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Healing the Past by Nurturing the Future – co-designing perinatal strategies for Aboriginal and Torres Strait Islander parents experiencing complex trauma: a framework and protocol for a community-based participatory action research study

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Keywords:	complex trauma, perinatal, parents, Indigenous, community-based participatory action research, intergenerational

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ABSTRACT

Introduction

Adverse childhood experiences and other potentially traumatic events can contribute to physical, social and emotional issues, including ‘complex trauma’. Many Aboriginal and Torres Strait Islander (Aboriginal) peoples are also affected by legacies of historical trauma and loss. Trauma responses may be triggered during the transition to parenting in the perinatal period. Conversely, becoming a parent offers a unique life-course opportunity for healing and prevention of intergenerational transmission of trauma. This project aims to co-design acceptable and feasible perinatal *awareness, recognition, assessment and support* strategies for Aboriginal parents experiencing complex trauma.

Methods and Analysis

This Aboriginal-led, community-based participatory action research (action research) project is being conducted in three Australian jurisdictions (Northern Territory, South Australia and Victoria) with key stakeholders from all national jurisdictions. Four action research cycles incorporate mixed methods research activities including evidence reviews, parent and service provider discussion groups, development and psychometric evaluation of a recognition and assessment process and drafting proposals for pilot, implementation and evaluation. Reflection and planning stages of four action research cycles will be undertaken in four key stakeholder workshops aligned with the first four Intervention Mapping steps to prepare program plans.

Ethics and dissemination

Ethics and dissemination protocols are consistent with the National Health and Medical Research Council Indigenous Research Excellence criteria of engagement, benefit, transferability and capacity-building. A conceptual framework has been developed to promote the application of core *values* of safety, trustworthiness, empowerment, collaboration, culture, holism, compassion and reciprocity. These include related *principles* and accompanying reflective *questions* to guide research decisions.

ARTICLE SUMMARY

Strengths and limitations of this study

- Comprehensive use of mixed research methods, action research and Intervention Mapping socio-ecological model to co-design acceptable and feasible perinatal awareness, recognition, assessment and support strategies for Aboriginal parents experiencing complex trauma.
- Conceptual framework inclusive of values, principles and reflective questions developed to guide research process.
- Indigenous Research Excellence criteria influence ethics and dissemination protocols.
- Initial validation of an awareness, recognition and assessment process for Aboriginal parents experiencing complex trauma in three Australian jurisdictions.
- Implementation and evaluation of the co-designed support strategies lies outside the scope of this formative study.

INTRODUCTION

Adverse childhood experiences (ACEs) contribute to a wide range of long-lasting physical, social and emotional health issues.[1-7] Complex post-traumatic stress disorder (complex trauma), proposed by the World Health Organization as a new disorder category for the International Classifications of Diseases system (ICD11), describes a symptom profile that typically follows severe stressors of a prolonged nature or repeated adverse events from which separation is not possible.[8] These stressors often involve interpersonal violation and occur within childhood family or institutional care giving systems[9] (e.g. childhood abuse, severe domestic violence, torture, or slavery).[8]

Aboriginal and Torres Strait Islander (Aboriginal¹) peoples in Australia are particularly affected by complex trauma, following a legacy of historical trauma[10] which includes state-sanctioned systematic removal of Aboriginal children from their families and ongoing discrimination.[11] The effects of ACEs are compounded in many Aboriginal communities by socio-ecological factors that are likely to amplify rather than counteract the effects, increasing the risk of experiencing complex trauma.[12, 13]

The transition to parenting during the perinatal period (pregnancy to two years after birth) is a critical risk time for parents who have experienced complex trauma as a result of ACEs.[14] Trauma responses may be triggered by the intimate nature of experiences associated with pregnancy, birth and breastfeeding;[15] and the attachment needs of the infant.[16] The long-lasting relational effects can impede the capacity of parents to nurture and care for their children, and may contribute to 'intergenerational cycles' of trauma.[17-19]

