

## ORIGINAL RESEARCH

# Cancer support services – are they appropriate and accessible for Indigenous cancer patients in Queensland, Australia?

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## ABSTRACT

**Introduction:** In Queensland, Australia, the incidence of cancer (all cancers combined) is 21% lower for Indigenous people compared with non-Indigenous people but mortality is 36% higher. Support services play an important role in helping cancer patients through their cancer journey. Indigenous cancer patients are likely to face greater unmet supportive care needs and more barriers to accessing cancer care and support. Other barriers include the higher proportion of Indigenous people who live remotely and in regional areas, a known difficulty for access to health services. This study describes the availability of cancer support services in Queensland for Indigenous patients and relevant location.

**Methods:** Using a set criteria 121 services were selected from a pre-existing database ( $n=344$ ) of cancer services. These services were invited to complete an online questionnaire. ArcGIS ([www.esri.com/software/arcgis/index.html](http://www.esri.com/software/arcgis/index.html)) was used to map the services' location (using postcode) against Indigenous population by local government area. Services were classified as an 'Indigenous' or 'Indigenous friendly' service using set criteria.

**Results:** Eighty-three services (73.6%) completed the questionnaire. Mapping revealed services are located where there are relatively low percentages of Indigenous people compared with the whole population. No 'Indigenous-specific' services were identified; however, 11 services (13%) were classed 'Indigenous-friendly'. The primary support offered by these services was



'information'. Fewer referrals were received from Indigenous liaison officers compared with other health professionals. Only 8.6% of services reported frequently having contact with an Indigenous organisation; however, 44.6% of services reported that their staff participated in cultural training. Services also identified barriers to access which may exist for Indigenous clientele, including no Indigenous staff and the costs involved in accessing the service, but were unable to address these issues due to restricted staff and funding capacity.

**Conclusion:** Further research into the best models for providing culturally appropriate cancer support services to Indigenous people is essential to ensure Indigenous patients are well supported throughout their cancer journey. Emphasis should be placed on providing support services where a high Indigenous population percentage resides to ensure support is maintained in rural and remote settings. Further efforts should be placed on relationships with Indigenous organisations and mainstream support services and encouraging referral from Indigenous liaison officers.

**Key words:** access, Australia, cancer, health services, Indigenous, support services.

## Introduction

Indigenous people have a similar or lower incidence of total cancer compared with other Australians, though patterns of incidence vary by site<sup>1,4</sup>. Cancer mortality is generally higher for Indigenous people than for non-Indigenous people. While cancer survival for non-Indigenous Australians has increased, this has not been shared by their Indigenous counterparts<sup>5</sup>. Cancer survival in South Australia, Queensland (QLD) and the Northern Territory is lower for Indigenous people than non-Indigenous people<sup>2,3,6</sup>. The under-ascertainment of Indigenous status in censuses, health surveys, and administrative datasets across some jurisdictions is likely to mean that the burden of cancer in Indigenous people is underestimated<sup>7,8</sup>.

In QLD, Indigenous people have an overall 21% lower incidence of cancer<sup>9</sup>. Indigenous people are more likely to have aggressive cancers and be diagnosed at a later stage<sup>2,8</sup>. They are also more likely to have higher rates of co-morbidities, wait longer from diagnosis to surgery, have interrupted treatment patterns and reach death earlier<sup>2</sup>. Indigenous people are 36% more likely to die from cancer in comparison with the total QLD population<sup>9</sup>.

Given the disproportionate rate of survival between Indigenous and non-Indigenous people, and the multi-faceted

reasons for this, the need for systematic delivery of cancer control programs and services is important<sup>10</sup>. Systems of belief and perception about cancer directly impact on the care-seeking behaviour of Indigenous people<sup>5</sup>. Age, socioeconomic status, race, language and culture, attitudes and family composition are consistently identified as likely factors that may result in inequitable access to cancer services<sup>10</sup>. Additionally, a higher proportion of Indigenous people live in more rural and remote areas and thus also experience the difficulties associated with distance from their homes to major treating centres, including travel time, cost, accommodation and separation from support networks which have been documented as possible reasons for inadequate and interrupted treatment in other Indigenous populations<sup>10,11</sup>. Specific cultural barriers may also exist, including history of racism, lack of Indigenous staff, limited to no culturally appropriate information available, isolating hospital environments, differences in communication styles between patients and health professionals, and lack of understanding about Indigenous culture and life circumstance<sup>12</sup>. Thus the role that support services can play in facilitating these difficulties cannot be understated.

