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## Measuring cancer care experiences of Aboriginal and Torres Strait Islander people in Australia: Trial of a new approach that privileges patient voices

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## Measuring cancer care experiences of Aboriginal and Torres Strait Islander people in Australia: Trial of a new approach that privileges patient voices

### Cover Page Footnote

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## Measuring cancer care experiences of Aboriginal and Torres Strait Islander people in Australia: Trial of a new approach that privileges patient voices

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### Abstract

This study examined a new method for measuring the care experiences of Aboriginal and Torres Strait Islander people with cancer: the Indigenous People's Experiences of Cancer Care Survey (IPECCS). The study assessed IPECCS: 1) performance; 2) ability to elicit information useful for service improvements; and 3) implementation potential. Three participant groups were recruited from five Australian cancer treatment sites: 1) Aboriginal and Torres Strait Islander people with cancer (+/- support person); 2) interviewers; and 3) health services staff. Trained interviewers administered IPECCS to participants with cancer in audiotaped sessions. Paper forms and transcripts were compared to assess performance, and problems/potential solutions reported by participants with cancer were assessed for actionability. All participant groups completed separate interviews regarding IPECCS. Selected implementation measures were assessed based on interviews and IPECCS administration. Participants (n=31) included 11 Aboriginal people with cancer, 7 support people, 4 interviewers, and 9 health staff. Aboriginal people with cancer spoke at length about their cancer care experiences and identified problems and potential solutions that could be acted upon by health services. Although some parts of the IPECCS form were well-completed, recording was inconsistent and inadequate. Aboriginal people with cancer and interviewers predominantly supported the IPECCS process; while most health staff supported the aims, they questioned its feasibility. Capturing domains of patient experience relevant to Aboriginal and Torres Strait Islander people requires a culturally safe, strengths-based approach. The tension between facilitating meaningful patient engagement and maximizing the efficiency of data collection and use must be resolved to realise the benefits of such an approach.

### Keywords

Indigenous, Aboriginal, Torres Strait Islander, First Nations, Australia, patient experience, patient- and person- and family- centred care, measurement, cancer, quality of care, health care

### Background

The adoption of person-centred care (PCC) in health service delivery has been accompanied by growth in assessment of patients' healthcare experiences,<sup>1,2</sup> which is a key component of knowing whether PCC has been delivered.<sup>2</sup> The consumer perspective is embedded in Australia's health system<sup>3,4</sup> as a core pillar of safe, high-quality care<sup>3</sup> yet there is evidence that the voices of some patient groups are less likely to be heard. Previous research has identified Indigenous people,<sup>5-7</sup> those living in rural areas,<sup>5</sup> or with chronic illness,<sup>5</sup> amongst others, as patients whose perspective may not be captured in routine survey-based patient experience data collection.

Aboriginal and Torres Strait Islander (hereafter respectfully referred to as Indigenous) people in Australia continue to experience an unacceptably high burden of

disease.<sup>8</sup> Healthcare for Indigenous people in Australia occurs in a context of ongoing colonisation,<sup>9</sup> amid a system that is yet to fully embrace a strengths-based approach to healthcare<sup>10</sup> and that does not reflect the holistic approach to health of many Indigenous people.<sup>11</sup> Disparities in cancer outcomes between Indigenous people and non-Indigenous people in Australia persist across the cancer continuum.<sup>12</sup> Action is required across all health system levels to address such disparities, however meaningful input from Indigenous people is a critical factor in designing effective strategies that address shortcomings in care by harnessing consumers' strengths and knowledge.<sup>10</sup> As an important marker of healthcare quality<sup>13</sup> and reflection of genuine person-centred care,<sup>2,6,14</sup> measuring the experiences of Indigenous patients is an integral part of improving outcomes.

Effective patient experience measurement requires consideration of the cultural context and social reality in which Indigenous people experience their cancer diagnosis and care,<sup>15-17</sup> and how these factors influence cancer treatment decision making.<sup>18</sup> Cancer diagnosis and treatment results in extended disruption to family and community life, which is a central aspect of life for many Indigenous people.<sup>19</sup> In Australia, this is compounded by geographical and other factors that compromise access to care and reduce engagement with care.<sup>20</sup> The presence of Indigenous staff is an important contributor to successful engagement of Indigenous people with their health care.<sup>21, 22</sup> However, significant underrepresentation of Indigenous people in the Australian health care workforce<sup>15, 23</sup> persists and contributes to a lack of cultural safety in health services.

Many negative experiences can be ameliorated, and appropriate supportive measures put in place, if problems experienced during cancer care are identified. There are increasing efforts in Australia to ensure that the perspectives of Indigenous people are reflected in patient-reported measures that contribute to health service improvement, including patient experience measurement. These include supportive cancer care needs;<sup>24</sup> wellbeing;<sup>25</sup> health related quality of life;<sup>26</sup> social and emotional wellbeing;<sup>27</sup> and recently, hospital-based cultural safety<sup>28</sup> and patient experience.<sup>15, 29</sup> These developments have potential to increase measurement specificity so that the unique healthcare interactions and experiences of Indigenous people are captured, thus enabling health services to develop appropriate improvement strategies.

