NATIONAL RURAL HEALTH ALLIANCE INC.

Submission to the

Senate Inquiry into Services and Treatment Options for Persons with Cancer

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Introduction

The National Rural Health Alliance is the peak non-government body concerned with rural and remote health issues in Australia. The Alliance is made up of 24 Member Bodies, each being a national body in its own right, representing health professionals, service providers and consumers. A list of the Alliance's Members and much other information about the organisation and its work is on its homepage at http://www.ruralhealth.org.au

This Submission represents the agreed views of the National Rural Health Alliance, but not necessarily the full or particular views of all of its Member Bodies.

The National Rural Health Alliance exists because the health status of rural and remote Australians is substantially lower than that of those who live in metropolitan areas. The first definitive work on this was the 1998 report by the Australian Institute of Health and Welfare (AIHW), *Health in Rural and Remote Australia*[1][2]. That report showed that death rates for males were around 6% higher in rural areas, and 22% higher in remote areas, than in metropolitan cities; the comparable figures for females were 4% and 24% respectively. The report showed that this differential in health outcomes is due to both inequalities in access to health services and broader socio-economic determinants.

The Incidence of Cancer in rural and remote areas

These general findings were confirmed and updated in the AIHW's *Rural, regional and remote health – a study in mortality*. This later study reported that between 1992 and 1999 death rates in Australia overall fell and reductions in death rates from cancer contributed 15% of the overall decrease.

For all cancers in 1999, death rates were 5% (1.05 times) higher for males in regional areas than in Major Cities, whereas for females the death rates from cancer were similar across all areas. In remote areas, rates were similar to those in Major Cities. The contribution of cancers to 'excess deaths'[3] was greatest in Inner Regional[4] areas and least

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[1] *Health in Rural and Remote Australia*, AIHW, Canberra, 1998.
[2] *Rural, Regional and Remote Health – a study in mortality*, AIHW, Canberra, 2003.
[3] Those in excess of the number that would have occurred if the national rate applied.
[4] The term 'Inner Regional' in the ASGC Remoteness classification system refers to areas with an ARIA index between 0.2 and 2.4. This means that Inner Regional places are those outside the major cities but

important in Very Remote areas, making it inversely related to remoteness: the more remote, the lower the proportion of excess deaths attributable to cancer. The report also found some gender difference.

We need better understanding of factors that affect the incidence of cancer. It is possible that rural and remote lifestyles and attitudes are related to rates of cancer, for instance attitudes to smoking, drinking and sun safety.

The RDAA report to the NH&MRC this year[5], identifies "modifiable risk factors" that increase the incidence of bowel and lung cancers. Both of these are affected by smoking, poor diet and nutrition, physical inactivity and excess weight. In turn, the occurrence of these risk factors is higher in communities of lower socio-economic status, which tend to be more common in rural and remote areas.

The report suggests that the higher incidence of these factors may in part be due to the failure of public campaigns aimed at promoting behavioural change, such as Sun Smart and screening programs, and the difficulty of engaging people from lower socio-economic and rural areas. Further, it appears that these campaigns are rarely adjusted for relevance to the rural environment.

Other studies have confirmed the links between lifestyle factors and cancer, so it should be a public health imperative to ensure that all Australians have access to information and education about the potential health benefits of changing lifestyle.

Rates of survival

As well as different rates of incidence of cancer, non-metropolitan areas also display some poorer rates of survival. Evidence presented at the *Cancer in the Bush* meeting held in March 2001[6] show that in South Australia, for example, country men had consistently lower survival for a number of cancers. A paper published this year in the Medical Journal of Australia reports that rural Australians have specifically poorer rates of survival after cancer diagnosis[7].

Cancer in the Bush – March 2001

The first *Cancer in the Bush* conference organised by the Clinical Oncology Society of Australia (COSA) and the Australian Cancer Society, was held in Canberra in 2001[8]. This was a gathering of specialists from all over Australia attempting to identify the

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with least access limitations; the other classifications, in order of increasing access difficulties, are: Outer Regional, Remote and Very Remote.