The aim of this study was to identify and describe the cancer support services available to all cancer patients in QLD. In particular, the suitability or potential cultural appropriateness of



these services for Indigenous cancer patients were examined and considered their location relevant to the population.

## Methods

### *Study design and sample*

The data reported here were collected in 2009 from a cross-sectional questionnaire of cancer support services in QLD. Support services were considered to be those that had the resources to help cancer patients with their physical, emotional, psychological and social needs, as well as providing information and practical support. The Cancer Council Queensland (CCQ) is considered to be the peak cancer advocating agency in QLD. The CCQ provides support and refers patients to support for their cancer, particularly through the cancer helpline. The cancer helpline database of all cancer support services and groups in QLD ( $n=344$ ) was ascertained. All services which met one of the following inclusion criteria were included: (i) had in their name or description included the word 'cancer' or an 'Indigenous term'; or (ii) included the words 'transport', 'accommodation' and/or 'financial'.

A snowball-sampling recruitment strategy was followed whereby services contacted from the CCQ list were asked to identify and provide details for other potential participants from among their own networks and acquaintances.

The manager from each service was contacted initially via telephone, a brief overview of the study was provided, and permission gained to forward a copy of the study questionnaire. The questionnaire was developed online using SurveyMonkey ([www.surveymonkey.com](http://www.surveymonkey.com)) which also acted as a data collection and storage tool. The questionnaire was forwarded either by email (with a web link and attached copies of the information sheet and survey), fax or post (at the discretion of the interviewee). Questionnaires completed via post, fax or email were entered into SurveyMonkey.

After 3 days from the initial point of contact, a follow-up phone call was made to ensure that the service had received

the questionnaire and to remind them it was due back within 7 days. At 7 days from the second contact a follow-up reminder phone call was made and, if requested, a second questionnaire was sent.

Questionnaires were completed by the Manager or relevant position (eg president etc) of the service.

### *Service classification*

The selected services were considered 'Indigenous-specific' if they only provided a service to Indigenous clientele or 'Indigenous-friendly' if they had provided a service to 10 or more Indigenous clients in the previous year or had a specific staff member available for Indigenous clients.

### *Analyses*

Data was downloaded from SurveyMonkey into Microsoft Excel 2007 and imported for analysis into SPSS v17.11 ([www.spss.com](http://www.spss.com)). Means were calculated, as were standard deviation (normally-distributed data), medians, range (non-normally-distributed data), inter-quartile range (IQR) and proportions. Using the service address (postcode), and Google Earth, the longitudinal and latitudinal coordinates of each service were derived. These coordinates were used to map the service location against 2008 population data reported for local government areas (LGA) to assess distribution of services in relation to the Indigenous population using ArcGIS v9.3. (<http://www.esri.com/software/arcgis/index.html>). Responses from open-ended questions were analysed separately by two investigators performing manual thematic analysis, and then cross-checked and combined to develop an overall interpretation of the data<sup>13</sup>.

### *Ethical approval*

Ethical approval for this study was obtained from the Human Ethics Committees of the Queensland Institute of Medical Research (#P1219) and the Australian National University (#2009/314).



## Results

There were 121 eligible services identified (five from snowballing), two were ineligible (did not service cancer patients), 113 agreed to participate in the study, and 83 completed a questionnaire. Eighty-three were included in the study (response rate 73.6% [83/119]) of which 36.1% of services returned the survey via the online option (SurveyMonkey).

