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## **Key Issues**

Indigenous Australians have unique needs with respect to radiation oncology for the following reasons:

- Different patterns of cancer incidence compared to non-Indigenous Australians;
- Later diagnosis and lower survival;
- Continued disadvantage in accessing treatments;
- Cultural considerations;
- Limited data and research on Indigenous cancer care, particularly in metropolitan settings.

### Objective

Aboriginal and Torres Strait Islander patients have access to radiotherapy services offered in a culturally appropriate and respectful way.

## **Defining Success**

A focus on improving Indigenous patients' outcomes in cancer control and radiotherapy specifically, including:

- Better data collection on Indigenous access to oncological services;
- Assessment of specific barriers to service access;
- Evidence-based strategies to improve access to treatments;
- Improved engagement between the hospital system, local communities and community-controlled Aboriginal and Torres Strait Islander health services.

### Introduction

The Australian health care system is failing to adequately prevent, diagnose and treat cancer among Aboriginal and Torres Strait Islander (hereafter respectfully referred to as Indigenous) Australians, a situation which is being confirmed by a growing body of research evidence<sup>1-2</sup>. Cancer survival is lower for Indigenous Australians than other people. It is the second leading cause of death among Indigenous people, accounting for a greater number of deaths each year than diabetes and kidney disease<sup>3-6</sup>.

The burden of cancer for Indigenous Australians has only recently begun to be fully appreciated. Compared with other Australians, Indigenous people have a similar or lower incidence of all cancers combined<sup>1,6,8</sup>, but a higher incidence of rapidly fatal cancers (e.g. lung, liver) and a lower incidence of cancers with better survival (e.g. melanoma, breast)<sup>1,2,8</sup>. In addition, many cancers that are amenable to prevention through reduction in exposure to risk factors or that are detectable early through screening programs are more common among Indigenous people<sup>1,2</sup>.

Advanced cancer at diagnosis<sup>1,4,6</sup>, reduced access to/uptake of treatment<sup>5</sup>, higher rates of co-morbidities amongst Indigenous patients<sup>6</sup>, and language barriers<sup>5</sup> are some of the factors that may lead to poorer cancer outcomes. However, these factors only partly explain the disparity. Indigenous people with cancer have poorer survival compared to non-Indigenous people even after taking into account stage at diagnosis, cancer treatment and presence of co-morbidities<sup>5</sup>. Further complicating the picture is that many Indigenous cancer patients are not identified as such in the state/territory cancer registries that are the key sources of data on cancer patterns<sup>1,2,7</sup>, this means that the burden of cancer among Indigenous Australians continues to be underestimated.

The need to improve cancer-related health services for Indigenous Australians is apparent however the available evidence is currently inadequate to effectively direct efforts. Limited access to cancer care services, including radiotherapy services, continues to have a detrimental impact on cancer outcomes of Aboriginal and Torres Strait Islander patients.

Radiation oncology plays an important role in the treatment of those cancers that are most common among Aboriginal people. Access to radiation oncology services for Indigenous patients warrants additional research and a greater emphasis.

### Demographics

Over half of the estimated resident Indigenous population reside in either<sup>9</sup> New South Wales (29%) or Queensland (28%); 15% in Western Australia and 13% in the Northern Territory. Over a third of the population was located in Major Cities (32%); 21% lived in Inner Regional areas; 22% in Outer Regional areas; 10% in Remote areas and 16% in Very Remote areas.

#### Socioeconomic factors

Indigenous Australians have a lower life expectancy, higher unemployment rate (16.5%) and a significantly lower weekly income compared to non-Indigenous Australians<sup>10</sup>. According to the National Aboriginal and Torres Strait Islander Social Survey 2008, 'Indigenous peoples aged 18 years and over were almost four times more likely than non-Indigenous people to live in households that were unable to raise \$2,000 within a week in an emergency (47% compared to 13%)<sup>10</sup>.

## Cancer Impact on the Indigenous Population

A recent study found that cancer was responsible for 18% of total deaths among Indigenous Australians<sup>11</sup>. Although cancer death rates were similar for Indigenous and non-Indigenous Australians aged less than 35 years or 65 years and over, Indigenous Australians in the middle age groups had higher mortality rates than non Indigenous Australians<sup>11</sup>. The study concluded that a difference in treatment between the two groups was mainly responsible for lower survival rate among Indigenous Australians.

The Rural Doctors Association in their submission to the Tripartite Committee stated that Indigenous Australians with cancer are twice more likely to die within five years of diagnosis than non-Indigenous Australians and urgent action is required to improve Indigenous access to multidisciplinary cancer care<sup>12</sup>.

Indigenous people are more likely to be diagnosed with cancers that have a lower survival rate than non-Indigenous people. A recent publication, reported that compared to other Australians, Indigenous Australians had much higher incidence of lung and other smoking-related cancers, cervix, uterus and liver cancer, but much lower incidence of breast, prostate, testis, colorectal and brain cancer, melanoma of skin, lymphoma and leukaemia. Incidence was higher in remote areas for some cancers (including several smoking-related cancers) but lower for others. The incidence rate ratios (IRRs) for smoking-related cancers were higher in younger than older people (Xiahua, Z and Condon, J. Est. cancer incidence in Indigenous Australians, 2011).

Cancer survival is lower for Indigenous than other Australians; two local studies indicated that fewer Indigenous patients received recommended treatment<sup>5,6,23</sup>.

A study from Queensland concluded that the lower survival rate for Indigenous patients is within the first two years after diagnosis and that the outlook for those who survive the first two years had a similar outlook to non-Indigenous people. This study has shown no disparity among people in relation to socio economic or remoteness factors<sup>14</sup>.