Conversely, the transition to parenthood offers a unique life-course opportunity for emotional healing and development.[20, 21] A positive strengths-based focus during this often-optimistic period has the potential to transform the 'vicious cycle' of intergenerational trauma into a 'virtuous cycle' that contains positively reinforcing elements and nurturing care that promote healing in the parent,[22] and are critical for optimal development of the infant.[23, 24] Frequent scheduled contacts with perinatal care providers before and after childbirth and across the first two years offer an opportunity for providing comprehensive system-based supports for people experiencing complex trauma during this period. This is particularly important because it may be the first time many of this predominantly young and healthy childbearing population have had contact with universal health services since leaving education. Despite these clear risks and opportunities, few interventions are available for parents with specific histories of abuse,[15, 25, 26] and there are no systematic, culturally informed processes or evidence of effective strategies to identify and support Aboriginal parents experiencing complex trauma.[27]

The benefits of involving communities in co-designing health-care strategies are increasingly recognised.[28] This is critical in the perinatal period for Aboriginal families experiencing complex trauma for several reasons. First, there is very limited evidence of effective interventions internationally. Australian guidelines for the treatment of complex trauma and trauma-informed care emphasise the need for complex trauma to be understood within relational networks and social environments if it is to be adequately addressed.[9] Aboriginal Australians, despite suffering great disadvantage and adversity, demonstrate strong resistance

¹ We use the term 'Aboriginal' to refer to both Aboriginal and Torres Strait Islander peoples' in Australia, and the term 'Indigenous' to collectively refer to Indigenous people's internationally. We respectfully acknowledge the diversity and autonomy of Torres Strait Islander and Indigenous people's encompassed within these inclusive terms.

to those actions that are foreign to Aboriginal culture, including separation from families, discrimination and removal from Country. Thus, we will engage in respectful collaborative research with and alongside Aboriginal peoples and keep Aboriginal peoples' strengths and protective factors to the fore. These strengths include rich cultural relationship and kinship networks that foster relatedness and connectedness for children.[29] Collaboration has been shown to be critical in adapting child trauma therapies among other Indigenous communities.[30] Second, Aboriginal conceptualisations of social and emotional wellbeing are holistic and incorporate connection to land, culture, spirituality, family, and community; all of which are impacted by complex trauma, which is sometimes referred to as 'relational trauma'. [31] The rich relational understandings of wellbeing may offer important insights for other Indigenous and non-Indigenous communities. Third, there are risks associated with identifying parents with complex trauma. Labelling individuals as 'at risk' has the potential to undermine parents' existing resilience and coping skills, and trigger inappropriate notifications to a potentially punitive child protection system. These concerns are particularly salient for Aboriginal communities, with the history of colonisation and forced child removals from families, which have had devastating ongoing intergenerational impacts. Finally, despite a history of childhood adversity, most parents are able to nurture and care for their children.[32] Evidence suggests that examining these 'cycles of discontinuity' are an important place to start to illuminate innovative strategies for support.[33]

Aims and objectives

Healing the Past by Nurturing the Future is an Aboriginal-led, community-based participatory action research (action research) project, which aims to co-design safe, acceptable and feasible perinatal strategies for Aboriginal parents experiencing complex trauma. Strategies will address four key areas:

- **Awareness** or 'trauma-informed' perinatal care.
- **Recognition** of parents who may benefit from assessment and support.
- **Assessment** of complex trauma symptoms.
- **Support** strategies for parents.

The objectives of this protocol paper are to:

1. Describe the conceptual framework, community involvement and major 'phase one' and 'phase two' research activities with ethics approval.
2. Briefly outline proposed activities for 'phase three' ethics submission.
3. Discuss ethical considerations and research dissemination plans.

METHODS AND ANALYSIS

Conceptual framework

To articulate the values for the project and address risks and contextual complexities, we have developed a Conceptual Framework (Figure 1) drawing on holistic Aboriginal constructs of social and emotional wellbeing. The framework incorporates two main elements:

1. Four main domains of awareness, recognition, assessment, and support
2. Eight core values with related principles and questions

<<insert Figure 1 about here>>

1. *Four main domains of recognition, assessment, awareness and support*

1
2
3 The four main domains were developed during the initial consultation stages of the project
4 which revealed concerns about the use of language such as ‘screening’ and ‘intervention’.
5 The domains of ‘recognition’ and ‘assessment’ more accurately articulate ‘screening’
6 strategies that incorporate a feasible two-tiered process for care providers to *recognise*
7 parents who may require more in-depth *assessment* for complex trauma; and ‘intervention’
8 approaches to improve trauma-informed perinatal care and minimise the risks of re-
9 traumatising parents (*awareness*), and provide trauma-specific *support*.