Health-related research with Indigenous people consistently highlights the importance of 'Yarning' as an accepted and legitimate research tool.<sup>15, 30, 31</sup> (Yarning is a widely used term for an Indigenous style of conversation and storytelling.<sup>32</sup>) This culturally respectful approach allows time for engaging, building relationships, and developing trust,<sup>30</sup> which is at odds with the widespread reliance on electronic administration of surveys in health services. There is clear evidence of deficiencies in survey approaches<sup>5, 33, 34</sup> including the likelihood of missing relevant content,<sup>7</sup> particular population groups,<sup>6, 7</sup> and important nuances of patient experiences.<sup>5</sup> Further, surveys do not routinely elicit patient-reported remedial strategies, which may limit the extent to which the data can inform improvement efforts. Analysis of text generated by 'open ended' questions, an aspect of surveys that continues to develop,<sup>35</sup> may mitigate the superficiality of survey-driven data to some extent. However, offering consumers different methods of providing feedback is consistent with a PCC approach and there is evidence that alternative methodologies are preferred by many Indigenous people in Australia.<sup>7, 15</sup> The need for streamlined population-based patient experiences data and systems that enable responsiveness to the data is

undisputed, however it is important that the human aspect of health care is not lost in the transition to digital data collection.<sup>2, 36</sup>

The policy imperative driving efforts to improve both cultural safety<sup>37-40</sup> and the collection and use of patient-reported experience measures<sup>38, 41</sup> for Indigenous people in Australia is well established. The study reported here is part of a program of work aimed at improving systematic monitoring of the care experiences of Indigenous people with cancer, which emerged in response to issues outlined above. The work was guided by recognition of the strength and resilience of Indigenous people, and the need to ensure that their voices were privileged, as this is imperative to drive effective health care improvement strategies.<sup>10, 42, 43</sup> Early work by our team sought to determine aspects of cancer care important to Indigenous people and how they should be measured.<sup>15</sup> This work enabled identification of gaps in existing measures<sup>44</sup> and development of a new tool and approach to measuring the care experiences of Indigenous people with cancer: the Indigenous People's Experience of Cancer Care Survey (IPECCS) (available from corresponding author on request).

This study examined initial testing of the IPECCS and sought stakeholder feedback regarding its implementation. Implementation research methods guided the study as they are appropriate for 'real world' testing with the primary audience, and enable detection of context-specific factors that require consideration.<sup>45</sup> The primary aims were to: 1) assess the performance of the IPECCS; 2) determine the extent to which the IPECCS process elicited information that could assist health services to improve patients' experiences; and 3) assess the potential for IPECCS implementation (based on selected implementation outcome variables,<sup>45</sup> outlined below).

## Methods

### *Ethical considerations*

The study received institutional ethics approval from the Human Research Ethics Committee (HREC) of the Northern Territory Department of Health and Menzies School of Health Research [2018-3070]. Approval from the relevant HREC and Research Governance Office of each site was also obtained, including the Aboriginal Health and Medical Research Council of New South Wales [1412/18]. The study design was informed by the Australian National Health and Medical Research Council's guidelines for *Ethical conduct in research with Aboriginal and Torres Strait Islander Peoples and communities*, and the six core values of reciprocity, respect, equity, responsibility, cultural continuity, and spirit and integrity.<sup>46</sup> The study was reviewed and supported by the Indigenous Cancer Research Advisory Group at Menzies School of Health Research.

**Study setting**

The study was conducted in 2018 by a team of experienced Indigenous and non-Indigenous researchers. A local investigator and interviewer/s were involved at each site. Sites were eligible if they provided cancer services to Indigenous people with cancer and had staff who were able to support the study as local investigators. Potential sites from diverse settings (e.g., primary health care and tertiary services, in urban and regional locations) were identified through existing networks of the research team, and five sites across four jurisdictions were ultimately included (two sites, a tertiary hospital and a cancer-specific treatment centre, were situated together with one pool of potential participants).

**The Indigenous People's Experience of Cancer Care Survey (IPECCS)**

The IPECCS was designed to assess Indigenous people's experiences of their cancer care and to prioritise Indigenous patients' voices. The IPECCS aimed to honour the preference for 'Yarning'<sup>32</sup>, while facilitating collection of actionable patient experience data using a pathway-oriented (rather than service-oriented) approach.

The IPECCS began with several closed-ended questions (Q1-20), then moved to open-ended assessment of 16 aspects of cancer care (Q21-36) (Table 1). For each aspect of care, the interviewer invited the participant to talk about their experience, listened to the person's story and, with participant input, determined whether there was a problem. If so, the interviewer recorded the nature of the problem, where the problem occurred (which service/staff role), and the participant's ideas about what would have improved the situation. If no problem was identified, the interviewer recorded this and moved on to the next question. This approach was informed by the Here and Now Aboriginal Assessment (HANAA),<sup>47</sup> a social and emotional wellbeing screening tool developed in Australia with and for Aboriginal people.

**Participants**

Eligibility and recruitment procedures for the three participant groups are outlined below. All participants were  $\geq 18$  years old, able to complete an interview in English and gave written consent to participate.