Some research indicates that clinical under-staging and non-staging of cancer in Indigenous patients could be linked to socioeconomic factors or lack of access to care as well as to possible physician bias<sup>15</sup>.

Lower participation rate in cancer screening programs among Indigenous Australians is a factor that leads to late diagnosis of cancer. For many patients, this is exacerbated by the limited access to care or patient preferences regarding treatments (especially in rural areas).

Data collection, and in particular consistent use of an Indigenous identifier, has improved in recent years but remains variable across the health jurisdictions. Nationally, the data is not adequate to enable analysis of the overall trends in cancer among the Indigenous population and their access to radiotherapy.

## Importance of Radiation Oncology

Radiotherapy is a cost effective efficient treatment mode for cancer and a valuable option in palliative care, to relieve pain and discomfort. The most commonly occurring cancers in Indigenous population (cancer of lip/mouth/pharynx, lung, oesophagus, pancreas, cervix and uterus<sup>22</sup>) respond positively to radiotherapy treatment.

Radiotherapy treatments can also be used effectively for symptom control, such as pain management. Considering the amount of late-stage disease in many Indigenous patients, radiotherapy can make a valuable contribution in the palliative setting<sup>17</sup>. It is understood, that issues around the late diagnosis need to be addressed separately, as cancer treatments have the best curative effect in early stages of cancer.

## Indigenous Access to and Utilisation of Radiotherapy

#### Access Issues

There are inherent systemic problems and historical bias in the health care system concerning access to services for Indigenous peoples<sup>18-20</sup>. Research shows that there are disparities between the cancer treatments received by Indigenous and non-Indigenous Australians.

For example, a study on survival of Indigenous and non-Indigenous Queenslanders after a diagnosis of lung cancer<sup>18</sup> has found that 46% of Indigenous patients received active treatment with chemotherapy, radiotherapy or surgery compared with 72% of non-Indigenous patients. The percentage of Indigenous patients who received radiotherapy was 31% compared to 42.8% for non-Indigenous patients. The study concluded that the differences in treatment between the two groups were mainly responsible for the difference in survival rates.

Stakeholder consultation during the development of this Plan highlighted concerns around the disadvantage experienced by Aboriginal and Torres Strait Islander patients in accessing radiotherapy services in a timely fashion.

The financial burden of cancer and the expenses associated with travel to receive treatments are a barrier to Indigenous patients living in rural and remote areas of Australia. These issues are explored in Supporting Regional and Rural Access to Radiation Oncology Services (on page 96).

Published research and information on Aboriginal and Torres Strait Islander cancer patients from metropolitan areas appears to be very limited.

### **Cultural Considerations**

There is limited availability of culturally appropriate educational resources for Aboriginal and Torres Strait Islander communities and patients with regards to cancer. As a result, awareness of cancer, including causes, prevention and treatment options, is limited.

Some research papers note that in certain communities patients believe that cancer is payback for offending a family member<sup>16</sup> or as punishment for wrongdoings<sup>17</sup> and a person who believes so would not seek treatment for cancer. Most Indigenous patients would prefer to be cared for by their community members.

In some communities, language has acted as a barrier to services as well. There are cultural and language variations across Indigenous communities in different geographical regions, and therefore cultural considerations must be tailored to suit local circumstances.

Compared to other areas in healthcare, oncology does not have a strong presence of workers with Aboriginal and Torres Strait Islander background who can bridge the language and cultural gaps. More emphasis needs to be placed on Aboriginal Liaison Officers within cancer-care facilities, including radiation oncology, to help culturally-appropriate service provision.

In the Northern Territory, initiatives in improving the understanding and uptake of radiotherapy treatment options and complementary support services have been given a boost with the establishment of the first radiation oncology facility in the Territory. These initiatives include: the development and integration of cancer knowledge into Aboriginal Health Worker (AHW) qualifications; the creation of placement opportunities for AHWs at the Cancer Care Centre; the production (and intended translation) of a DVD resource to explain and demystify radiation treatments; and continued promotion and evaluation of prevention messages<sup>21</sup>.

### Recommendations

Lack of and reduced access to radiation oncology is an important factor affecting the cancer outcomes for Indigenous patients. While acknowledging the fact that there is a need for a comprehensive approach, the recommendations below relate specifically to radiotherapy access. The recommendations below are based on the relevant research 11,12,14-18,20,22, and responses received during the stakeholder consultation process.

#### Better data collection on Indigenous access to oncological services

67. Development and implementation of a national radiation oncology dataset should include data collection on Indigenous patients.

#### Assessment of specific barriers to service access

- 68. Further research to identify the reasons for the lower survival rates of Indigenous peoples diagnosed with cancer.
- 69. Additional research to identify issues and barriers for Indigenous patients living in metropolitan areas.

#### Evidence-based strategies to improve access to treatments

- 70. Indigenous patients must have access to radiotherapy as close to their community as possible.
- 71. Accommodation facilities for Indigenous patients and their families must be appropriate and available.
- 72. Education and information strategies about cancer including causes, prevention and treatment options must be developed for Indigenous patients.

# Improved engagement between the hospital system and community-controlled Aboriginal and Torres Strait Islander health services

- 73. Planning for radiation oncology services must take into account specific access issues for Aboriginal and Torres Strait Islander patients.
- 74. Planning must be undertaken with reference to and in close consultation with the local Aboriginal community-controlled health services.
- 75. Specific strategies, including Aboriginal Liaison Officers at cancer centres, must be developed.
- 76. Initiatives to support Indigenous people to join the radiation oncology professions must be considered and encouraged.

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