12 2. *Eight core values with related principles and questions*

13 We identified seven frameworks that included trauma-informed values and principles[9, 34-
14 39] using online searches and team members’ knowledge. Further values and principles
15 relating to cultural and emotional safety were identified in the first key stakeholder workshop.
16 These were mapped and consensus reached by the project team. This process resulted in
17 identification of eight core **values**: *safety, trustworthiness, empowerment, collaboration,*
18 *culture, holism, compassion and reciprocity*. Each contains action-oriented **principles** that
19 enable the core values to be realised, and are accompanied by **questions** developed to aid
20 reflection on whether the activity under consideration is consistent with the core value
21 (Supplementary file 1).

25 **Community (patient and public) involvement**

26 This project involves Aboriginal people at every level, as detailed in the Indigenous Research
27 Excellence Criteria (Supplementary file 2). The need for this research has been identified in
28 national Aboriginal conferences and by two Aboriginal community controlled ‘peak bodies’
29 who supported the funding proposal for this research. The majority of the investigator team
30 are Aboriginal with extensive expertise in this area.

31
32
33 There is currently insufficient evidence to identify potentially acceptable, feasible and
34 effective strategies to support Aboriginal parents experiencing complex trauma, hence the
35 focus of this project is formative research. We are using an **action research model** which
36 draws on phenomenology and critical theory to generate constructivist grounded theory using
37 mixed methods.[40] It involves a practical community based focus and collaboration for
38 action.[41] The focus of the first year has been meaningful *community engagement* to enable
39 action research. This includes formal partnerships with Aboriginal Community Controlled
40 Health Organisations (ACCHO) who play a leading role in Aboriginal health initiatives,[42]
41 key stakeholder workshops involving a majority of Aboriginal people, and a discussion group
42 with Senior Aboriginal women.

43
44
45 Ongoing community involvement is built into the research plan. Our research aims will be
46 achieved by an iterative co-design process comprising four ‘plan-act-observe-reflect’ cycles.
47 The ‘reflect’ and ‘plan’ action research stages will be conducted in four key stakeholder
48 workshops which align with the first four steps of IM.[43] The ‘act’ and ‘observe’ stages of
49 the action research cycles involve a series of mixed method research activities that will be
50 refined in each ‘reflect’ and ‘plan’ stage within the workshops.

51
52
53 Due to the evolving nature of action research and co-design research, submissions for HREC
54 approval are planned in three distinct ‘ethics phases’, following key stakeholder co-design
55 workshops one, two and three. At the time of submitting this protocol, phase one and two
56 ethics had been approved, and HREC submission is planned for phase three in late 2019.
57 Therefore, this protocol includes a detailed description of ‘phase one and two’ activities, with
58 a brief outline only of anticipated phase three activities. See Figure 2 for a summary of
59 HREC approval phases, action research cycles and stages, and IM steps.

The research plan is also designed in accordance with:

- *Intervention Mapping* (IM),[43] using “theory and evidence as foundations for taking an ecological approach to assessing and intervening in health problems and engendering community participation”. [43, p 7] This research addresses steps one to four (see Figure 2). Steps five and six (implementation and evaluation) will form the basis of a subsequent project.
- *Power Threat Meaning Framework* (PTMF),[44] “an over-arching structure for identifying patterns in emotional distress, unusual experiences and troubling behaviour, as an alternative to psychiatric diagnosis and classification”. [44, p 5] We will incorporate the PTMF by reframing behaviours related to complex trauma as normal self-protective responses to threatening situations rather than pathological deficits.
- *Principles for population-based screening*[45] to assess the benefits, risks, costs, acceptability, accuracy and harms of recognising and assessing parents experiencing complex trauma.
- *Indigenous research methodologies*[46] that involve privileging Aboriginal worldviews, self-determination and Aboriginal community control.

<<Insert Figure 2 about here>>

Setting

Research activities will be conducted in three of seven Australian jurisdictions selected on the basis of existing research relationships and expressed interest by key stakeholders: Northern Territory, South Australia and Victoria. Approximately 23% of Australian Aboriginal people live in these three jurisdictions across mixed urban, rural and remote demographic contexts.[47] We recognise the leadership of four partner organisations in this project, including: Central Australian Aboriginal Congress (Northern Territory); Nunkuwarrin Yunti of South Australia Inc. and Women’s and Children’s Health Network (South Australia); and the Bouverie Family Healing Centre (Victoria).

