Author’s response to reviews

Title: Indigenous traumatic brain injury research: Responding to recruitment challenges in the hospital environment

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Author’s response to reviews:

Reviewer comments

Technical Comments:

- Please include list of abbreviations. If abbreviations are used in the text they should be defined in the text at first use, and a list of abbreviations should be provided. The list of abbreviations used in the manuscript and their meanings after the Conclusions section.

Author response:

The following list of abbreviations has been added after the conclusion section on page 23:

List of Abbreviations
Reviewer reports:

Reviewer 1

Angela Colantonio (Reviewer 1): Please include all comments for the authors in this box rather than uploading your report as an attachment. Please only upload as attachments annotated versions of manuscripts, graphs, supporting materials or other aspects of your report which cannot be included in a text format.

Please overwrite this text when adding your comments to the authors.

Thank you for the opportunity to review this important manuscript examining recruitment challenges in the hospital environment relevant to Indigenous traumatic brain injury.

1. This manuscript addresses a serious gap in the literature on a very important topic. Traumatic brain injury in indigenous populations are understudied despite the likely large numbers of persons affected. I applaud the authors for sharing these challenges with a greater audience. This issue of transitions after brain injury is an important one overall but in particular
to indigenous patients and has been identified in other countries. I believe expanding the relevance to the work in the introduction could strengthen the paper eg see Keightley et al., 2011

Author response: The authors thank the reviewer for their valuable comments on the manuscript. On the basis of this suggestion, the authors have strengthened the introduction including references regarding the high rates of TBI in other Indigenous populations outside of Australia, and the characteristics of Indigenous TBI patients in Australia. In addition, the importance of understanding the lived experience, particularly the transition period to inform policy and practice is reinforced.

References including as Bonevski et al., 2014 have been cited to situate the paper as an opportunity to inform others about why it is difficult to engage ‘hard to reach’ populations, such as Indigenous Australian patients in hospital.

2. I believe there could be further points of clarification in the manuscript. First, some information about how the data was collected, eg numbers of persons collecting information and their training.

Author response:

The research team recorded all interactions (face-to-face, telephone, email) with patients identified as fitting eligible criteria, family members of patients and hospital staff in a central project database. For each interaction, the type and date of interaction, description of interaction including key points from conversations and length of time of interaction were recorded. For more significant interactions, research reflections were documents. The first author (MF) reviewed the database and reflections to categorise the experiences of the research team.

The following paragraphs have been included on page 10 to address the reviewers comment:

Research team

During the course of the project there were six project staff recruited patients and caregivers. The research workers had previously worked in the areas of occupational therapy, social work, psychology and Indigenous public health research. Between them, they held many person-years of experience working with and engaging Aboriginal and Torres Strait Islander people and communities in a range of research projects including follow-up on illicit substance misuse including cannabis and behaviours largely associated with TBI such as unhealthy alcohol use and drink driving. Prior to data collection, the six project staff completed relevant training including an accidental counselling short course, and training in Indigenous research methodologies and qualitative inquiry (lead by author JG).
Documentation of project staff recruitment experiences

During the project, research team members recorded any interaction (face-to-face, telephone, email) with patients, family members of patients and hospital staff in a central project database. The database contained sensitive information and was stored according to university policy. For each interaction, the date and type of interaction, key points interaction, and length of time of interaction were recorded. For more significant interactions, researcher reflections and action points were also documented.

3. What was the process of synthesizing the data? What qualitative methods were used?

Currently there is very little detail.

Author response: The field notes were analysed using an inductive approach to thematic analysis. More information about the documentation of recruitment experiences is offered on page 10:

First author (MF) reviewed the database and research reflection notes to categorise the challenges in recruitment of Indigenous patients following TBI into five major groups. The first author also reviewed and summarised the changes made to the eligibility and recruitment process (e.g. ethics amendments) to document how the research team responded to the major recruitment challenges. Using an inductive approach to thematic analysis (Braun & Clarke, 2006), author MF identified emergent subthemes within the data. Subthemes were verified by authors TC and JG.

4. Comparing and contrasting with other literature would also be a welcome addition to the manuscript. Overall, the manuscript was a pleasure to read.

