

# Improving outcomes for Aboriginal and Torres Strait Islander people with cancer requires a systematic approach to understanding patients' experiences of care

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**Abstract.** Indigenous Australians experience a greater burden of cancer than other Australians, but there is little systematic information about their experiences of cancer care. Patient-centred care is increasingly recognised as one of the core domains of quality care, alongside clinical effectiveness and patient safety. Qualitative studies have identified significant issues relating to Indigenous patients' experiences of cancer care, but these data are often insufficient to inform and evaluate health service improvement. We need to establish appropriate methods that will lead to systematic, routinely collected, accurate, population-based data on the experiences of care of Indigenous people with cancer, and determine how best to translate these data into improvements in the delivery of care to this population. Genuine Indigenous leadership and involvement will be necessary, with the whole approach underpinned by the primary aim of improving health outcomes for this population.

## Introduction

A growing body of evidence indicates that Aboriginal and Torres Strait Islander Australians (hereafter respectfully referred to as Indigenous Australians) experience a higher burden of cancer than other Australians, with higher mortality rates (for all cancers combined and for some specific cancers), a higher incidence of cancers with poor prognosis, more advanced disease at diagnosis, higher rates of comorbid conditions and lower survival.<sup>1-4</sup> Less well understood is how Indigenous people experience their cancer care. In particular, we know little about whether, or to what extent, the care they receive is patient centred.

Patient-centred care is increasingly being recognised as a critical element in quality healthcare, alongside safety, effectiveness, timeliness, efficiency and equity.<sup>5,6</sup> When care is patient centred, the patient's needs, values and preferences are not only respected, but are integral to clinical decision making.<sup>5</sup> This has obvious relevance for Indigenous Australians, whose needs, values and preferences may differ from those of other patients, including other Indigenous patients. The evidence base supporting patient-centred care is growing,<sup>6</sup> and there is evidence that positive patient experiences are associated with improved clinical effectiveness and patient safety.<sup>7</sup>

## Patient-reported experience measures in cancer care

Determining whether the care provided by health services is patient centred requires an understanding of experiences of care from the patient's perspective. Numerous instruments have been developed to collect information on various aspects of a patient's experience for a variety of health conditions.<sup>8</sup> The focus can range from improving the care of an individual patient in real time to population-based surveys aimed at improving the delivery of health services. With regard to cancer, large-scale population-based patient surveys have been undertaken in many countries, including the UK,<sup>9</sup> Canada,<sup>10</sup> Norway,<sup>11</sup> the US,<sup>12</sup> Germany<sup>13</sup> and New Zealand.<sup>14</sup> For example, the UK's National Health Service (NHS) has used an 80-item mailed questionnaire to collect information on the experiences of care of approximately 70 000 cancer patients over several

years.<sup>9</sup> This has allowed comparison of patient experiences across demographic groups, including by ethnicity, and the identification of disparities in the cancer care journey.<sup>9</sup> The NHS survey tool has recently been adapted for use in some Australian jurisdictions, to enable pilot surveys of cancer patients to be undertaken.<sup>15-17</sup> In another jurisdiction, work is underway to use patient narratives to develop a measurement tool for Indigenous cancer patients for close to real time use.<sup>18</sup> In addition, Cancer Australia is currently developing a set of national indicators for cancer care, including indicators relating to patient experiences.<sup>19</sup>

Although these activities may eventually add to our understanding of patient experiences at a national or jurisdictional level, there are important limitations. For example, the extent and scope of the data to be collected may not match what is needed to drive service improvement, and there is a risk that the approach will be focused on particular organisational units (service centred) rather than on the whole life of the patient (person centred).<sup>20</sup> Importantly, it remains unclear whether the experiences of Indigenous people with cancer will be adequately captured through the surveys currently under development. There may be no single 'best' strategy, and it is possible that a variety of complementary methods will be necessary to gain a full understanding.

### **What do we know about Indigenous patients' experiences of cancer care?**

There is a small but rich body of qualitative work examining the experiences of care of Indigenous Australian cancer patients, their carers and health professionals, as summarised in a recent literature review.<sup>21</sup> These studies have highlighted several key areas of concern, such as communication, service access, cultural wellbeing and health literacy. Respect for the individual patient and his or her cultural perspective, a key element of patient-centred care, was regularly cited as being central to the patient's experience in these qualitative studies. Although these data are valuable in illuminating the lived experiences of Indigenous patients, they do not provide the sort of robust, systematic, routinely collected, comparable, population-based data that are required to direct and evaluate large-scale service improvements.

### **What next?**

Our ultimate aim is to improve outcomes for Indigenous people with cancer by ensuring the best possible care. Although data alone are not sufficient, the delivery of patient-centred cancer care to Australia's Indigenous people will be compromised if we do not understand the experiences of care for this population. Research is urgently needed to establish the most effective and appropriate ways for understanding Indigenous patients' experiences and the resulting methods need to be integrated as far as possible with systems being developed for the general population. Meaningful Indigenous leadership and involvement is critical across all aspects of the research. Important methodological issues need to be addressed, including the suitability of existing tools, the mode and timing of delivery, sample selection etc. Consideration of how the data will be used to inform changes in service delivery is necessary and the data collection shaped accordingly. Although our immediate concern is the care of Indigenous cancer patients, this work is likely to be applicable more broadly, particularly to other Indigenous patient groups.

Indigenous Australians with cancer have a right to high-quality healthcare, as do all Australians. However, without good data on patients' experiences of care, it remains difficult to know whether they are actually getting it.

### **Competing interests**

None declared.

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