Participants in this study include Aboriginal parents, perinatal service providers, Aboriginal Elders and key stakeholders (service providers, researchers, policy-makers and community leaders working to address complex trauma). We invite key stakeholders from all Australian jurisdictions to participate in the four co-design workshops to enable broader national collaboration in planning for subsequent program implementation and evaluation.

Data storage and triangulation

All data will be securely stored using REDCap software,[48] and accessible only to members of the project team. Wherever possible, data will be stored in de-identified form. However, where concerns exist about the health of a participant, the safety plans and responses relating to that participant will be stored to enable appropriate follow-up by healthcare professionals.

Multiple data sources will be triangulated within this project (as described below), which will increase confidence in the findings through the confirmation of proposed ideas from two or more independent sources.[49]

Description of activities with ‘phase one’ HREC approval

Action research cycle 1

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3 This first action research cycle includes: (a) evidence reviews, (b) the first key stakeholder
4 workshop, (c) mapping domains included within existing assessment tools, and (d) a pilot
5 discussion group with senior Aboriginal women.
6

7
8 *1a: Evidence reviews: Scoping review and evidence map of studies involving parents in the*
9 *perinatal period with a history of childhood maltreatment; and comprehensive systematic*
10 *reviews*

11 The purpose of the scoping review and evidence map was to identify preliminary evidence,
12 and enable development of protocols for a series of comprehensive systematic reviews
13 (Supplementary file 3). The scoping review findings have been incorporated into subsequent
14 research activities and has been critical to refine the search strategy for a series of
15 comprehensive reviews.[50]
16

17
18 *1b: Key stakeholder workshop 1*

19 The purpose of workshop 1, aligned with IM step 1, was to provide a forum for preliminary
20 engagement with key stakeholders to:
21

- 22 • Introduce the rationale for the project and share preliminary evidence from the
- 23 scoping review to enable informed discussion and clarification of goals (logic model).
- 24 • Establish safety protocols for working with parents, service providers, key
- 25 stakeholders, team members, and the wider Aboriginal community.
- 26 • Understand the context and issues for key stakeholders regarding identifying and
- 27 supporting Aboriginal parents experiencing complex trauma.
28
29

30
31 Recruitment and sample: Key stakeholders were identified through consultation and using
32 snowballing during an ongoing process of advertising about the project through Aboriginal
33 and academic health networks, professional meetings and conferences. People expressing
34 interest in the project were included in a key stakeholder email list, and received updates
35 about the project and invitations to the workshops which were cost-free to enable attendance.
36 Approximately 40 people participated in workshop 1.
37

38 Data collection and analysis: A facilitation guide was developed to address the aims of the
39 workshop (Supplementary file 4) and promote a culturally and emotionally safe environment.
40 Strategies to support participants who may experience trauma ‘triggering’ during the
41 workshop and psychological support were provided.
42

43 Data were collected in the form of workshop materials developed by participants (butchers
44 paper notes) and observer notetakers. Data were collated into themes and circulated to
45 workshop participants to check the accuracy of the interpretations. A summary of the
46 workshop is available on the project website.[51] Findings were used for planning workshop
47 2 (2a) and developing the conceptual framework and a detailed safety protocol.
48
49

50
51 *1c: Scoping assessment tools*

52 The purpose of scoping existing assessment tools for complex trauma and/or a parental
53 history of child maltreatment was to:
54

- 55 • Map the range of areas of distress included within existing assessment tools.
- 56 • Enable informed consultation with key stakeholders about each of the main areas of
57 distress and if all important areas were considered.
58

59 Data collection and analysis: Assessment tools were identified through the scoping review
60 and consultation. For each tool, data were extracted on: description of the tool; key

1
2
3 references; validation information; symptoms of distress and/or trauma exposures measured.
4 Data were synthesised into summary ‘areas of distress’ (Supplementary file 5), and further
5 refined by the research team for presentation to key stakeholders at workshop 2.
6

7 *1d: Pilot discussion group with senior Aboriginal women*

8
9 The purpose of this discussion group was to:

- 10 1. Consult with community leaders about the effects of complex trauma during the
11 perinatal period for Aboriginal parents, and what might help or hinder the parenting
12 transition.
- 13 2. Pilot qualitative methods proposed for use with parents, and gather feedback on the
14 safety and appropriateness of these approaches and tools.
15
16

17
18 Recruitment and sample: A convenience sample of six to eight senior Aboriginal members of
19 a community group that had expressed interest in the project.