Author response: As outlined in the first comment, references have been added to the introduction to strengthen the argument regarding TBI harms and the role methodological papers such as this paper have in improving the way research investigating the lived experiences of Indigenous Australians with TBI is conducted. Throughout the manuscript, the results are discussed with the support of existing literature.

Reviewer 2

Tatyana Mollayeva (Reviewer 2): Fitt's et al.'s perspective for performing their research "Indigenous traumatic brain injury research: Responding to recruitment challenges in the hospital environment" was that clinical and rehabilitation environments can create unique challenges to recruit research participants. As such, researchers described and reflected on the specific
challenges they encountered when recruiting indigenous participants with traumatic brain injury, at 2 tertiary hospitals in Northern Australia. Researchers utilized data from three sources, qualitative records summarizing research staff contact with patients, family members, clinical service providers, and field trip notes. It appears that by recruiting participants researchers wanted to understand cognitive health, well-being and recovery of indigenous participants with traumatic brain injury during 6 months from hospital to home discharge. By doing so, they encountered challenges during recruitment process, including those concerning discharge against medical advice (AMA), the need to apply the Westmead post-traumatic amnesia (PTA) scale by clinical staff to determine the capacity of patients with TBI to consent to the research, restricting ability of patients under adult guardianship and difficulty to coordinate research around patients commitments and treatment, to get involved in research. Researchers concluded that in order to maximize recruitment and reduce ethics amendment during the research program, it is important to develop a simplified recruitment protocol and employ hospital staff as research officers.

According to researchers' description, their original recruitment strategy was a three-step program: 1) a nominated health staff member identified eligible patient and notified the research team; 2) a research team member approached the patient to explain the study and provide an information sheet; 3) once consent form was obtained (i.e., prior to that patients had to be emerged from PTA, assessed by the Westmead PTA scale) and assessment completed (unclear what was involved in this assessment, participants were asked to nominate a caregiver or significant other to participate in the study.

It seems like the recruitment for the main study was purposive, i.e., deliberate selection of participants who were indigenous and experienced hospitalization due to TBI. It seems like recruitment took place at two hospital, settings and the sample may be representative of people of varying injury severity and mechanisms, as well as their significant others. It is difficult to comment on the age distribution, sex, and well as severity of injury in men and women with TBI, and the structure and characteristics of their family members, as this information was not presented. Likewise, personal characteristics, credentials, experience and training of research personnel was not presented. This observation points to the high likelihood of sampling issues, raising the concern of potential inadequate exposure of researchers to recruitment phenomena, and thus questionable potential to generalizability of conclusions made.

Below are methodology-related comments that need to be presented:

1. What theoretical framework was in place when designing this research?

The research is underpinned by Indigenous Standpoint Theory. Research methods grounded in Indigenous Standpoint Therapy building the capacity of Indigenous people through engaging with them both directly during the research and during research translation. The following paragraph has been insert in the manuscript on page 8 to address this comment:
This study and the larger project were underpinned by Indigenous Standpoint Theory [17, 18]. The theory is not an “Indigenous” way of doing research but rather, the theory offers an alternative to the practice of subjugating Indigenous people as the cultural other through prioritising the personal experiences of Indigenous peoples in the research process. Indigenous Standpoint Theory ensures the research is planned, owned and controlled by Indigenous people and ensure that Indigenous people are intimately involved with all aspects of the research [19]. Through capturing and reflecting on patients’ experiences as well as our own as researchers in the hospital, this study demonstrates how Indigenous peoples (patients) personal experiences have influenced the protocol and processes of this study.

2. Did participants provide feedback or commented on the study research objective? findings?

Author response:

At the point of recruitment, patients were told the research aim and objectives. Some patients reported that the research aim and objectives were ‘interesting’ and saw the value of the research. In some cases, it appeared that patients’ interest in the project aim was motivation to participate in the project. As this paper only reported on recruitment, patients did provide feedback or comment on the findings as there were no preliminary results to report at that time.

3. How many participants (patients with TBI, family member, etc.) were in the study? How many you were planned to recruit and how many have been recruited? Number of interviews, focus groups, fields notes, etc.

Author response:

The aim was to recruit approximately 200 participants with TBI and their caregivers. The following statement has been included (page 7) in the manuscript to address the first question in point 3:

Approximately 200 participants with TBI and their caregivers will be recruited.

