patient travel and accommodation assistance schemes varies significantly within local areas. The schemes are generally decentralised and subject to a wide range of processes, variously involving travel clerks, specialists, medical superintendents etc. at referring regional hospitals, and some corresponding professionals at metropolitan treating hospitals.

Evidence indicates that clerks in some jurisdictions use a variety of interpretations of criteria in the guidelines in their decision-making for approval for both patients and their escorts to receive assistance. Priority is given to purely physical or medical, criteria rather than psychosocial considerations such as the patient's emotional state, financial situation and need for support.¹³

The literature on cancer treatment issues for isolated patients indicates that the lack of consistency within locations adds to the schemes' bureaucratic burden and the potential for confusion experienced by patients. Moreover, this lack of centralisation limits the efficiency of data collection and therefore prevents policy makers from undertaking adequate research on how to improve the schemes locally.

Cross-border issues

There are multiple examples of cross-border issues compromising the effectiveness of existing patient travel and accommodation schemes throughout Australia, including:

- Patients travelling interstate to access facilities closer to home (e.g. residents of Far Western NSW being treated in Adelaide) receiving a lower subsidy than other isolated patients in the same facility;
- Administrative complications between refereeing hospitals in one jurisdiction and treatment hospitals in another jurisdiction;
- An additional administrative fee for processing interstate applications charged in some jurisdictions.

Evidence shows that cross-border complications and inconsistencies are contributing to poor usage of the schemes and to patients making decisions about their treatment that lead to inferior outcomes.¹²

The absence of reciprocal arrangements between jurisdictions, as summarised against term of reference a), further reflects the inefficiencies of a fragmented, decentralised system.

Solution

A robust national framework, built around highest common denominator minimum standards and agreed to by all jurisdictions, would significantly reduce the disparities between and within jurisdictions and associated administrative inefficiencies.

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| <p>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;</p> |
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Current position and impact

There is significant evidence showing that established travel and accommodation assistance is under-utilised because eligible patients are not sufficiently aware of the schemes' existence and how to access support.

A study of 80 rural women travelling to the city for breast cancer treatment found that only 39% of them received financial assistance and 19% of these had trouble claiming money for which they were eligible.²⁴ The *National Service Improvement Framework for Cancer*¹ refers to a study of 192 people with haematological malignancies who travelled for treatment, with one quarter of those surveyed identifying that they had never heard of the local assistance scheme. Scheme awareness was also identified as a major impediment to access in the *Radiation Oncology Jurisdictional Implementation Group Final Report*.²⁵

Solution

As well as facilitating increased funding and efficiency, a national framework would enable improved promotion of travel and accommodation schemes to eligible patients.

Accreditation or other quality assurance mechanisms could include measures to better promote the schemes, such as building standardised information about the schemes into treatment protocols for eligible patients. (As set out in Attachment 1, a national quality assurance framework is required for all components of cancer treatment and care services in rural/remote areas. Promoting travel and accommodation assistance would be part of such an approach.)

- e. variations in patient outcomes between metropolitan and rural, regional and remote patients and the extent to which improved travel and accommodation support would reduce these inequalities;

Current position

There is a growing evidence base showing that the 670,000+ Australians who live outside state capital cities²⁶ are at risk of significantly poorer survival rates following a cancer diagnosis than people with similar diagnoses in the major metropolitan centres.²⁷

For example, a report published in the *Medical Journal of Australia* in 2004 showed that people with cancer in regional NSW were 35% more likely to die within five years of diagnosis than patients in cities. Mortality rates increased with remoteness. For some cancers, remote patients were up to 300% more likely to die within five years of diagnosis.²⁸ The limited evidence on cancer in indigenous people in non-metropolitan areas also indicates significantly poorer treatment outcomes than those in the mainstream.²⁹

The COSA mapping report of 2006³⁰ provided statistical analyses of the provision of cancer care services by remoteness, with evidence that access to services across all disciplines reduced markedly as isolation increased.

The evidence and views expressed against term of reference (a) further outline the inherent cross-border and local inefficiencies in the schemes, and how they may relate to measurable inequities in treatment outcomes.