### *Service characteristics*

The characteristics of participating services are summarised (Table 1). The majority of services were located in the South-east QLD region. Over two-thirds (67.1%) of the services were funded by a charity and/or religious organisations, and 32.9% were government funded (state, federal or both). All 83 services provided support to cancer patients, and some also supported their families and friends. The type of support offered by the participating services included providing information about cancer (75.9%), counselling (49.4%), transport (49.4%), financial aid (22.9%), assistance with equipment and care (15.7%) and accommodation assistance (13.3%; this could be paying for accommodation, providing accommodation or helping to locate suitable accommodation). All services delivered support face to face, 68.7% ( $n=57$ ) also delivered support by telephone and 50.6% ( $n=42$ ) provided support through information (eg pamphlets or brochures about cancer). Of the services included, 44% ( $n=36$ ) targeted specific cancer types, with the most common being breast cancer. The median number of staff employed was 1.5 ( $n=75$ , range 0-300 and IQR 0.0-16.0); however, 37.3% ( $n=28$ ) reported no employed staff (ie services were run entirely by volunteers). The median number of volunteers in a service was 17.5 ( $n=58$ , range 1-2500 and IQR 4.4-70.0).

### *Indigenous specific characteristics*

No 'Indigenous-specific' services were identified. Eleven services (13.8%) were considered 'Indigenous-friendly'. In the preceding 12 months, eight of the 'Indigenous-friendly' services saw a median of 28 Indigenous clients (range 10-500 and IQR 12.5-

63.8) and five services saw a median of 10 Indigenous cancer clients (range 3-20). Six services (8.1%) had at least one specific staff member designated to supporting Indigenous clientele; all of these staff were non-Indigenous. The service positions held by these staff were diverse (breast cancer nurse, psychologist, community development worker, president and secretary of support group). Only these 11 services of the 83 saw either Indigenous clientele or had a staff member specific for Indigenous clients.

Fourteen services indicated that their service employed an Indigenous staff member (range 1-10) although four of those did not identify the number employed. The use of strategies to encourage Indigenous clientele to use their services was reported by 32.5% of services. The most common strategy used was displaying Indigenous posters and artwork followed by the provision of support groups and targeted reading material. Thirty-five services (42.2%) had no strategies in place.

Services were also asked if their staff participated in cultural training ('Have your staff participated in cultural training/awareness/competency? If yes, please describe'), of which staff from 37 services (44.6%) reported they did. This training varied from general multicultural training, awareness days, mandatory training in cultural diversity from Queensland Health and workshops with Indigenous people and or Elders. There was a general consensus from services that did not provide cultural training to staff that 'all cultures are treated the same' or that they did not have the capacity to undertake this training. Additionally, services were asked to report if they had established working relations with local Indigenous organisations. Thirty-six services (43.4%) reported never having contact with an Indigenous organisation, 26 (31.3%) sometimes did, and seven (8.4%) frequently had contact. Fourteen services did not report on having contact with an Indigenous organisation. One-third of services (33.7%) had provided a service to an Indigenous person in the previous 12 months. The number of Indigenous cancer patients reported by these services ranged from 1 to 20.



**Table 1: Characteristics of cancer support services in Queensland**

Characteristic	Frequency <i>n</i> (%)
Region	<i>n</i> =83
South East	53 (63.6)
South West	10 (12.0)
Central	7 (8.4)
North	11 (13.3)
State-wide	2 (2.4)
Funding source	<i>n</i> =82
Government funding	27 (32.9)
Charity/religious funding	55 (67.1)
Support type	
Information about their cancer	63 (75.9)
Counselling	41 (49.4)
Transit assistance	41 (49.4)
Accommodation assistance	11 (13.3)
Financial aid	19 (22.9)
Equipment and care	13 (15.7)
Mode of delivery	
Face-to-face	83 (100)
Telephone	57 (68.7)
Staff	
Employ Indigenous staff	14 (18.7)
Staff specifically support Indigenous patients	6 (8.1)
Cultural competency	
No strategies	35 (42.2)
Strategies to encourage Indigenous access	
Indigenous posters / artwork displayed	16 (19.3)
Relevant reading material	13 (15.7)
Child friendly	9 (10.5)
Education programs	6 (7.2)
Support groups	14 (16.9)
Cultural training of staff	37 (44.6)
Cientele	
Client referral	
GP	52 (62.7)
Hospital staff	35 (66.3)
Indigenous staff	10 (12.0)
Community nurse	35 (42.2)
Family	45 (54.2)
Self	61 (73.5)

Services in this study documented a number of perceived barriers to Indigenous people accessing their specific cancer support service. A range of themes emerged including: a lack of awareness or knowledge about their service, lack of

referral, limited culturally appropriate resources including Indigenous staff, lack of confidence by Indigenous people described as 'shyness', and the cost involved in accessing their service.