In total 62 patients were identified as being eligible for participation, with approximately 500 contact points recorded in the database between project staff and hospital staff, patients or their family members during the consent and recruitment process. Twenty-four patients were recruited to the study. This information has been included at the start of the results section on page 11.
Formal data collection including surveys were only completed with patients and caregivers who consented to participate in the project. Analysis of this information is reported in other manuscript developed from the project. Focus groups were not completed in this study. The aim of this commentary-style manuscript is to report on our experiences recruiting Indigenous patients admitted with a traumatic brain injury.

4. What are the important characteristics of the sample? e.g. demographic and injury-related data, clinical data, etc.

Author response:

Demographic and injury related data regarding all patients identified as meeting the eligibility criteria were not captured as part of this process. Under approved ethics, patient demographic and injury-related characteristics and clinical data could only be collected after patients consented to participate in the study.

5. What are the important personal characteristics, credentials, experience and training of research personnel, including cultural competence about indigenous people values, power relationships between them and research personnel? research and clinical personnel at two hospital sites?

Author response:

The project staff employed have between them many person-years of experience working with and engaging Aboriginal and Torres Strait Islander people in a range of research projects involving follow-up. The following paragraph has been included on page 10:

Research team

During the course of the project there were six project staff who recruited patients and caregivers. The project staff had previously worked in the areas of occupational therapy, social work, psychology and Indigenous public health research. Between them, they held many person-years of experience working with and engaging Aboriginal and Torres Strait Islander people and communities in a range of research projects including follow-up on illicit substance misuse including cannabis and behaviours largely associated with TBI such as unhealthy alcohol use and drink driving. Prior to data collection, the project staff completed relevant training including an accidental counselling short course, and training in Indigenous research methodologies and qualitative inquiry (lead by author JG).
6. Were field notes made during and/or after participants' recruitment?

Author response:

The field notes were made after any type of contact including face to face or telephone regarding patients that were recruited and not recruited to the project. More information about the documentation of recruitment experiences is offered on page 10:

During the project, research team members recorded any interaction (face-to-face, telephone, email) with patients, family members of patients and hospital staff in a central project database. The database contained sensitive information and was stored according to university policy. For each interaction, the date and type of interaction, key points interaction, and length of time of interaction were recorded. For more significant interactions, researcher reflections and action points were also documented.

7. Provide the data analysis steps of results that were reported.

Author response: The following information has been added to the methodology to describe the data and the analysis:

First author (MF) reviewed the database and research reflection notes to categorise the challenges in recruitment of Indigenous patients following TBI into five major groups. The first author also reviewed and summarised the changes made to the eligibility and recruitment process (e.g. ethics amendments) to document how the research team responded to the major recruitment challenges. Using an inductive approach to thematic analysis (Braun & Clarke, 2006), author MF identified emergent subthemes within the data. Subthemes were verified by authors TC and JG.

8. Describe how you dealt with private information, potential biases of a researcher, participants who provided consent but left AMA, participants without family members or significant other, and patients with language problems?

Author response:

Private information was stored according to university policy. All patients who provided informed consent could participate in the study. This included patients who consented in the hospital but discharged against medical advice. Finally, it was not part of the eligibility criteria for patients to nominate a caregiver or significant other.
The following statement has been included in the manuscript:

The database contained sensitive information and was stored according to university policy. (page 10)

All patients who provided informed consent could participate in the study. This included patients who consented in the hospital but discharged against medical advice. (page 9)

Nomination of a caregiver was not a requirement of the study and did not preclude patients from participating in the study. (page 9)

9. This descriptive study is very important because it described challenges researchers faced when recruited indigenous people with head injury at the early stages after the injury. However, researchers' conclusion, about the need of simplification of the recruitment process, is difficult to accept as evidence-based, taking into account that researchers did not report on important characteristics of key groups (indigenous people with TBI, their family members, research personnel, ethics board members), that can affect or be affected by the research program described in this research. The presence of decision-making capacity, is not only an essential element of valid consent, but also involves law relating to consent, where there are clear legal consequences, if the researcher acts in its absence. Overlapping or multiple relationships (researcher-practitioner and research participant, as proposed by researchers) can become by itself the major source of ethical conflicts faced by research team. Therefore, to be in the position to accept any change proposed by researchers, the reader needs to be provided with an information of each party needs, interests, and values, to detect the very target root cause that influenced recruitment process. It might turn out, that recruitment at hospital discharge or when people are discharged to community, will suit better research focused to understand outcomes of indigenous people with TBI.