Impact

Inequities in cancer treatment outcomes across the metropolitan/rural divide have, until recently, been severely under-researched. The evidence base that has accumulated to date shows:

- a clear association between geographic isolation and poorer cancer treatment outcomes in terms of survival and mortality;^{17,18}

- a clear association between geographic isolation and the reduced availability of cancer treatment services;^{15,30}
- increasing indications that psychosocial wellbeing can have an impact on overall cancer treatment outcomes;²⁶
- a clear association between geographic isolation and reduced participation in cancer clinical trials.⁹

Solution

More research into the specific causes of the significant disparities in cancer survival and mortality between metropolitan and non-metropolitan people is urgently required. From what is understood, access to appropriate treatment and care is the key to the inequity. On this basis, measures to improve the accessibility, effectiveness and efficiency of travel and accommodation schemes would have a measurable impact on reducing geographical disparity.

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| <p>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;</p> |
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Current position and impact

There is a growing evidence base showing the benefits to cancer patients of a multidisciplinary approach to care, built on patient-centred, coordinated treatment and support plans utilising a range of clinical and allied health professionals.

Evidence shows that the further from a major centre a patient lives, the poorer their access to multidisciplinary care.

Solution

As outlined in Attachment 3, a long-term reform plan centred on regional cancer centres of excellence, with capacity to provide multidisciplinary care, would substantially reduce the distance travelled by cancer patients in isolated areas. For example, developing capacity in larger regional centres, such as Albury-Wodonga or Wagga Wagga, would effectively halve the distance patients might otherwise have to travel from remote NSW or Victoria to Sydney or Melbourne respectively.

While these trips would still require assistance, the burden on patients, and on the schemes, would be significantly reduced. Therefore, better access to multidisciplinary care could clearly be facilitated through improvements to travel and accommodation assistance schemes.

In the shorter term, with multidisciplinary care generally far more accessible in capital cities and the largest regional centres (e.g. Newcastle in NSW), improvements to travel

and assistance is pivotal to helping isolated patients gain access to coordinated treatment and support.

- g. the relationship between initiatives in e Health and Patient Assisted Travel Schemes;

e Health initiatives may have some potential to improve access to cancer care services for people in rural and remote locations, particularly in the context of multidisciplinary care. However, substantial infrastructure reform would be required before any tangible benefits would be available, particularly for people in the most isolated areas.

The Cancer Council Australia and the Clinical Oncological Society of Australia would support investigation of options that could utilise e Health to reduce the consumer and system imposts derived from patient travel and accommodation assistance schemes. However, it is important to note that for many of the services required to treat cancer – such as radiation oncology – patient transportation to an appropriately equipped treatment centre is essential.

- h. the feasibility and desirability of extending patient assisted travel schemes to all treatments listed on the Medicare Benefits Schedule – Enhanced Primary Care items such as allied health and dental treatment and fitting of artificial limbs; and

As evidence-based cancer control organisations, The Cancer Council Australia and the Clinical Oncological Society of Australia's remit is generally to comment on cancer-related issues.

Cancer is the leading cause of death in Australia and the largest overall disease burden.¹⁶ And, as summarised throughout this submission, cancer has been shown to cause significantly higher relative mortality rates in more remote areas and generally requires ongoing treatment over extended periods. Our organisations therefore strongly contend that cancer should be a priority illness for any proposed improvements in travel and accommodation assistance.

We would, however, enthusiastically support any reforms that would help to reduce the burden of other illnesses, particularly those that are life-threatening or seriously debilitating, on isolated patients.

There are also significant numbers of patients who develop an additional illness because of their cancer treatment and who should be eligible for assistance. A good example is lymphatic drainage massage for cancer patients who have developed lymphoedema. Several reviews have concluded that treatments administered by trained health professionals, such as complex decongestive therapy, manual lymphatic drainage, laser therapy and pneumatic pump therapy, generally result in significant improvements in limb volume.^{31,32} Physiotherapists need to be adequately trained to perform lymphatic

drainage massage, therefore a patient may have to travel to seek an appropriately trained therapist rather than the nearest general physiotherapist.

In general terms, adoption of our longer-term proposal to introduce cancer centres of excellence in larger regional centres would be likely to attract a wider range of skilled healthcare professionals skilled in treating other disease groups to those areas. This would lead to overall improvements in health services at strategic sites that would significantly reduce the distance patients would otherwise need to travel to capital cities.

