Utilising the CREATE quality appraisal tool to analyse Aboriginal and Torres Strait Islander peoples' involvement and reporting of cancer research in Australia

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Abstract

Objective: We aimed to evaluate Aboriginal and Torres Strait Islander involvement in research focusing on cancer experiences using an Aboriginal and Torres Strait Islander quality appraisal tool (the QAT).

Methods: We conducted a systematic review of the peer-reviewed literature on Aboriginal and Torres Strait Islander peoples' experiences associated with cancer, recently published elsewhere. We then appraised articles for the inclusion of Aboriginal and Torres Strait Islander-led research, community consultation, and involvement.

Results: 91 articles were appraised. A lack of Aboriginal and Torres Strait Islander-led research and consultation was reported in the majority of articles, only 10 (11%) demonstrated success across seven (50%) or more questions of the QAT.

Conclusions: This review underscores the need for anti-racist research and publication practices that actively engage Aboriginal and Torres Strait Islander peoples and researchers. This approach is vital to enhance cancer outcomes within these communities.

Implications for public health: To advance and prioritise appropriate involvement of Aboriginal and Torres Strait Islander peoples in cancer research, the onus must be on 'systems owners,' including academic journals and institutions, to require and report genuine engagement as standard practice. Researchers will produce higher-calibre research with a strengths-based focus, advancing the cause of equitable research.

Key words: Aboriginal and Torres Strait Islander, Indigenous, self-determination, quality-appraisal, cancer

Background

NB: This article uses the term 'Aboriginal and Torres Strait Islander peoples.' However, some examined articles use the term 'Aboriginal' or 'Indigenous', which will be maintained if used by the authors.

In Australia, cancer outcomes differ significantly between Aboriginal and Torres Strait Islander and non-Indigenous peoples, with Aboriginal and Torres Strait Islander peoples 14% more likely to be diagnosed with cancer.[1] Aboriginal and Torres Strait Islander peoples also experience increased mortality and poorer cancer outcomes compared to non-Indigenous people.[1] The positive impact of genuinely involving Aboriginal and Torres Strait Islander voices in research and decision-making is well-established[2]; therefore, research must be conducted with Aboriginal and Torres Strait Islander leadership and involvement and appropriate support from academic journals to enable authors to disclose their cultural affiliations. Community-led approaches to cancer research may improve outputs, such as health promotion activities, advocacy, and preventive care approaches, thereby improving outcomes for Aboriginal and Torres Strait Islander peoples.

The use of culturally appropriate quality appraisal tools (QATs) is an important methodological requirement to assess research in a way that is inclusive of Aboriginal and Torres Strait Islander peoples' culture and values. Most QATs use Western research principles and ideologies to appraise research quality and design and

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do not typically consider the needs of study participants and their communities.[3,4] The Aboriginal and Torres Strait Islander QAT is a culturally appropriate tool that can be used to assess research.[3] An increased use of culturally appropriate QATs could ensure a strengths-based approach is taken, benefitting health outcomes for Aboriginal and Torres Strait Islander peoples.[4]

Objectives

This review assessed Aboriginal and Torres Strait Islander-led research and consultation in peer-reviewed articles related to cancer experiences using the Aboriginal and Torres Strait Islander QAT, developed by the Centre of Research Excellence in Aboriginal Chronic Disease Knowledge Translation and Exchange (CREATE) Methods Group.[5]

Materials and methods

In 2020, Cancer Council Australia (CCA) recruited two Aboriginal and Torres Strait Islander researchers (JG and MH) to assist CCA to improve its cultural competency and policy advice relating to cancer in Aboriginal and Torres Strait Islander populations. JG and MH, in partnership with CCA, commenced a systematic review and quality appraisal of existing research regarding Aboriginal and Torres Strait Islander peoples' experiences of cancer. The two key outputs were a systematic review of cancer experiences and supportive care needs using traditional Western methods, published elsewhere,[6] and this evaluation of the quality of research about Aboriginal and Torres Strait Islander cancer experiences.