20
21 Data collection and analysis: A facilitation plan was developed that included use of: visual
22 tools and natural materials to facilitate discussions; cards illustrating the main themes from
23 the scoping review to build on existing research; third person scenarios to increase safety and
24 minimise the ‘directness’ of sensitive discussions so they are not intrusive; use of metaphors
25 and symbolism; and a ‘strengths-based’ focus on ‘healing’ rather than ‘trauma’. The
26 discussion group was facilitated by an Aboriginal psychologist (YC) and Aboriginal midwife
27 (CC) with expertise in conducting discussion groups with Aboriginal people. Additional
28 psychological support was available in line with the detailed safety plan.
29

30
31 A detailed discussion group protocol was developed (available on request). Data were
32 collected in the form of visual notes and images provided by group participants, observer
33 notes and a recording of the discussion which was transcribed verbatim. Two Aboriginal
34 researchers (YC, CC) independently coded data into themes (thematic analysis)[52] and these
35 were discussed with participants to check the interpretation of the data accurately reflected
36 both what was said as well as the intent. Themes were shared with key stakeholders at
37 workshop 2.
38

39 **Action research cycle 2**

40
41 The second action research cycle includes: (a) a second key stakeholder workshop, (b)
42 refining the assessment tool domains and preliminary questions for parents, (c) identifying
43 ‘gold standard’ assessment for comparison in psychometric testing, training and cultural
44 adaptation (if required), and (d) first round of discussion groups with parents who have
45 experienced complex childhood trauma.
46

47 *2a: Key stakeholder workshop 2*

48
49 The purpose of workshop 2 was to reflect on the activities from action research cycle 1 and
50 plan for ethics phase 2. This is aligned with IM step 2 and includes refining the project
51 objectives and consulting with key stakeholders regarding:

- 52 • The areas of distress to be included in an assessment tool.
- 53 • Reflection on pilot discussions with senior Aboriginal women regarding areas of
54 strengths and pre-testing the proposed approach for working with parents.
55
56

57
58 Recruitment and sample: Key stakeholders were identified as described in 1b, with
59 approximately 60 participants attending.
60

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3 Data collection and analysis: A facilitation guide was developed to address the aims of the
4 workshop (Supplementary file 6) and promote a culturally and emotionally safe environment.
5 A traditional healer (*Ngangkerre*) worked alongside the registered psychologist to cater for
6 different support needs and recognise the equal value of respective expertise.
7

8
9 Data regarding the 12 summary areas of distress were gathered using a modified Delphi
10 approach. Each area of distress was allocated to a table and facilitator. Participants gathered
11 in groups of six to eight at one table and were given individual forms (non-identified) with a
12 description of the area of distress, with additional information provided by the facilitator.
13 They were asked to indicate the degree of ‘importance’ (1-5) of the area of distress, and
14 discuss and/or document any comments about why, who, where and how questions regarding
15 this area of distress should be asked. Participants rotated around all 12 tables. Data were
16 transcribed and imported into NVivo for thematic analysis and future triangulation with data
17 to be collected at workshops 3 and 4.
18

19
20 Reflections regarding the discussion group with senior Aboriginal women and pre-testing the
21 discussion group approach for use with parents were recorded by participants pictorially
22 using sticky notes on butchers paper. These were photographed, coded into themes and
23 imported into NVivo for thematic analysis and future triangulation.
24

25 *2b: Developing assessment tool areas of distress and strength questions for parents*

26
27 The purpose of refining the assessment tool ‘areas of distress’ and strength questions is to
28 enable initial evaluation of ‘face validity’ of the questions with parents and identify any
29 important issues requiring direct discussion with parents.
30

31 Data collection and analysis: Data collected in key stakeholder workshop 1 (1b), scoping
32 assessment tools (1c) and workshop 2 (2a) will be collated in NVivo for thematic analysis.
33 These themes and issues will be refined in consultation with the research team to propose
34 questions related to ‘areas of distress’ to be included in an assessment tool. Questions for
35 assessing each of these areas of distress will be drafted, based on questions validated in
36 existing tools (International Trauma Questionnaire and a version of the Harvard Trauma
37 Questionnaire adapted for Aboriginal people and cultural resources regarding mental health
38 literacy).[53, 54]
39