Regarding client referral to the participating services, most were self-referral (73.5%), hospital staff (66.3%), GPs (62.6%), community nurse (42.2%) and families (54.2%). Fewer referrals were received from Indigenous health workers' (ILOs; 12.1%).

Mapping revealed services were located where the majority of the QLD population resides, in the south-east of the state. The services identified as 'Indigenous-friendly' were also located in the south-east, with fewer located in the northern and western parts of the state. The percentage of Indigenous people per LGA for all services and Indigenous-friendly services are presented (Figs 1 & 2, respectively).

## Discussion

The majority of cancer support services are located in South-east QLD, including those services identified as 'Indigenous-friendly'. Services were located in areas where the greatest absolute number of Indigenous people are, but were lacking in more remote areas where the percentage of Indigenous people is higher. Access to medical practitioners, health services and allied health professionals are limited for persons who live in rural and remote areas<sup>1</sup>. A recent review by van Schaik et al found that during cancer diagnosis and treatment stress is increased by a lack of social support networks if the patient must travel to and from hospital for treatment and with deliberation of costs, logistics, social obligation, emotional and physical distance and community isolation<sup>14,15</sup>. Areas identified by mapping where the proportion of Indigenous people is high tend to be more rural (and thus would have to travel for treatment) and without cancer support services. Indigenous cancer patients living in these rural areas will continue to suffer from the health, social and transport inequalities if a lack of support services is not available.

Most services were charity funded, indicating a potentially unstable source of support for cancer patients in QLD. Almost half the services target specific cancer types (eg breast

cancer), further restricting access to support to those patients with less common cancers.

There were no 'Indigenous-specific' services identified and only a handful of services were classed as 'Indigenous-friendly', and most did not have Indigenous staff. There were no strategies to encourage Indigenous clientele or cultural training for staff in over one-third of the services. Most referral was by self-referral or hospital staff and GPs, with fewer referrals from ILOs.

Utilization of official support services by cancer patients is generally low, which has also been reflected here by low numbers of Indigenous clientele accessing the support services in the preceding 12 months<sup>16,17</sup>. Support services should consider utilising ILOs and engaging with Indigenous community organisations to increase referral of Indigenous cancer patients. This may especially be useful to overcome any issues of distrust Indigenous people often experience regarding westernized medical systems by having an ILO refer the patient to a service that may not be Indigenous-specific<sup>12,15</sup>.

Information was the most commonly reported form of support; however, while providing information is highly valuable, it is unknown how relevant or appropriate this information is for Indigenous people. To ensure that the information provided is beneficial to Indigenous cancer patients, it should be easy to understand, culturally appropriate, and contextualised<sup>5,18</sup>. It is likely that the information currently provided by these support services is not culturally relevant to Indigenous patients due to the large proportion of services having no contact with local Indigenous groups and the considerable numbers of staff within services not participating in cultural training. This is an area that, if addressed, could vastly improve the support and knowledge for Indigenous cancer patients provided by these support services. This could be achieved by implementing and fostering relationships with local Indigenous groups to ensure the cultural adequacy of the information provided<sup>19</sup>.