**1) Indigenous people with cancer and support people**

Indigenous people with cancer were eligible if they were well enough to undertake the interview and diagnosed with any cancer (initially in the past 12 months but this was later extended to the past 24 months to aid recruitment). Interviewers, who were employed by the overseeing institution, liaised with local investigators at each site to identify potential participants. Following introduction to the study by local investigators or their delegate, potential participants were given more information about the study by the interviewer and, if they agreed, consent was

obtained. Support people were included at the participants' discretion. Participants' contributions were acknowledged through the provision of an AUD\$50 gift card under conditions stipulated by the institutional HREC.

**2) Interviewers** were recruited based on having appropriate interpersonal skills to undertake sensitive interviews with Indigenous people and the ability to establish a trusting rapport with interviewees. Where possible, interviewers were Indigenous people local to the site area, with interviewing experience and/or health knowledge. Following completion of interviews with people with cancer and support people, each interviewer took part in a structured interview with MG to explore their perspectives on the process.

**3) Health services staff** were eligible if they had involvement and knowledge which enabled informed comment on patient experience measurement processes and feedback mechanisms in health and supportive care for Indigenous people with cancer. Identification of and contact with potentially eligible participants was facilitated by local investigators. Staff were formally invited to participate by MG or the local interviewer.

**Interviewer training**

The interviewer training protocol included orientation to the study background, ethics and governance issues, the study protocol and other documentation, informed consent processes, audio recording procedures, data security and management of study documents, field notes and the IPECCS instruction booklet and questions. Training was primarily by phone and at least two mock interviews were conducted between MG and the interviewer. This continued until the interviewer was comfortable to proceed with recruitment of potential participants and interviews.

**Data collection**

Interviews with three participant groups (Table 2) were conducted to assess the IPECCS and the process of using it. Face-to-face interviews were arranged where possible, though phone interviews were permitted. Interviews were audiotaped, professionally transcribed and checked against the audio file by MG, then provided to participants to check for accuracy and provide feedback if desired. Participant transcripts were available only to the relevant participant and the study team. The second last question of the IPECCS interview asked if participants wanted contact with health staff about anything that had been talked about. The IPECCS included guidelines for the interviewer if this was requested.

**Table 1. Overview of the Indigenous People's Experience of Care Survey (IPECCS)**

Section (Question numbers)	Topics
Guidelines for interviewers (N/A)	Interview guidelines; purpose of questions; prompts; background, acknowledgement of contents.
Screening question (1)	How person is feeling at the moment (to assess whether fit to participate).
About you* (2-9)	Aboriginal and/or Torres Strait Islander origin; year of birth; gender; main language; postcode; education; general health; comorbidities.
About your cancer** (10-20)	Stage in treatment; cancer type; when first diagnosed; whether understood explanation of what was wrong**; whether given written information**; whether offered written assessment and care plan**; whether asked to participate in a clinical trial; primary treatment site; whether asked about Aboriginal and Torres Strait Islander status; whether had access to Indigenous care providers; previous cancer diagnoses.
About your experiences of cancer care*** (21-36)	<p>Diagnosis; being asked about Aboriginal and Torres Strait Islander origin; cultural needs and cultural safety; seeing an Indigenous care provider; being away from home for diagnosis or treatment; involvement of family/friends; practical aspects of access to care (transport, accommodation, financial); time in hospital/treatment centre; communication with staff; information provided about illness/treatment; involvement in decision-making; care coordination; going home from hospital; supportive or palliative care; support services for family; carers' wellbeing.</p> <p>For each aspect of care, the same questions were asked, as shown below:</p>
	 <p><b>23. Cultural needs and cultural safety</b> Problem <input type="radio"/> No problem <input type="radio"/></p> <p><i>This includes things like: if you felt welcome and respected by staff ' if your cultural needs were met while in hospital ' if you felt culturally safe.</i></p> <p>a) Tell us about it:  <input type="text"/></p> <p>b) Which service or role/title?  <input type="text"/></p> <p>c) What would have made it better?  <input type="text"/></p>
Your experiences overall (37-40)	Up to three things you would tell someone close to you about your experience (positive or negative); any other comments; whether person wants to be contacted by health staff about issues raised; who was present at interview.

\* Q 2-9 Based on established measures.<sup>59</sup>

\*\* Q 13, 14, 15 Cancer Australia patient experience measures.<sup>60</sup>

\*\*\* Refers to cancer care experiences during most recent diagnosis: for each aspect of care listed, answer as per example Q23.

**Data management**

To ensure data integrity and assess the capacity of the IPECCS process to capture relevant patient experiences information, the following steps were followed:

- A) IPECCS data from the paper form was entered into a REDCap<sup>48</sup> database, then compared with transcripts by MG. Additional variables were created to capture relevant information contained in the transcript but not recorded on the form.