JG, a Yuin man from the NSW South Coast and Professor of Sociology in Indigenous Health, specialises in disability studies. JG has extensive experience in disability and ageing research and community development with Aboriginal and Torres Strait Islander communities, government, and non-government stakeholders. JG is passionate about Aboriginal-owned and driven research in influencing policy. MH, an Indigenous scholar living on Dharug country in NSW, is a lecturer at the University of Sydney and a dedicated LGBTIQA+ advocate and researcher in sexuality, sexual health, Indigenous studies, intersex studies, youth, and mental health in the Department of Sociology and Social Policy. Both researchers bring a multidisciplinary lens and provide insights into the lived experiences of marginalised populations.

The CCA Cancer Control Policy team (JM, DM, AM and TB) brings a multidisciplinary lens with backgrounds in health care policy development across the cancer continuum.

Data synthesis and quality

We utilised the QAT to appraise 91 articles from an Aboriginal and Torres Strait Islander-informed perspective. The QAT has been tested for its rigour and cultural veracity,[4] and the questions are informed by Aboriginal and Torres Strait Islander peoples' values and ethics, so research can be appraised through this lens.[4] The questions are answered as "yes", "no", "partially" or "unclear" based on the evidence provided in the article being appraised.[4]

The QAT Companion Document (the Companion Document) was utilised to determine the appropriate response to each question and resolve discrepancies between authors. The Companion Document includes definitions of key terms used, indicators that would support a 'yes' response, and examples that help support consistency of responses.[4] Half the articles were appraised by the two Aboriginal authors (JG and MH); the other half were independently appraised by two non-Indigenous authors (JM and DM), with discrepancies resolved by discussion. A 'yes' response was given when clear and demonstrable evidence of the article meeting the question's criteria was met. A 'partially' response was given if there was evidence of work towards meeting the criteria and 'unclear' was given when there was insufficient detail provided to assign a definite response. A 'no' response was given when there was no evidence to indicate the criteria had been met or the article did not meet the criteria.

This tool is used to appraise research quality in terms of the values and ethics of working with Aboriginal and Torres Strait Islander communities, such as the National Health and Medical Research Council Aboriginal and Torres Strait Islander research protocols.[3,7] The tool appraises how research was conducted and the levels of participant involvement. Therefore, the aim of this research is to assess the methodological quality of the included articles using an Indigenous epistemology.

Results

Characteristics of included articles

Of the 91 articles included, 51 were quantitative, 31 were qualitative, seven were quantitative-descriptive, and two were mixed methods. The detailed characteristics of the articles are in the supplementary material (Table S1). Most qualitative articles explored the perceptions, beliefs, and experiences of Aboriginal and Torres Strait Islander peoples living with cancer, including barriers to accessing care,[8–25] understanding the perspectives of health care providers and care givers,[26–30] and the role of Aboriginal and Torres Strait Islander health care workers in providing culturally appropriate health care.[31–33] Most qualitative articles used in-depth interviews and Yarning methods to collect data, as accepted culturally appropriate and respectful methodologies in Aboriginal and Torres Strait Islander research. [34,35] Of the quantitative articles, five assessed outcomes in children; [36–40] the remainder assessed outcomes in either adults and children or adults alone.[41–86] It was common among quantitative articles to assess survival outcomes and disparities.

Aboriginal and Torres Strait Islander quality appraisal tool appraisal

No articles met the criteria for all 14 questions in the QAT. Only 10 (11%) articles clearly met the criteria (i.e. sufficient information for a 'yes' response) in seven or more questions. 13 (14%) articles did not meet any of the criteria assessed by the tool. Across the QAT, the most successful responses were seen for the question, "Was community consultation and engagement appropriately inclusive"? 33 articles (36%) provided sufficient information for a "yes" response. For the question "Did the researchers negotiate agreements in regards to rights of access to Aboriginal and Torres Strait Islander peoples' existing intellectual and cultural property"? no articles met the criteria for a "yes" response. 19 (21%) and 23 (25%) articles demonstrated Aboriginal and Torres Strait Islander research leadership and governance, respectively. However, only 16 (18%) articles were recorded as responding to a need or priority that was determined by the community.