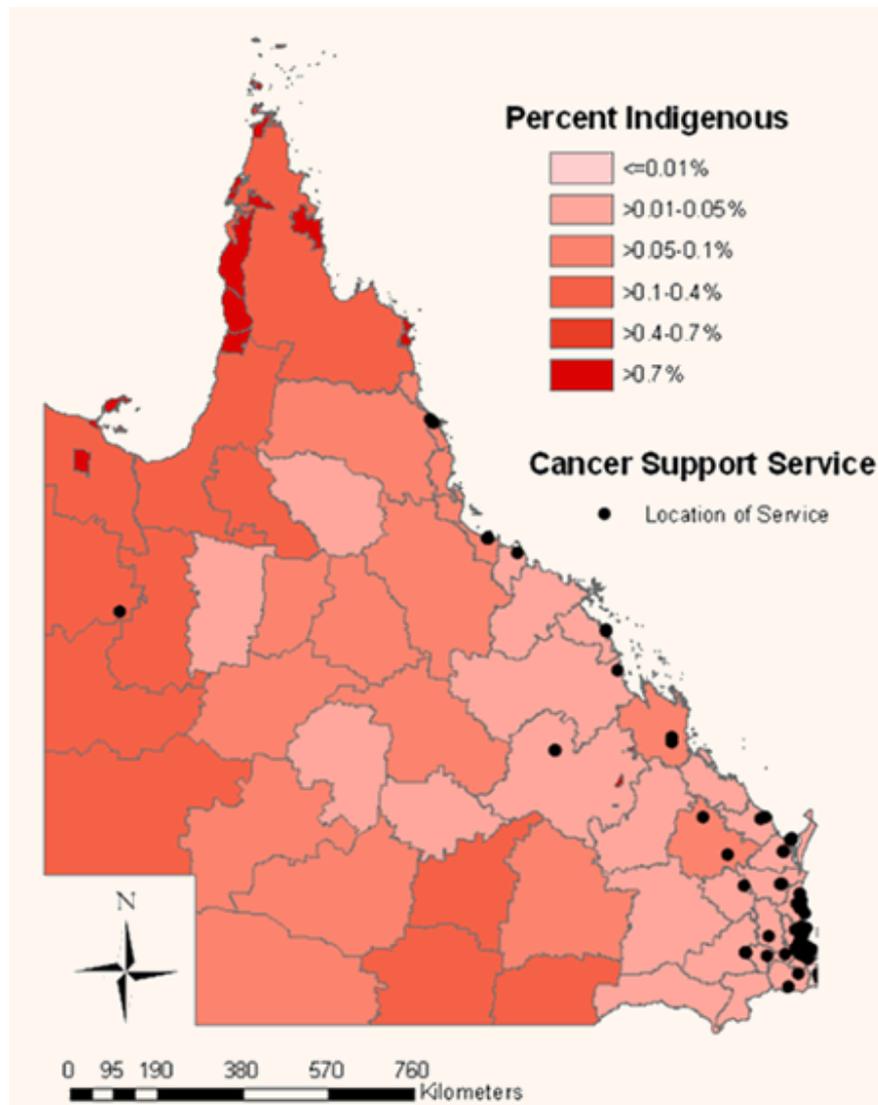
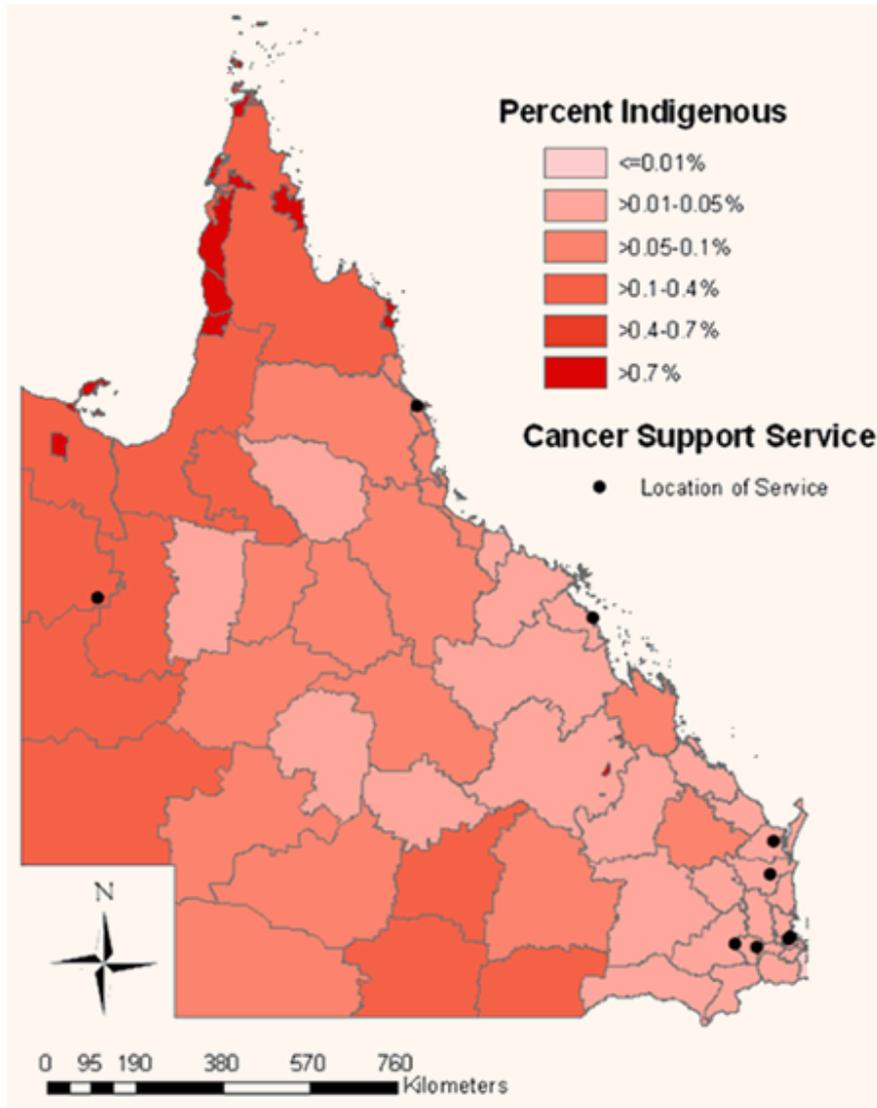