Author response:

Under the project’s ethics approval, the demographic and injury characteristics of patients and family members were not captured.

In response to the challenges of using the Westmead PTA Scale, the development of a suitable and ethical process to determine a patient’s presence of decision-making capacity and suitability to consent was discussed between the research team and hospital staff at length before the study protocol was amended and submitted for approval from the ethics committee. The approved process to determine a patient’s suitability to consent was for the research team to consult with the patient’s treating team including treating medical professionals prior to approaching the patient for consent. In the manuscript, changes have been made to reflect this. For example, please see page 15 and page 19:
liaising verbally with the treating medical team… (page 15)

“…for example through using medical practitioners allied health knowledge and skills to determine capacity rather than the Westmead PTA Scale…” (page 19)

Capturing information about the hospital experience is important to understand the full transition experience. As described here and in other studies, there is a high rate of discharge against medical advice among Indigenous patients including Indigenous patients admitted with traumatic brain injury. Understanding the reasons for why Indigenous people with TBI self-discharge will be valuable towards improving the experience Indigenous Australians have with receiving hospital care. The following statements have been added on page 20:

To ensure employed hospital workers approaching patients in a research capacity is conducted in a safe and ethical manner, staff must be in a uniform that demonstrates they are affiliated with the research institution and must not directly be a part of the patient’s treating team.

The reviewer does make an important point regarding the recruitment from community. Following submission of this manuscript, the research team did seek approval to recruit through key Indigenous health and rehabilitation services. Information regarding this strategy has been included in the manuscript on page 18:

Recruitment from community health services

To overcome the challenges experiences in hospital recruitment, the research engaged with community-based Indigenous health and rehabilitation services to recruit community members who have experienced a TBI. To participate in the project, community members were still required to have attended hospital for treatment within the last 6 months and met all other eligibility criteria (outlined in Figure 1). Recruitment practices were tailored according to what was appropriate for service staff and their clients. Strategies included posters displayed in the health services with information on the project and treating clinicians and health workers speaking to patients of the health service who met the eligibility criteria. Interested patients could self-refer themselves to the project by contacting project staff to participate or provide consent to allow the clinician to provide the research team with the person’s contact details. Although this recruitment strategy prevented survey data collection the first-time point (prior to hospital discharge), qualitative information about the hospital and transition period could still be provided by patients during the subsequent time points (three and six months after discharge).
Reviewer 3

John Yue (Reviewer 3): Review for BMC Medical Research Methodology Indigenous traumatic brain injury research: Responding to recruitment challenges in the hospital environment.

General: Overall, the manuscript addresses a pertinent topic within TBI. Ensuring that clinical conclusions are generalizable should be an ongoing priority of the field. This requires representative patient populations in research studies. Highlighting the challenges faced when incorporating historically marginalized groups into research is important. Considerations below to bolster the manuscript for publication.

1. Page 10, line 15-16: A claim that earlier contact decreases DAMA is made. Is there any data from before and after said changes as they relate to rates of DAMA?

   Author response:

   The first four patients identified as meeting the eligibility criteria DAMA or ‘absconded’ from the hospital. However, DAMA remained an ongoing challenge for project staff. Earlier contact with patients meant there was an increase in the number of eligible patients approached to participate. It is difficult to say with certainty that earlier contact with patients resulted in more patients being approached or if it was stronger relationships with staff after refining recruitment processes. The following sentence have been amended to reflect this in page 14:

   As described in Figure 1 (Box 5), it was identified by project and hospital staff that earlier contact with eligible patients was required to improve contact rates between patients and project staff in the hospital

2. Page 10-11 lines 24-1: "In certain cases a single score of 12/12 was deemed sufficient by their treating medical officer, as opposed to three consecutive days. These varying circumstances resulted in some eligible patients being discharged without formal emergence from PTA and therefore deemed unsuitable to consent." Should clarify that a single score of 12/12 was deemed sufficient for DISCHARGE not study eligibility. Is it also possible to include numbers of how many patients were discharged prior to meeting study eligibility criteria?