40
41 Strengths questions will be developed by the research team, based on strength themes
42 identified from the scoping review, workshop activities, pilot discussion group and other
43 strength-based tools. The core values from the conceptual framework will be applied to
44 assess the degree to which each of the proposed questions is consistent with the values and
45 principles of the project, and discussed in relation to key issues raised in the thematic
46 analysis. The preliminary over-inclusive question list will be discussed with the research
47 team, and ‘pretested’ in a convenience sample of Aboriginal colleagues. The proposed
48 questions will be incorporated into the first round of discussion groups with parents to
49 evaluate preliminary ‘face validity’ of the proposed questions.
50

51 *2c: Identifying ‘gold standard’ assessment for comparison in psychometric testing, training 52 and cultural adaptation (if required).*

53
54 The purpose of this activity is to identify the best possible ‘gold standard’ for comparison
55 with our proposed assessment tool.
56

57 Data collection and analysis: A preliminary list of suitable tools for use as a ‘gold standard’
58 was generated by consensus within the research team following a systematic and transparent
59 process of consideration. From this, the trauma section of the WHO World Mental health
60

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2
3 Composite International Diagnostic Interview (CIDI) has been proposed. Consultation about
4 the proposed ‘gold standard’ will also be conducted with three or four additional key external
5 psychiatric and psychological experts.
6

7 Up to six Aboriginal psychologists will train together in the use of the ‘gold standard’
8 structured clinical interview to enable them to reflect and use their cultural and clinical
9 expertise. They will advise whether any aspects need adaptation for use with Aboriginal
10 parents.
11

12 **Description of activities with ‘phase two’ HREC approval**

13 *2d: First round of discussion groups with Aboriginal parents*

14 The purpose of the first round of discussion groups with Aboriginal parents is to:
15

- 16 • Understand key perinatal experiences affecting Aboriginal parents and what kinds of
17 awareness (trauma-informed care) and support strategies might help or hinder the
18 transition to parenting for parents experiencing complex trauma; and
- 19 • Evaluate the ‘face validity’ of draft questions in a preliminary assessment tool.
20
21
22

23 Recruitment and sample: Approximately 24 Aboriginal parents will be invited to participate
24 in discussion groups, one to three groups per participating jurisdiction with up to eight
25 parents in each. The size of the group will be determined by the study coordinator in
26 consultation with service provider staff regarding the most appropriate mix of: gender, the
27 level of comfort of participants in group discussion and language. We estimate that this will
28 be sufficient to produce theoretical saturation of thematic categories, particularly when
29 triangulated with data from the pilot discussion group and key stakeholder workshops.
30 However, if saturation of themes is not reached we will consider further discussion groups as
31 needed.
32
33

34 Individual parents will be recruited through the services they attend for perinatal care using
35 direct and indirect methods. Service providers will be given written and verbal information
36 about the study by the research team. Service providers will then ask potentially eligible
37 parents if they give consent to be contacted by the research team to discuss the study in more
38 detail and consider if they would like to consent to participate in the discussion group.
39 Parents may be asked if they would like to be contacted by the research team in a private area
40 while waiting to attend for services, after a consultation, or during other community
41 activities. Additionally, flyers will be displayed describing the purpose of the study and
42 providing contact details for parents to contact the research team directly.
43
44

45 Inclusion criteria: Participants will be eligible to participate if they identify as Aboriginal
46 and/or Torres Strait Islander, are aged 16 years or older, and they or their partner are
47 currently pregnant or have a child less than two years of age.
48

49 Exclusion criteria: Parents experiencing current serious mental illness (e.g. acute psychotic
50 episode or other issue which may affect their capacity to provide informed consent and/or
51 pose a risk to the safety of the parent and other participants in the discussion group). This will
52 be assessed by service staff prior to asking for consent to be contacted, and by the research
53 team prior to asking for consent to participate in the discussion group.
54
55

56 Data collection and analysis: A facilitation plan will be refined based on feedback from the
57 pilot discussion group (1d) and workshop 2 (2a). The discussion group will be facilitated by
58 an Aboriginal researcher with expertise in conducting discussion groups with Aboriginal
59 peoples. Psychological support will be provided. A facilitation plan (Supplementary file 7)
60

has been developed that includes use of: visual tools and natural materials to facilitate discussions; cards illustrating the main themes from the scoping review to build on existing research; third person scenarios to increase safety and minimise the ‘directness’ of sensitive discussions so they are not intrusive; use of metaphors and symbolism to explain complex phenomena; and a ‘strengths-based’ focus. Data will be collected using visual notes prepared by participants in a ‘tree of life’ activity to frame discussions about the needs for Aboriginal parents experiencing complex trauma, and transcribed audio recordings of the discussions.