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| <p>i. the role of charity and non-profit organisations in the provision of travel and accommodation assistance to patients.</p> |
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State and territory Cancer Councils throughout Australia provide a range of support services to facilitate isolated patient travel and accommodation. These include accommodation services; subsidised meals; one-off financial assistance packages; referral and advice; and advocacy support. In NSW, The Cancer Council is developing partnerships with transport providers to increase their capacity in high-need areas.

As organisations dedicated to reducing the impact of cancer, the Cancer Councils do what they can within their limited means to provide this important contribution towards what is essentially a government program. Our members provide a wide range of other support services to people living with cancer, ideally positioning us to participate in a national review of the schemes.

The Cancer Council strongly believes that it is the responsibility of government in this prosperous nation to ensure that patient travel and accommodation schemes are adequately funded and efficiently managed to better reduce the stark inequities in cancer treatment outcomes across Australia's metropolitan/non-metropolitan divide.

* See Attachment 1 – Recommendations for rural/regional cancer services reform

Appendix 1 – Recommendations for rural/regional cancer services reform

The existence of some regional cancer-care capacity and a range of guidelines, studies and recommendations, provide a strong foundation on which to expand rural/regional cancer services in Australia in a cost-effective, strategic way.

The immediate challenge for governments – both national and state – is to pull these many strands together and invest in improved coordination and an expansion of existing resources to deliver much needed improvements in cancer-care services for Australia's substantial rural and remote population.

The first ever mapping report of regional oncology services,³⁰ commissioned and published in 2006 by the Clinical Oncological Society of Australia, indicate that the next steps towards equity should be:

- Formal recognition of the problem and a collaborative government response;
- Building regional oncology centres of excellence;
- Establishing a national quality assurance framework; and
- Short-term capacity-building measures while systemic reform is phased in.

Formal recognition, collaborative response

There are encouraging signs that governments are becoming increasingly focused on the problems of cancer care in regional Australia and are working more strategically to improve outcomes.

Initiatives such as the Australian Government's rural mentoring program, commitments in state government cancer plans and the emergence at both federal and state level of dedicated cancer control agencies present opportunities to begin building now to reduce the imbalance between rural/remote and city patients over the longer term.

The Council of Australian Governments (COAG) is scheduled to meet in June 2006 and expected to discuss a number of healthcare reforms, including improved coordination of chronic disease management and Medicare support for case-conferencing of cancer specialists. The Australian Health Ministers' Advisory Council has also agreed to a rural health reform agenda, aimed at addressing high-priority issues as a matter of urgency.

This may be an ideal time for governments at both levels to consider and agree to actions to address specific areas of cancer care for people in rural and remote areas. Proposed solutions, which would require commitment and collaborative approach, are outlined as follows.

Regional oncology centres of excellence

Based on the evidence and the experience of cancer care professionals working in regional areas, the establishment of "regional oncology centres of excellence" would be the most cost-effective and efficient way to roll out a sustainable framework for reducing disparities in treatment outcomes between urban and rural Australia.

Moreover, the establishment of regional oncology centres also has the potential to yield wide-ranging benefits in other areas of clinical practice and contribute to overall improvements in rural/regional life. The problems of attracting and retaining GPs and allied health professionals would potentially be reduced in centres that offer services such as multidisciplinary cancer care.

The logical starting point for building regional oncology centres of excellence would be treatment facilities that already have radiotherapy capacity.

Rationale

Around half of all cancer patients require radiotherapy. Radiation oncology is therefore essential to the provision of multidisciplinary cancer care. While it is the most expensive treatment modality in terms of capital outlays and maintenance, and the least mobile due to hardware requirements, in terms of cost versus efficacy radiotherapy is the most cost-effective treatment to administer once the infrastructure is in place.³³

There is, therefore, a strong case for building multidisciplinary cancer centres in the 10 non-metropolitan centres that already have radiotherapy infrastructure. These are:

Coffs Harbour, Port Macquarie, Wagga, Wollongong (NSW); Albury-Wodonga, Ballarat, Bendigo, Geelong, Latrobe Valley (Vic); and Townsville (Qld).

