

Inquiry into services and treatment options for persons with cancer

Submission

- a) The delivery of services and options for treatment for persons diagnosed with cancer, with particular reference to:
 - iii) **Differing models and best practice in delivering services and treatment options to regional Australia and Indigenous Australians**

and

- iv) **Current barriers to the implementation of best practice in the above**

Research data now suggest that people living in rural and remote Australia have worse survival after a diagnosis of cancer. This is particularly the case for Indigenous Australians. Higher incidence rates, poorer cancer care and later stage of diagnosis are some likely contributors, but the relative contribution of each of these is unknown. Recent data from the Northern Territory has shed some light in this area, reporting that Indigenous Australians are more likely to be diagnosed with advanced disease than non Indigenous Australians.

Rural and remote Australians rely on a mix of cancer services that are either located close to their home or some distance away in larger regional centres or metropolitan areas. Of concern is that people decide not to travel for radiotherapy or chemotherapy and choose a course of treatment that is locally based, but not always compatible with the best outcome. There is very limited research available about the type of treatment decisions these cancer patients make and the reasons for these decisions. This information would help assist people living in these areas to make the best decisions about their treatment.

One challenge is in defining the right mix of services for people in rural and remote areas that will deliver the best outcomes. There are good quality data showing that the best outcomes for some cancers are obtained by practitioners and surgeons that have high caseloads, which are invariably located in large regional centres or metropolitan centres. Currently there are a number of State and Federal Government initiatives aimed at increasing primary health care services in rural and remote areas. This should assist in an earlier diagnosis of cancer but whether this will improve outcome is unclear. Limited Australian data suggest that the best model of care in rural and remote regions is one involving specialist outreach in a shared care arrangement with local practitioners. In this situation, initial treatment would require travel to a major centre, but subsequent treatment could be delivered effectively closer to home where local practitioners can regularly contact specialist centres for advice. Very little information is available about the best

model of care for Indigenous cancer patients, although one study at least has shown that a shared care model with primary health care workers which include Aboriginal health care workers can improve access for remote Aboriginal communities.

Two factors that coexist with rural and remote areas of residence are the greater proportion of Indigenous Australians and people who are socioeconomically disadvantaged. Cancer survival is worse for these two groups of people and we need to understand why this is so. Information is needed on the extent to which remoteness of residence and the patient's own circumstances (such as co-morbidity, communication difficulties and beliefs, attitudes and knowledge about cancer) impede their ability to access and receive health care. Fundamentally, information is also needed about the way in which the health care system operates for these groups of people. For example, are socioeconomically disadvantaged or Indigenous people discriminated against in terms of the type of cancer service offered to them? Are there systematic differences in the type of health care worker these disadvantaged groups access as their first port of call and do their levels of expertise and training or in their ability to access high quality diagnostic and treatment services differ compared to other health care workers?

Currently there is not a coherent approach to cancer care in Australia. Primary health care, diagnostic, treatment and palliation services occur in many different institutions and are funded from different arms of Government. Communication about the patient is not often well coordinated between and within institutions and other services, and it would not be uncommon for many patients, particularly in rural and remote areas, to 'fall through the cracks'.

We are not sure of the extent to which fragmentation of cancer care both within and between institutions impacts on cancer outcomes and whether this is worse for people in rural and remote Australia. In the absence of this information, interventions are needed now that will at least help ease the impact of a cancer diagnosis on patients living in rural and remote areas. One solution is to develop information systems that establish a pathway for each patient, specifically tailored to their needs. Importantly, health care workers should know how to access this system. The system could also contain standardised interactive information to assist both the clinician and the patient, such as referral pathways, diagnostic, treatment and palliative care services and travel and accommodation options for patients travelling to specialised care centres.