**Table 2. Participant groups, data collection and outcome measures**

Participant group	Data collection method	Topics	Implementation outcome variables <sup>45</sup>
Indigenous people with cancer +/- support person/s	a) Guided interview; IPECCS form completed by interviewer on paper.	Sociodemographic, health, cancer characteristics; Indigenous specific questions; cancer care experiences (see Table 1).	Acceptability Appropriateness
	b) Short follow-up interview immediately after (a).	General opinion; language; appearance; comprehensibility; comprehensiveness; mode of administration; modifications needed; recommend to others.	Acceptability Appropriateness Feasibility
Health services staff	Structured interview with MG or local interviewer.	Value; feasibility; challenges to routine use; data usefulness; responsibility for measurement; feedback mechanism.	Acceptability Appropriateness Feasibility Fidelity
Interviewers	Structured interview with MG.	General opinion; language; appearance; comprehensibility; comprehensiveness; mode of administration; modifications needed; recommend to others.	Acceptability Appropriateness Feasibility Fidelity

- B) A second researcher (JC) listened to each audiotaped interview with Indigenous people with cancer and completed a separate IPECCS form, which was also entered into REDCap.
- C) Two researchers (MG and JC) independently assessed the problems reported and improvement strategies suggested by Indigenous people with cancer and determined the extent to which health services would be able to use the information to improve patient experiences (actionability). Discrepancies were resolved through discussion between MG and JC. Interview transcripts and field notes were managed using NVivo11.<sup>49</sup>

### Analysis

- To assess the performance of the IPECCS form and process, individual items were classified according to whether they were: a) administered correctly; b) understood and accepted by interviewee; c) able to be answered in an interview context; and d) adequately recorded on the IPECCS form (classified as: Always; Usually; Approximately half the time; Sometimes; Rarely). For problems that were raised during the interview (based on the transcript), the recording of information on the IPECCS form during the interview was categorised as: Sufficient (essence of the problem was recorded on the IPECCS form well enough to enable interpretation or categorisation); Partial (problem was incompletely recorded on the form); or Not recorded (problem was not mentioned on the form). Discrepancies were resolved through discussion between MG and JC.
- To assess the extent to which the IPECCS process elicited information that would assist health services to improve the patient experience, IPECCS forms and transcripts were used to determine: a) the types of problems reported and their actionability; and b) whether remedial strategies suggested by participants were likely to be useful to health services in improving the patient experience.
- To assess IPECCS's implementation potential, thematic analysis of all participant interviews and field notes was conducted, based on the interview guides (available from corresponding author on request). Themes were mapped to selected implementation outcome variables<sup>45</sup> including: *acceptability* (whether stakeholders perceive that an intervention is agreeable); *appropriateness* (the intervention's perceived fit for a setting or target audience); *feasibility* (the extent to which an intervention can be carried out in a particular setting or organisation); *fidelity* (the degree to which an intervention was implemented as designed in an original protocol); and resource use (as a component of *implementation cost*; cost of the implementation strategy and implementation itself was not possible for this study). Implementation outcome variables not assessed due to the preliminary nature of the study included *adoption*, *coverage* and *sustainability*.

## Results

### *Participants*

A total of 31 participants (11 Indigenous people with cancer and 7 support people; 4 interviewers; and 9 health service staff) were recruited from five sites. Participant recruitment was impacted by study factors (e.g. time, funding, geography), site factors (e.g. staff shortages, IT systems) and patient factors (e.g. medico-social reasons, competing priorities, survey and research fatigue). No information was available about those who did not participate.

Of the 11 Indigenous people with cancer, all were female, with an average age of 52 years (range 34-72 years). Breast cancer was the most common cancer type (n=6). Of the seven support people, five were female. Relationship of the support person to the person with cancer included: child (3); spouse (1); aunt (1); friend (1); unknown (1). The majority of interviews were conducted face-to-face (n=10) and they averaged 61 minutes length; this included both administration of the IPECCS (59:57 minutes) and the follow-up interview (1:41 minutes). Support person engagement was diverse: some participants added comments to the person with cancer's dialogue; others finished the interview due to fatigue of the person with cancer; another completed a separate interview entirely. Recruitment of Indigenous people with cancer across sites ranged from zero to six people (which was the target).

All four interviewers were Indigenous women. The average length of the follow-up phone interview with MG was 20 minutes.

Health services staff were from a range of senior and leadership positions; eight of nine participants were female. Average interview length was 20 minutes; seven were face-to-face.

The following results focus on IPECCS administration, problems and strategies reported, and participant feedback regarding implementation of IPECCS.

### **1) The IPECCS form**

Questions 1-20 of the IPECCS were 'always' or 'usually' administered correctly, understood and accepted by interviewees, able to be answered in an interview context and adequately recorded on the IPECCS form. In one site that provided services to a high proportion of Indigenous people, questions about the patient's Indigenous status were regarded as obvious and potentially unnecessary given the patient base. Questions 21-36 were designed to facilitate a guided narrative, with the interviewer categorising participants' experiences into the presence or absence of a problem, then, if relevant, collecting details about the problem and what could have improved the problem. While participants appeared happy to share their

stories, interviewers experienced considerable difficulties synthesising these stories and fully completing the IPECCS form in real time, particularly when problems were complex. The first three questions in this section (on diagnosis, being asked about Aboriginal or Torres Strait Islander status and cultural needs/cultural safety) were 'usually' administered correctly, understood and accepted by interviewees, able to be answered in an interview context and adequately recorded on the IPECCS form. However, for the remaining questions, these were the case 'about half the time' or 'rarely'. Almost half of the 'problem/no problem' circles were not completed, with wide variation across participants. Recording of answers on the form was inconsistent and reliance on the audiotape was evident in two interviews in which complex problems were described (e.g., "*listen to recording*" noted on the IPECCS form). Of the 56 separate problems reported (based on interview transcripts), 22 problems were sufficiently recorded on the IPECCS form during interview and a further 10 were partially recorded.