Study design influenced how closely the articles met the criteria, with qualitative studies being more likely to meet the QAT criteria than quantitative and quantitative descriptive designs. Nine (29%) qualitative articles had sufficient evidence to demonstrate that they met the criteria in 50% or more of the QAT questions, compared with one article (2%) with a quantitative and quantitative descriptive design. There were two mixed-methods articles; one did not demonstrate success across any of the 14 questions, and the other demonstrated success across only four of the QAT questions.

We also analysed the results of the QAT by year of publication to determine whether the publication date had a substantial impact on research practice in the past two decades and levels of success after the tool was developed. These results are provided in Table 1.

There was no significant increase in articles achieving success in seven or more QAT criteria in the more recent years of publication, and the range that achieved the highest levels of 'yes' was between 2005 and 2009.

The detailed responses to all Aboriginal and Torres Strait Islander QAT questions can be found in the supplementary material (Table S2) and an overview of the responses is provided in Table 2.

Discussion

To our knowledge, this study is the first to apply an Indigenous lens to the appraisal of research on Aboriginal and Torres Strait Islander cancer outcomes and experiences. The use of the QAT provides a unique and comprehensive appraisal of research on cancer experiences among Aboriginal and Torres Strait Islander peoples.

This review demonstrated the lack of transparency and proactive approach to appropriately engaging Aboriginal and Torres Strait Islander peoples in research. The appraisal showed an extremely low number of positive responses across all 14 criteria of the QAT. Only 11% of articles met the criteria in at least half of the questions. This clearly demonstrates that across all included articles, there is a lack of partnership with and guidance from Aboriginal and Torres Strait Islander participants in research conducted about them, and where it has taken place, there is limited or no capacity for authors to report this in the subsequent publications.

Research should be conducted such that articles are appraised on their ability to meet the QAT criteria, and journals enable authors to report this information. The QAT questions provide a multi-faceted view of the key issues within research conducted with and about Aboriginal and Torres Strait Islander peoples. The lack of positive responses strongly suggests that research about Aboriginal and Torres Strait Islander communities is regularly being conducted with little to no engagement. One of the reasons for the development of the QAT was the "history of colonisation of Aboriginal and Torres Strait Islander peoples",[4] resulting in researchers treating participants as research objects[4] rather than working collaboratively. Further, the results of the QAT reveal a distinct lack of articles including Aboriginal and Torres Strait Islander governance. Many articles did identify a key enabler for Aboriginal and Torres Strait Islander peoples' participation in health and treatment services was receiving care that respects their understanding of cancer and acknowledging the importance of family, community and staying connected to country. [14,67,74,84] Of the 91 included articles, none demonstrated success in all 14 QAT criteria, indicating that cancer research requires greater involvement of Aboriginal and Torres Strait Islander researchers and participants and utilising a decolonised research methodology that accounts for Aboriginal and Torres Strait Islander ways of knowing, being, and doing and adopts a clear anti-racist approach.[87] Additionally, none of the articles did or could demonstrate that researchers had negotiated agreements for rights of access to Aboriginal and Torres Strait Islander peoples' existing intellectual and cultural property,[4] highlighting how participants are frequently not viewed or considered as research collaborators with the right to own their work.

It is important to note that while only 19 of the 91 articles appraised were listed as having Aboriginal and Torres Strait Islander leadership, at least 37 had an Aboriginal or Torres Strait Islander author that wasn't identified. While it is promising to see Aboriginal and Torres Strait Islander authorship included in research, it is disappointing that the journal didn't provide an opportunity to declare cultural affiliations. The reader should not need in-depth knowledge of Aboriginal and Torres Strait Islander authors to identify whether appropriate leadership and authorship are included in research. This information should be provided and clearly highlighted by the publishing journals.

The QAT was not published until 2020, so the majority (n=79) of included articles were published prior to its release. Our analysis revealed only 8.86% of articles published prior to the QAT received a 'yes' response in ≥50% of the criteria, as opposed to 16.67% of articles published after its release, although with a smaller sample size (n=12). Articles published prior to the QAT may not have had the ability to report Aboriginal and Torres Strait Islander leadership and involvement, even if it occurred in the research. There is a need for improvement in the articles published after the QAT, as the low success rate demonstrates further work is needed to ensure genuine involvement with Aboriginal and Torres Strait Islander peoples and reporting in publications.