Figure 1: Location of all cancer support services in Queensland and Percentage of Indigenous Australians by Local Government Area (2008).

Other barriers reported in the literature that affect Indigenous patients uptake of services include lack of Indigenous staff, lack of understanding about culture, language barriers, failure to establish ongoing relationships and differences in communication style<sup>12</sup>. The present study shows that fewer services offered practical support such as transport, financial assistance and accommodation and more

information based support, information that may not be culturally appropriate for Indigenous cancer patients. Most services could identify barriers to Indigenous patients accessing support but were restricted by capacity and funds to make changes that would address these barriers.



**Figure 2: Location of ‘Indigenous Friendly’ cancer support services in Queensland and Percentage of Indigenous Australians by Local Government Area (2008).**

It is likely that these identified barriers can influence treatment decisions<sup>14,20</sup>. Appropriate support services have the capacity to improve Indigenous cancer patients experiences by supporting and assisting better access to care. Further research into the use of support services by Indigenous cancer patients is vital to understanding gaps which currently exist in the lack of Indigenous

clientele using existing services demonstrated in this study. Furthermore, increasing culturally safe environments in mainstream support services is recommended as an important step. Fostering relationships with ILOs, local Indigenous health organisations and Elder groups in community and



hospital settings is central to supporting Indigenous cancer patients.

## Limitations

A notable limitation of this study is the selection of services from the CCQ database, which may mean some services were not included in the study. The CCQ is the central place for cancer patients' referral for support services; therefore, its database of services is likely to be comprehensive. In addition, given the use of snowballing, it is anticipated that selection bias has been limited. Some services did not complete the questionnaire and were not included in the study. There is no way of knowing how these non-responders differed from participating services. Recall bias should also be considered when interpreting these results because the numbers of staff and volunteers may have been reported from the manager's memory rather than from official records. Furthermore the number of Indigenous clients who accessed the service should be interpreted with caution because most services did not identify Indigenous status. Thus it is unclear as to how those estimates were made.

## Conclusions

There is much room for improvement in supporting Indigenous patients in QLD who have cancer. The known barriers documented in this study should be addressed. Greater emphasis should be placed on providing support services where a high percentage Indigenous population resides to ensure support is maintained in rural and remote settings. Further efforts should be placed on establishing and developing relationships between Indigenous organisations and mainstream support services, and also in encouraging referrals from ILOs. Further research should be undertaken into the best models for providing culturally appropriate cancer support services to Indigenous people. These improvements are essential to ensuring

that Indigenous patients are well supported throughout their cancer journey, in order to achieve higher rates of survival for Indigenous cancer patients in QLD.

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