### **2) Reporting of problems and improvement strategies**

Several problems were reported by multiple participants, resulting in 34 distinct problems. These were evident across all aspects of cancer care and included: delays in diagnosis/treatment; lack of access to an Aboriginal Liaison Officer (ALO); financial and logistical barriers to care; inadequate information/communication; inadequate care coordination; and insufficient support for the patient, family and/or carers. Commonly, problems involved more than one aspect of care. A reported problem could, for example, be categorised as either or both of the following aspects of care: 'involvement of family and friends' and 'support for family and friends'. Problems often related to cultural needs or were specific to the experiences of Indigenous people, e.g., regarding access to Indigenous care providers or cultural safety. Participants also commonly reported positive experiences of care, including feeling welcomed in the service, access to appropriate services following discharge, and good coordination of care. Of the 34 problems reported, 30 were assessed as actionable by health services. Two problems were unable to be assessed due to insufficient information, and two (addressing specialist shortages in regional areas and a problem with a particular staff member) were considered partially actionable.

Many individual and service level strategies were suggested to address the problems reported by participants, although not every problem was accompanied by a proposed solution. Service level strategies included: having more ALOs; better explanations and/or communication strategies; assistance with transport and finance; inclusion of family in discussions; improved coordination between the cancer treatment centre and primary health care/allied health services; improved specialist services in regional areas; and better access to supportive care. Most service

level strategies were assessed as actionable, though a small number were unable to be determined, or considered partially actionable. Some were specific to Indigenous patients, such as requesting an ALO be involved in doctors' rounds in hospital, needing more ALOs and culturally respectful care. The capacity of some participants to influence their own experience was evident, with people reporting advocating for oneself, doing one's own research, organising family support, using bush medicine or going on Country. (Connection to Country reflects a spiritual, emotional and cultural relationship to land, central to the identity of Indigenous people in Australia.)<sup>19</sup> For other participants, the need for service-level strategies was apparent, as outlined above.

### 3) Implementation of IPECCS: overview and participant views

As noted above, Indigenous people with cancer demonstrated a strong willingness to talk about cancer care, and reported both positive and negative experiences, as well as strategies that did or could have assisted them. Reports from Indigenous people with cancer and interviewers strongly suggested that culturally appropriate processes contributed to this sharing of information. Participants explicitly mentioned that the opportunity to talk with an Indigenous person was a positive aspect of their involvement and some participants reported that they would not have shared all problems they experienced with non-Indigenous health staff. Although there were inconsistencies in interviewer technique and recording on the paper form, it was clear that participants were comfortable, felt respected, and engaged fully with the interview style. The skills and respectful approaches of the interviewers were integral to this. Discussion of sensitive aspects of cancer care meant that some interviews verged on a therapeutic discussion rather than merely collection of patient's experiences.

Feedback from participants regarding IPECCS characteristics and implementation outcome variables is detailed in Tables 3 (Indigenous people with cancer and their support people, and interviewers) and 4 (Health services staff), (see Appendix). Results are presented separately as the first two groups had direct experience of using the IPECCS, while health services staff only viewed the form. Across all participant groups, patient experience measurement for Indigenous people was seen as an important area to develop. The IPECCS was viewed as comprehensive, though some areas of duplication were identified. Indigenous people with cancer reported that the opportunity to talk with another Indigenous person about cancer care experiences was a key component of the process; three people (107, 304, 307) stressed it was the talking aspect that they would recommend to others, not self-completion. Most interviewers also supported the approach as documented in Table 3, however it was not seen as feasible to implement in its current form by health

services staff, primarily due to the additional resources required to conduct an interview (see Table 4, Appendix).

## Discussion

The IPECCS approach to measuring the care experiences of Indigenous people with cancer in Australia demonstrated that a culturally appropriate approach is a key factor in the reporting of sensitive health care experiences. The approach constituted more than simply testing a new questionnaire; it represented an attempt to prioritise Indigenous voices through an appropriately designed measure, while balancing health system realities. There are challenges regarding the efficient collection of patient experience data, particularly other than surveys, and further work is necessary to develop inbuilt mechanisms for the routine collection and use of patients' experiences that are meaningful to Indigenous patients. Meeting this challenge is consistent with a move to retain the humanity that is at the heart of health care.<sup>2, 36</sup>