Table 1: The QAT results by year of publication.

Publication range	Number of articles	Articles with 'yes' ≥ 7 (%)
2000-2004	4	0
2005-2009	11	27.27
2010-2014	19	5.26
2015-2019	39	7.69
2020-2022	18	16.67
Pre-QAT (2000-2020)	79	8.86
Post-QAT (2021-2022)	12	16.67

QAT, quality appraisal tool.

Implications for public health

This review highlights that more needs to be done in cancer research to achieve true partnership with Aboriginal and Torres Strait Islander communities and researchers. This would build robust and culturally sensitive research, which is likely to improve cancer outcomes. Research with Aboriginal and Torres Strait Islander leadership and governance helps ensure a strengths-based approach to research is being undertaken.

Journals have a critical role to play by embedding in standard practice research leadership, governance, and consultations conducted in

Table 2: The QAT criteria and articles recorded as "Yes".

QAT Question	Total articles n=91 (%)	Qualitative articles n=31 (%)	Quantitative articles n=51 (%)	Quantitative descriptive articles n=7 (%)	Mixed methods articles n=2 (%)
Did the research respond to a need or priority determined by the community?	16 (18%)	8 (26%)	7 (14%)	1 (14%)	0 (0%)
Was community consultation and engagement appropriately inclusive?	33 (36%)	18 (58%)	14 (27%)	0 (0%)	1 (50%)
Did the research have Aboriginal and Torres Strait Islander research leadership?	19 (21%)	13 (42%)	5 (10%)	0 (0%)	1 (50%)
Did the research have Aboriginal and Torres Strait Islander governance?	23 (25%)	15 (48%)	7 (14%)	0 (0%)	1 (50%)
Were local community protocols respected and followed?	24 (26%)	19 (61%)	3 (6%)	1 (14%)	1 (50%)
Did the researchers negotiate agreements in regards to rights of access to Aboriginal and Torres Strait Islander peoples' existing intellectual and cultural property?	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)
Did the researchers negotiate agreements to protect Aboriginal and Torres Strait Islander peoples' ownership of intellectual and cultural property created through the research?	4 (4%)	3 (10%)	0 (0%)	1 (14%)	0 (0%)
Did Aboriginal and Torres Strait Islander peoples and communities have control over the collection and management of research materials?	18 (20%)	15 (48%)	3 (6%)	0 (0%)	0 (0%)
Was the research guided by an Indigenous research paradigm?	20 (22%)	20 (65%)	0 (0%)	0 (0%)	0 (0%)
Does the research take a strengths-based approach, acknowledging and moving beyond practices that have harmed Aboriginal and Torres Strait peoples in the past?	12 (13%)	8 (26%)	3 (6%)	1 (14%)	0 (0%)
Did the researchers plan and translate the findings into sustainable changes in policy and/or practice?	6 (7%)	3 (10%)	3 (6%)	0 (0%)	0 (0%)
Did the research benefit the participants and Aboriginal and Torres Strait Islander communities?	8 (9%)	6 (19%)	2 (4%)	0 (0%)	0 (0%)
Did the research demonstrate capacity strengthening for Aboriginal and Torres Strait Islander individuals?	15 (16%)	12 (39%)	3 (6%)	0 (0%)	0 (0%)
Did everyone involved in the research have opportunities to learn from each other?	16 (18%)	12 (39%)	4 (8%)	0 (0%)	0 (0%)

QAT, quality appraisal tool.

Aboriginal and Torres Strait Islander communities and providing opportunities for author declarations of their Indigenous status and other relevant information. Universities could facilitate meaningful relationships between researchers and Aboriginal and Torres Strait Islander communities, as trust and partnership are critical for meaningful research but are hindered by pressure on researchers to produce outputs.[88] Universities must therefore work to 'appropriately value' this foundational, relationship-building work.[88] It is also critical that both universities and journals work to value the processes that allow culturally safe research to be completed, rather than Western metrics of success viewed from a colonial perspective.[88]

There is clear interest from authors and researchers for journals to provide a framework for culturally appropriate research and Indigenous authorship declarations, as evidenced in the recent call for action in *Tobacco Control* for a publication protocol that upholds ethical research.[89]

Strengths and limitations

The large number of included articles provided a strong base for appraisal using the QAT across a variety of research designs and cancer types.