There is commitment from the Northern Territory and Australian governments to fund radiation oncology services in Darwin, which could form the basis of a multidisciplinary centre to service the Top End. At the time of writing there were signs that additional services were also being considered for the NSW North Coast. (In Newcastle, a multidisciplinary cancer treatment service already operates at the Newcastle Mater Hospital, servicing people in the NSW Hunter region.)

The combined population of these 11 centres is more than 1.5 million people. It is estimated that an additional 700,000 people live within 150km of these centres. Based on current cancer prevalence rates, this equates to around 630,000 people living in or relatively near these centres who are likely to be diagnosed with cancer by age 75 and who, under current arrangements, would in many cases need to travel considerable distances to access multidisciplinary care in a state capital city.

Attracting two medical oncologists and a range of allied health service providers to each centre where radiation services already exist is the most cost-effective way to introduce multidisciplinary cancer care into the regions. It would also be consistent with the Australian Medical Workforce Advisory Committee's recommendations around practitioner-to-patient numbers according to critical population mass. In addition to treating substantial local populations, these centres would operate as relay points for supporting remote services and communities, providing mentoring and referral links for rarer cancers. They would also serve as a template for setting up future centres in regional areas with similar populations that currently have no radiotherapy capacity.

In the opinion of experienced rural/regional cancer care professionals, the establishment of regional cancer centres would also help to attract GPs and other clinical practitioners

to regions where there are current shortfalls, by contributing to an overall culture of local medical best-practice.

An informative example of the potential of regional oncology centres of excellence is the centre at Albury-Wodonga, a former outreach facility that now features five resident oncologists, a clinical trials unit, oncology pharmacist and a two-machine radiotherapy service. Outreach clinics are performed within the region from Albury-Wodonga. Reported benefits include an increase in the number of new patients able to be treated locally from 150 to 750 a year, an eight-fold increase in chemotherapy day treatments performed locally, the establishment of multidisciplinary clinics and more than 10% of new patients participating in a clinical trial.³⁴

A national quality assurance framework

Medical groups have done considerable work developing guidelines to underpin best practice in cancer care in Australia, yet there is no national framework for ensuring such guidelines are universally adopted.

The Australian Medical Workforce Advisory Committee has released a number of recommendations on infrastructure requirements for cancer services; the Australian Cancer Network is developing a model for accrediting cancer services and credentialing individual practitioners and has produced (with NHMRC endorsement) a range of clinical practice guidelines; and the Medical Oncology Group of Australia has scoped minimum standards for medical oncology services for rural and remote Australia.

There may be a role for the Australian Government's new national cancer agency, Cancer Australia, to endorse these and other similar documents and negotiate, with appropriate federal and state/territory government agencies, a framework for their adoption as standard practice.

The application of evidence-based guidelines would be particularly helpful in regional centres, which currently lack the economies of scale to develop their own mechanisms for quality assurance.

Shorter-term capacity building

There are a number of shorter-term measures that would help reduce inequities in treatment outcomes while longer-term reforms are being developed. These include:

- Investment in clinical data systems to audit, monitor and plan oncology services;
- Investment in psychosocial support services for people in rural and remote areas, who have been shown to have significantly poorer access to such services;
- Support for distance education, mentoring and innovative models such as telemedicine in remote areas; and
- Improved coordination of government-funded travel and accommodation schemes for cancer patients and their families in remote areas.

By formally identifying improved cancer care in rural and remote Australia as a policy priority in the context of existing government reform frameworks, formal structures can be put in place to develop targeted solutions to the challenges outlined above.

Appendix 2 – Research by Dr Pam McGrath

The Cancer Council Australia and the Clinical Oncological Society of Australia acknowledge the work of Dr Pam McGrath, one of Australia's leading researchers in the area of patient travel and accommodation assistance. Dr McGrath's widely published research provides valuable information about the schemes in Australia.

The following papers are recommended as additional reading material for individuals interested in the more detail about the schemes. They are generally searchable on the internet; copies in PDF form can be emailed. Please contact Paul Grogan on (02) 9036 3252 or paul.grogan@cancer.org.au if you would like PDF versions of any of these papers:

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