Though the current study enrolled a small cohort, the problems reported by participants were largely consistent with other reports,<sup>7, 15, 20, 50, 51</sup> and predominantly reflected actionable areas for improvement. A strengths-based approach provides a mechanism for Indigenous people to meaningfully appraise and guide health services, helping to shift emphasis to strategies that make sense to Indigenous people and reflect their priorities.<sup>10</sup> Participants in this study who reported problems regarding their cancer care experience were asked what would have improved the situation for them; this aspect of the design was intended to align with a strengths-based approach. It was evident in the interviews that participants had pride and strength in being an Indigenous person. The individual and service level strategies suggested by participants included those specific to Indigenous people, such as increasing ALO access and attending to cultural needs, in addition to strategies that would improve cancer care experiences for all patients. These data support including consumers in planning health service improvement initiatives, rather than only identifying deficits. Alongside this, the data reflects the growing calls for the delivery of person-centred care to be more effectively implemented and measured in health services.<sup>2, 6, 52, 53</sup>

Indigenous people with cancer and interviewers predominantly supported the IPECCS process. There was tension in the feedback from health services staff, most of whom were supportive of the process but did not view it as feasible, primarily due to requiring an interviewer as the data collector. Several health services participants pointed out the imperative to collect this data despite its resource intensive nature. Numerous system-level considerations consistent with previous research were also pointed out by this participant group, such as the need for high-level endorsement and departmental authority to act on

measurement results.<sup>54-56</sup> Factors that would affect individuals' participation in experiences of care measurement were also raised by health services staff, such as patient fatigue, health at the time of measurement and appointments.

The Yarning approach was reported as acceptable to and appropriate for the key user group (Indigenous people), as was the content of the interview. Facilitation of an initial 'social yarn' (as distinct from the 'research yarn'), was very important in establishing a culturally appropriate approach. Bessarab and Ng'andu<sup>30</sup> describe this two-way sharing of information and establishing trust during the social yarn, as determining what will be told or withheld in the research interview. The process of incorporating relationship-building served to demonstrate respect and care for the individual. Jennings describes this as reducing "*the power differentials between Indigenous clients and the healthcare system*"<sup>257,p109</sup> and caring for these clients "*as human beings*."<sup>257,p114</sup> This underscores the capacity of such an approach to elicit more nuanced information than through other measurement approaches, which has been identified as a deficiency in Australian patient experience measurement.<sup>5</sup> Other elements that supported a culturally appropriate approach and may have contributed to the richness of the interviews included: an Indigenous interviewer; study procedures that ensured confidentiality; welcoming the participation of support people; and conducting the interview at a location of the participant's choice.

Fidelity to Indigenous research principles was sound, including providing both the physical space for sensitive interviews and the emotional safety provided by talking with an Indigenous person. These principles are particularly important given the historical and current context in which Indigenous people's healthcare is experienced, and the resultant lack of trust in the system.<sup>7, 15, 57</sup> Although there were inconsistencies in interviewer technique and recording on the IPECCS form, the engagement of participants and desire to share their stories was undeniable, indicating strong acceptability and appropriateness. In some cases, the depth of discussions held may indicate an unmet need for such support, though a culturally safe approach to addressing this is important.<sup>24</sup>

A number of feasibility challenges were identified including: interview length; synthesis of complex problems into categories that can be readily interpreted and acted upon; who undertakes the measurement, particularly considering the skills required; the need for confidentiality and separation from the service; and efficient data feedback to the service to facilitate action, which needs to be evident to patients and families.<sup>1</sup> These issues are complex for health services to address and underscore the need to measure patients' experiences in multiple complementary ways in order to capture the perspectives

of different populations including Indigenous people.<sup>6, 38, 53</sup> This is underpinned by evidence of persistent differences between patient experiences of Indigenous people and non-Indigenous people,<sup>50, 51, 58</sup> and the drive to build culturally safe health services in Australia.<sup>38</sup> The challenges mentioned above could be addressed when designing inclusive patient experience measurement systems, as it is likely that other populations are similarly underserved through overreliance on a survey approach.<sup>5, 6, 53</sup> Further, robust studies examining the impact of interventions that seek to improve health care quality through the use of patient feedback are warranted,<sup>52</sup> alongside incorporating the capacity to monitor changes over time.

Findings from this study, together with recently developed patient experience<sup>29</sup> and cultural safety<sup>28</sup> survey questions for Indigenous inpatients, could inform the development of a patient experience monitoring system that captures Indigenous voices. For example, following suitable validation, appropriate patient experience questions could perform a screening function, thus identifying individuals with more complex problems, who could be invited to take part in a more detailed exchange (either face-to-face, or via computer-based options e.g., Skype or Zoom). Such a system is likely to have application to patient-reported measures more generally and would benefit from also eliciting positive experiences and remedial strategies. This study has demonstrated that a Yarning approach is a crucial aspect, which may necessitate audio recording and subsequent completion of a digital survey. Similarly, existing approaches, such as using post-discharge SMS questions or volunteers at the bedside, could be employed to ask Indigenous people about known problem areas, such as logistical barriers, cultural safety, and involvement of family. The use of alternative methodologies such as voice memos may provide an avenue to collect care experiences of Indigenous people that are crucial. Those areas of care which consistently emerge from studies as problematic for Indigenous people could be the subject of an annual short term 'blitz' in patient experience measurement, incorporating the option of a discussion with an Indigenous person along the lines of this study. Clearly, further initiatives need to be developed with Indigenous people at the helm and underpinned by Indigenous research principles and design approaches.