[5] RDAA – Preventive Healthcare and Strengthening Australia's Social and Economic Framework Report to NH&MRC Jan. 2005.

[6] Held by the Clinical Oncology Society of Australia (COSA) and the Australian Cancer Society.

[7] Jong KE, Vale PJ & Armstrong BK (2005) – Rural inequalities in cancer care and outcome. *Medical Journal of Australia (MJA)* 182:1 p13.

[8] COSA - Cancer in the Bush – Optimising clinical services. A report from a meeting held at the National Convention Centre, Canberra March 2001.

unique problems facing people who live in rural and regional Australia, and who are already diagnosed with cancer.

The Workshop found that these patients face extra physical, financial and emotional burdens in accessing the treatment and support services they need, compared with patients in metropolitan areas.

The key issues identified were:

- transport and the need to remove inequities in the current IPTAAS/PATS arrangements;
- improved patient support including implementing the breast cancer nurse model nationally, and the need for a cancer nurse demonstration project;
- training and workforce planning, and the need for them to be nationally co-ordinated and funded;
- workforce planning, including for disciplines covering the special needs of rural areas;
- networking and national accreditation;
- epidemiology and quality of life;
- reimbursement and the need for new item numbers; and
- other issues of national priority.

Cancer in Rural and Remote Australia: The Key Current Issues

Rates of cancer for men are higher in some non-metropolitan areas than the major cities, and there is also evidence of poorer rates of survival after diagnosis.[9] This double-whammy illustrates a number of issues in relation to cancer in the bush.

1 As with other parts of the health sector, there are serious health and health-related **workforce shortages** in rural and remote Australia. Workforce shortages affect health status and outcomes at all stages and cancer is a particular case in point. The prospects for early diagnosis is jeopardised, treatment entails higher costs and may be determined by distance as well as by clinical need, and end0stage care may be hard top obtain or unavailable. It is to be hoped that the recently announced Productivity Commission Inquiry into Health Workforce will consider specifically the need for cancer specialists and support workers.

2 In almost all categories of cancer, **early detection** leads to more positive treatment outcomes but, because of workforce shortages, people in rural and remote areas currently have less chance of an early diagnosis.

[9] This is another example of the situation in which the epidemiology and rates of morbidity and mortality associated with a particular disease or condition are different in non-metropolitan areas and, on top of this, the effects (duration, impact, sequelae) of incidences of a particular condition are also distinct. The latter phenomenon is usually the result of lower levels of access to the healthcare system and its professionals. So, for example, the rate of breast cancer in remote areas may be no higher, but the impacts of the same rate may be more severe.

3 At every turn in the health sector, but particularly where cancer is concerned, there is a clear need for better **health-related transport**. Delegates at the 8th National Rural Health Conference in Alice Springs recognised this particular need and called for a national inquiry into the state-run health transport schemes (PATS, IPTAAS, etc). There have been calls for reimbursement of travel costs not just to patients but also to specialists and other health professionals required to travel to more remote areas.

A related issue is the need for accommodation for people from rural and remote areas at specialist centres in the major cities.

Patients living in rural and remote areas are lucky if they are within an hour's drive of a town that has at least one GP. Just to visit a doctor to have a cancer diagnosed can be in itself a traumatic experience, and sometimes it is put off largely because of this difficulty. GPs in rural and remote areas sometimes lack the specialised training needed to make such critical diagnoses, so that patients may have to be referred to a larger town, up to three or four hours' drive away. Often there have to be repeated visits and tests to come up with an accurate diagnosis.

Once a positive diagnosis is made, it is even more traumatic to access treatment. Because of the scarcity of specialist oncological services in rural and remote areas, patients have very limited options, and nearly all involve considerable travel, which brings serious physical, financial and emotional problems. Transport difficulties, such as the patient's discomfort during long travel (especially by road, which may be the only mode available), the medical risks during long travel, and the problems related to the transport of specimens, blood etc, are part and parcel of the additional suffering.