   Author response:

   The section the reviewer is referring to has been amended to clarify that a single score of 12/12 was deemed sufficient for discharge not study eligibility:

   While the Westmead PTA scale was not specifically referred to in the original study protocol [5], it was standard practice for allied health staff to use the Westmead scale in accordance with its protocol to measure PTA. As described in Box 3, the Westmead scale’s protocol determines that an individual has emerged from PTA once they score all twelve questions correctly for three
days consecutively. It was identified early in recruitment that patients’ PTA performance was not always considered by treating teams when determining discharge suitability. When PTA was considered, in certain cases a single score of 12/12 on the Westmead Scale was deemed sufficient evidence by their treating medical officer that a patient had emerged from PTA and was suitable for discharge. The varying conditions under which PTA and discharge suitability were determined resulted in some eligible patients being discharged without being approached by research staff to participate in the project, deemed unsuitable to provide informed consent.

3. - For each barrier to recruitment (DAMA, guardianship etc.) it would would be instructive if a percentage was included to give the reader an idea of the prevalence/effect.

Author response:

The reviewer makes a good suggestion. To provide a better understanding of the prevalence of each challenge, the authors have provided details regarding the number of patients identified as meeting the eligibility criteria, the number of recruited to the project and the percentages for these challenges experiencing during recruitment. Please see the following inclusions in the manuscript:

• In total 62 patients were identified as being eligible for participation, with approximately 500 contact points recorded in the database between project staff and hospital staff, patients or their family members during the consent and recruitment process. Twenty-four patients were recruited to the study. (see page 11)

• One in five patients (19.4%) identified as meeting eligibility criteria DAMA or ‘absconded’ from the hospital. (see page 12)

• Patients under adult guardianship orders (9.6% of patients identified as meeting the eligibility criteria) were impacted most by this issue. (see page 15)

4. - The results/discussion reference patient quotes where patients felt stereotyped/targeted (due to race, perceived alcohol consumption). Is there a role for training house staff and research officers for cultural sensitivity to address this lack of comfortability indigenous people feel in the hospital environment?

Author response:

The authors thank the reviewer for this suggestion. To address it, the following paragraph has been added on page 21:
In addition to identifying the challenges of recruiting patients, the findings also identified several examples of patients’ describing poor interactions with hospital staff. As reported here and elsewhere, poor communication with treating clinicians can contribute towards desire to self-discharge [28] as well as patients’ limited understanding of their injury and their understanding of the importance of completing treatment [34, 35] Most hospitals, including the two in this study, already have a requirement for staff to complete ‘cultural competency’ training. A review of existing training packages to address obvious shortfalls in the cultural competency skill level of some hospital employees is recommended. Finally, it is recommended better practices to obtain regular feedback from Indigenous patients about the performance of hospital staff in meeting their needs are implemented.

5. The paper is instructive. Including concrete data behind the authors' experiences would provide a better methodology from which to base future research studies.

Author response:

As described above, the authors have included proportions of the major challenges to demonstrate the prevalence during recruitment.

To strengthen the manuscript, examples of research notes have been included on the following pages:

Page 12

…“hospital staff accused me of drinking on the weekend. Just because I'm black, I've been out drinking.” The patient stated that he no longer wants to stay at the hospital. He stated that he was happy to stay to get better but doesn’t want to stay if the staff do not believe him.” These claims also impacted on caregivers’ and thoughts about what perceptions staff have of the family’s capacity to care for their family member: She [family member] reported that they [family member and patient] were angry because the doctors and nurses assume 'we allowed him to be drinking over the weekend'.

Page 16

In the following example, the project staff member travelled to the hospital at a time suitable to the Indigenous liaison officer (ILO) so they ILO could introduce the project staff member to the patient. Upon arrival the ILO advised the project staff member he had to assist the patient with urgent banking matters prior to speaking with the project staff member: “….he (ILO) has been working with the patient and is assisting with the patient getting access to his bank account and
money. He stated that the patient has lost his bank cards. [ILO] and [project staff member] arranged to meet with the patient in 30 minutes.”

Page 17

“The patient had two QCS [Queensland Corrective Services] officers guarding him. One of the officers stated that although the patient has been flagged as suitable, I did not have the correct approvals to speak with him given he was in custody.”