### Limitations

The study was conducted in a limited number of sites with relatively small participant numbers. No Torres Strait Islander participants were recruited and it is not clear to what extent the results apply to other jurisdictions or to other Indigenous groups. Our sample may be biased as patients who experienced problems may have been more likely to participate. All Indigenous people with cancer and all interviewers were women, thus the study may not reflect the perspectives of Indigenous men. Although this

is a frequent pattern in studies of this nature, it is a gap that should be addressed in future, larger studies.

## Conclusion

There is a critical tension between facilitating patients to talk in detail about experiences that are important to them and maximising the efficiency and immediacy of data collection and use which needs to be resolved. This challenge is exemplified by the high value placed on face-to-face interaction by Indigenous people in Australia, contrasted with the widespread adoption of digital assessment of patient-reported experience measures by health services. Limitations of existing approaches need to be acknowledged, particularly as some patients have complex, multifaceted problems. It is recognised that in-person patient experience assessment may be difficult to operationalise within the existing health system and that significant steps have been taken to ensure the perspective of Indigenous people is captured via surveys. However, retaining the human face of health care and providing options for patients are important aspects of PCC. Further, failure to build evidence of both negative and positive health care experiences of Indigenous people and their ideas for improvement will limit the capacity of health services to take relevant action, which is likely to have serious consequences for a part of the population that already experiences a significant disease burden. Capturing domains of patient experience relevant to Indigenous people requires a culturally safe, strengths-based approach. While simply measuring patient experience will not improve care, it is a necessary first step and must include the perspectives of Indigenous people to drive improvement initiatives.

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## Appendix

Table 3. Summary of feedback about the IPECCS questionnaire and the interview process from Indigenous people with cancer and their support people, and interviewers

	Indigenous people with cancer and their support people (n=18)	Interviewers (n=4)
Aspect/characteristic (implementation outcome variables)	Summary of feedback Indicative quotes (source)	Summary of feedback Indicative quotes (source)
General opinion (acceptability, appropriateness)	Positive. Participants felt comfortable, respected. “... a good way [to ask about cancer care].” (102, 301); I'd encourage it... because you and I have a conversation. I feel very comfortable” (107); “It's relaxing; it's not intimidating” (302); “I was really nervous, but it's not as bad as I thought it would be” (303); “You were very polite, respectful and mindful of how I was going at all times.” (304)	Mostly positive (3 out of 4) “I think (the survey) is really important.” (804); “You've really hit the nail on the head with this survey” (801); “For our people, Indigenous people...it's almost like a tick a box and I don't think we want that. We want the real stories so that we can make changes and we want to leave the participant feeling empowered and strong, that their stories are being heard and listened to... we have to give back to participants, not just take their knowledge.” (802)
Language, comprehensibility (acceptability, appropriateness, fidelity)	Generally understandable. (Note: language was sometimes modified in the interview by the interviewer.) [Re words used] “Very good, and easy to understand.” (102) “they were good” (107) “They were fine for me, but might not necessarily be for all” (306) “Words were lovely - not too big or hard” (405)	Generally positive, some language changes suggested. “... a checklist would also make it easier to ask the question” “longer questions, (especially Aboriginal and Torres Strait Islander question) felt unwieldy” (Field Notes) (804); “rewriting in a way that is more easily understood .... in line with the way conversations occur” (802) “It's just like us sitting around like we're family having a conversation about this, instead of making it too structured (803)
Appearance (acceptability, appropriateness)	No changes suggested. (Generally happy with appearance of survey) “Looks good.” (101) “Very good, overall.” (102) “It looked good like that” (301)	Mixed. Insufficient graphics. Too many words. “beautiful” (801); “daunting... cold... so busy” (802); “I like the design and layout... The artwork, everything was appropriate” (803).
Process (feasibility, fidelity)	Overwhelming support for culturally safe approach used and for a face-to-face interview to gather information. “... (I'm) happy Yarning, this is a better way to do it ... than tick and the flick... This would be more engaging. I'd be distracted on the phone and ... more interested in what's on TV.... you'd get more responses and better outcomes from people in this forum than over the phone....” (302)	Mostly positive, though one interviewer had reservations. Process allowed for cultural protocols to be followed. Person who introduces the process is critical. “... if you get the process right, then the outcomes will come... there's a whole process around qualitative interviewing with Indigenous people that has to occur otherwise it's very superficial.” (802); “allowing that time to meet with these people and connect with them” (804); “I felt the connection immediately with all the participants. It provided a really culturally safe and sensitive way of doing things. It was cultural protocol that I followed that produced the good outcomes” (803).