Whilst this is a review and does not fit the criteria to be assessed by the QAT, we considered how we could align with the criteria, so if it were considered for appraisal, it would be assessed favourably. Our two lead authors are both Aboriginal individuals, providing leadership to ensure the review was conducted through a culturally safe lens. We also ensured clear acknowledgement of the cultural affiliations of the Aboriginal authors, in recognition of the importance of providing space for Aboriginal and Torres Strait Islander researchers to share and acknowledge their culture.

A limitation of this review is the unintended consequences of comparing success in the QAT across study types. For example, the results revealed that qualitative papers were more likely to provide information to achieve a 'yes' response. However, we note that qualitative studies have less restrictive word counts, and these nuances between study types should be considered when interpreting the results of the QAT. Further to this, not every question of the QAT is relevant for some study types, and these articles should not be penalised as a result. For example, local community protocols may be less achievable for secondary data analysis, and research translation may fall outside of the scope of a single paper.

Challenges were found in ascertaining the exact level of Aboriginal and Torres Strait Islander involvement and consultation in the articles due to constraints or restrictions in the publishing journals. Whilst researchers are ultimately responsible for their article, it is important to acknowledge pressures from external sources to exclude design elements or methodological choices in a publication. This is a systemic issue that needs to be addressed from multiple avenues.[90] As such, we know that the level of consultation and engagement with Aboriginal and Torres Strait Islander communities may be higher than indicated in these articles, but it has not been reflected within the methodology. However, due to lobbying from Aboriginal and Torres Strait Islander researchers, the editorial teams of prestigious journals are now working to address this constraint. For example, the *Medical Journal of Australia* has introduced plans to increase the presence of Indigenous voices.[91] Similarly, a joint statement by editors of *Rural and Remote Health,* the *Australian Journal of Rural Health,* and the *Canadian Journal of Rural Medicine* has suggested their publications explicitly recognise the contributions of Indigenous researchers to research about Indigenous peoples.[92]

Conclusions

This systematic review highlighted the challenges that currently exist in research conducted about and with Aboriginal and Torres Strait Islander peoples affected by cancer. Research about Aboriginal and Torres Strait Islander peoples' experiences with cancer is often conducted without appropriate consultation and involvement. Furthermore, for articles where culturally safe Aboriginal and Torres Strait Islander-led research has been conducted, there are limited opportunities for authors to declare their cultural affiliations. Several articles were unable to demonstrate success in addressing the questions in the Aboriginal and Torres Strait Islander QAT, highlighting that the lack of involvement of Aboriginal and Torres Strait Islander peoples in research is a far-reaching issue. Cancer research that aligns to the QAT will ensure higher-quality, culturally safe research. Authors should be more cognisant to develop research that aligns with the criteria, with greater consideration of the consultation and involvement of Aboriginal and Torres Strait Islander peoples and consideration of the benefits to their communities. Journals can facilitate this process by prioritising the publication of well-designed Aboriginal and Torres Strait Islander-led cancer research and creating opportunities for researchers to clearly state their Aboriginal and Torres Strait Islander status.

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Ethics approval and consent to participate

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Authors' contributions

Conceptualisation, JG, MH. and MV.; Methodology, MH and JG.; Software, FN.; Validation, MH, JG, FN, JM. and DM.; Formal Analysis, MH, JG, FN, JM and DM.; Investigation, X.X.; Data Curation, MH, FN, and JM.; Writing – Original Draft Preparation, MH, JM and FN.; Writing – Review & Editing, MG, JG, JM, DM, AM, TB and MV.; Supervision, MH, JG, MV.; Project Administration, JM.; Funding Acquisition, MV.

Consent for publication

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Availability of data and materials

All data analysed during this study have been included in the published article and in the supplementary files.

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Conflicts of interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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Appendix A Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.anzjph.2024.100142.