These problems remain throughout the entire time that the patient is suffering from cancer.

All of this travel imposes costs on the patient and family. Despite programs such as IPTAAS, there are always additional costs, accommodation, time away from work, child care and babysitting, that are not experienced by a patient living in a metropolitan area who can travel to receive specialist treatment with much less disruption to their life.

Then there are emotional difficulties related to having to travel long distances. There is often resistance to leaving the support of family and communities to travel to services in regional or metropolitan centres. Many patients opt to stay at home rather than travel to a city for the treatment they need.

4 The situation relating to cancer in the bush raises a number of issues around **information technology**, especially telecommunications. The possibility of

telephone support and counselling for cancer patients and their carers will depend on reliable and affordable telephone systems. The same applies to the possibilities for teleoncology. Also, much of the learning, training and support needed around cancer issues could be provided by internet, videoconferencing and teleconferencing. Again, these require sustainable and affordable IT infrastructure. These are some of the reasons why the Alliance remains concerned about the future of telecommunications, especially as it will be affected by the full privatisation of Telstra. It is not just a question of relative costs and efficiency now but whether, under a new regime, rural and remote telecommunications will continue to have the special investments needed to maintain their relativity with metropolitan areas.

5 As with other parts of the health system, there needs to be **closer interaction** between specialists and specialist services located in capital cities or major regional centres, and the GPs and other health care providers in rural and remote areas. GPs need to be upskilled for the task of dealing with cancer patients at all stages of the condition in a locality where referral to other health personnel is not an easy or cheap option.

6 Even where life expectancy and survival rates are not worse, it is clear that the **quality of life** as the result of cancer interventions is often worse in more remote areas. There is ample anecdotal evidence that the type of intervention chosen by a cancer patient, their family and/or their health professional is often more radical due to the difficulty of accessing the continuity of care required for less radical treatment. At worst, remoteness can lead to interventions being left until it is too late.

The MJA paper[10] reports that the poorer rates of survival after cancer diagnosis are "at least partially due to more advanced conditions at diagnosis and poorer treatment subsequently". The Rural Doctors' Association of Australia in its Media Release *Give Rural Cancer Patients a Better Chance at Life*[11] reports that "country people are about a quarter less likely to access radiotherapy and half as likely to access chemotherapy, [which] has major implications for their health outcomes. Even if the decision is made to undergo distant treatment, the impact of being away from home for lengthy periods of time, and the associated travel and accommodation costs for patients and their families, can be detrimental to the whole recovery process".

It is imperative that better facilities be provided in rural areas so that patients have much easier access to initial diagnosis and ongoing treatment. Initial diagnosis requires good access to medical technology, pathology and microbiology, as well as formal training in medical oncology and skill acquisition for rural GPs. On-going treatment requires better access to chemotherapy, radiotherapy and psychosocial counselling.

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[10] Jong, Vale & Armstrong Op cit.

[11] RDAA – Give Rural Cancer Patients a Better Chance at Life, Media Release, Friday 4 February 2005.

7 Access to **psychosocial support** is also poorer for people in remote and rural areas. Often the professionals and carers required are simply not available. This is said to be balanced by a higher quality of emotional and social support in rural communities but these informal systems can be compromised by privacy issues.

8 To the extent that for their initiation or success they require personal access to therapists, people in rural and remote areas are also disadvantaged where **alternative and complementary therapies** are concerned.

9 Access to **cancer drugs** and drug therapies may also be compromised by remoteness.

Cancer at the 8th National Rural Health Conference

The 8th Rural Health Conference was held in Alice Springs from 10-13 March 2005. It included a Workshop entitled *Cancer service delivery in regional and rural Australia – the problems and prospects,* as well as a number of concurrent session papers relating to cancer. These Conference contributions represent a significant and very contemporary view of issues related to cancer in rural and remote areas. The Alliance will collate the key issues from those papers and make a supplementary submission to the Senate Inquiry as soon as possible.

Other references

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