**Table 3. Summary of feedback about the IPECCS questionnaire and the interview process from Indigenous people with cancer and their support people, and interviewers (cont'd.)**

	<b>Indigenous people with cancer and their support people (n=18)</b>	<b>Interviewers (n=4)</b>
Mode of administration <i>(acceptability, appropriateness, feasibility, fidelity)</i>	<p>Preferred option is face-to-face with an Indigenous person. Some acceptance of a staff member as interviewer.</p> <p>Explore digital options.</p> <p>(Note: relevant comments emerged in response to other questions.)</p> <p><i>"I prefer to do it with you."</i> (307)</p> <p><i>"... how you've done it here..."</i> (protect family; may not trust or have rapport with staff) (306);</p> <p><i>"I would find it too overwhelming... if I was to do it on my own."</i> (303)</p> <p><i>"...you were able to clarify a bit more"</i> (SP309)</p> <p><i>"Somebody (to) help me."</i> (102)</p> <p><i>"Sometimes I wouldn't understand. [Would rather complete survey] with other people..."</i> (family or hospital staff) (301).</p> <p><i>"I'd be less engaged with the hospital staff than what I would with you mob."</i> (302)</p>	<p>Preferred option is face-to-face with an Indigenous person.</p> <p>Test a digital version including Zoom etc., and offer different options for administration.</p> <p><i>"...definitely Indigenous people."</i> <i>"This is something where I can empower them and ... the most important thing that I can do is reassure them that I'm not there for them to be just another tick box. I'm there to listen."</i> (803);</p> <p><i>"People need to have options... Because it is about the patient. We have to accommodate the patient."</i> (801).</p> <p><i>"I think older people, they want to have a conversation, especially for what you're asking about... 'cause you sit with doctors and they're all tap tapping away and barely looking at you"</i> (804)</p>
Recommend to other Indigenous people with cancer? <i>(acceptability, appropriateness)</i>	<p>All respondents who were asked would recommend to other Indigenous people with cancer (the talking aspect, not self-completion).</p> <p><i>"And you've treated me both with respect and thank you for that."</i> (307);</p> <p>[If asked to self-complete] <i>"I'd look at it and get overwhelmed and wouldn't be able to do it. So many people have given me bits of paper... I've just looked at it and then started crying. I'm better talking face-to-face to people at the moment."</i> (304)</p>	<p>Three out of four interviewers would recommend.</p> <p><i>"I certainly would."</i> (801)</p> <p><i>"Not in the current form."</i> (802)</p> <p><i>"Yes I would."</i> (803) (804)</p>
Other considerations or suggestions <i>(feasibility)</i>	<p>Clarify relevant timeframe for some questions.</p>	<p>Ensure interviewers are appropriately supported.</p> <p>Retain instruction booklet and the question on 'what would have made it better'.</p> <p>Consider an item on the impact of connection to culture and Country on cancer experience (but may be too sensitive).</p> <p>Add an explanation of the art work.</p> <p><i>"...as Indigenous researchers, we also are living and researching within our communities, so we really need to have some support and structures put in place for particularly younger or less experienced qualitative researchers. I think that's something that needs to be put in place."</i> (802)</p> <p><i>"I think we need to always remember that within our communities, research has done a lot of damage and it needs to be a lot safer. We need to give back a lot more to our community people"</i> (802)</p>

**Table 4. Feedback from health services staff (n=9) about the IPECCS instrument and proposed process**

<b>Aspect/characteristic (Implementation outcome variables)</b>	<b>Summary of feedback Indicative quotes (source)</b>
General opinion ( <i>acceptability, appropriateness</i> )	Overwhelmingly positive but recognised challenges. Captures Indigenous voices (106, 203, 204); <i>“nice balance between structured survey and check boxes - flexible ..could be a very long interview, or it could be a very short one”</i> (202).
Process ( <i>feasibility, fidelity</i> )	Seen as important, but not feasible in current form. Need for an interviewer a challenge for routine use. [Using existing staff, it's] <i>“not going to happen”</i> (203); <i>“people will always say, we're time poor - if we're going to be patient-centred, it's imperative - how do we make the time”</i> (103).
Challenges ( <i>acceptability, appropriateness, feasibility, fidelity</i> )	At the service level: high level support necessary, departments need authority to respond to data. At the individual level: patient fatigue, health and appointments. <i>“... if you had the wrong person administering this, people will say nothing; they'll be silenced.”</i> (202)
Usefulness of data ( <i>appropriateness, feasibility</i> )	Data generated would help shape services. Process may detect problems not otherwise revealed. Staff belief regarding their control over problem identified will affect data use. Support for inclusion of 'What would have made it better?' question. May be useful for non-Indigenous population. <i>“Framing of the questions was good”</i> (510); <i>“lot of value in the questions”</i> (203); [Likely to be lots of] <i>“easy quick fixes”</i> (202).
Feedback mechanisms ( <i>feasibility</i> )	Use existing feedback systems. <i>“If you're not going to act on it, you ... don't ... have any business administering it.”</i> (202).
Other comments ( <i>feasibility, fidelity</i> )	'Blitz' certain aspects known to be problem areas (e.g., 'transition home' or 'communication') for short periods of time. Develop abridged and smartphone version. Consider measurement timing and response variability as patient progresses. <i>“...if we're not asking the right questions to the right population in the right way we're probably not drawing the right information out to make changes to our service to ensure that everybody is receiving the service that ... is appropriate for them.”</i> (108).