Two researchers will independently conduct thematic analysis and discuss draft themes with participants to check the interpretation of the data. The themes from this discussion group will be triangulated with data from previous project activities and shared with key stakeholders participating in workshop 3.

Action research cycle 3

The third action research cycle includes: (3a) key stakeholder co-design workshop 3, (3b) psychometric evaluation of assessment tool, (3c) a second round of discussion groups with parents, and (3d) discussion groups with service providers.

3a: Key stakeholder co-design workshop 3

The purpose of workshop 3, aligned with IM step 3, is to co-design the preliminary recognition and assessment process/tool and possible awareness and support strategies.

Recruitment and sample: Key stakeholders will be identified as previously described, with up to 60 participants anticipated.

Data collection and analysis: A facilitation guide will be developed to address the aims of the workshop and promote a culturally and emotionally safe environment as per previous workshop. The workshop will incorporate triangulated data from previous action research cycles to foster informed decision-making for preliminary ‘co-design of awareness, recognition, assessment and support strategies’ aligned with IM step 3.

Brief outline of activities to be submitted for ‘phase three’ HREC approval

The detailed methods for the following activities will be refined based on feedback from ‘reflection’ and ‘planning’ from activities described in ‘phase one and two’ and consultation with partner organisation staff and submitted for ethical approval. This will include recruitment processes, eligibility criteria, data collection and analysis strategies. A brief outline of main activities, aims and sample size estimates are included below.

3b: Psychometric evaluation of assessment tool, which aims to develop a valid assessment tool that enables perinatal care providers to accurately identify strengths, as well as complex trauma symptoms (measurement sensitivity) whilst minimising the erroneous identification of parents who are not experiencing complex trauma symptoms (measurement specificity).

The sensitivity of a complex trauma assessment will need to be high for the inventory to be effective and appropriate for use in practice, where our priority would be that all parents who could benefit from further assessment and support are recognised. Based on previous estimates of Post Traumatic Stress Disorder (PTSD) and complex trauma,[54-63] we conservatively estimate that 20% of Aboriginal parents will meet sub-threshold criteria of at least two symptoms. Identifying parents meeting sub-threshold criteria will maximise the sensitivity of the instrument to identify PTSD and complex trauma and we estimate that a sensitivity of 90% would be achieved. Thus, a sample size of 173 participants will be required to yield an estimate of the instrument sensitivity with a 2-sided 95% confidence

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3 interval with a width of 10% of the estimate. This sample size will also enable estimation of
4 the specificity of the instrument to correctly identify participants who had not experienced
5 complex trauma.
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8 *3c: Second round of discussion groups with parents*, which aim to assess the acceptability of
9 the proposed recognition and assessment process; and awareness and support strategies.
10 Approximately 24 Aboriginal parents will be recruited to participate in discussion groups,
11 one to three groups per participating jurisdiction with up to eight parents in each.

12
13 *3d: Discussion groups with service providers*, which aim to assess the feasibility of the
14 proposed recognition and assessment process; and awareness and support strategies.
15 Approximately 24 service providers will be recruited to participate in discussion groups, one
16 to two groups per participating jurisdiction with up to eight service providers in each.
17

18 **Action research cycle 4**

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20 The fourth and final action research cycle includes a fourth key stakeholder workshop and
21 drafting plans.
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23 *4a: Key stakeholder workshop 4*, which aims to reflect on the research findings and refine
24 plans for seeking funding to pilot, implement (IM step 5) and evaluate (IM step 6) perinatal
25 awareness, recognition, assessment and support strategies.
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27 **ETHICS AND DISSEMINATION**

28 **Ethics**

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30 Action research poses unique challenges for seeking HREC approval. While there is an
31 overarching structure and an outline of main activities, the detail required for ethical approval
32 evolves during the action research process. In this project, submissions for HREC approval
33 will be submitted to relevant jurisdictional authorities in three phases. This is particularly
34 important in a project involving sensitive content such as complex trauma, where the HREC
35 need to examine draft tools and resources to consider risks for triggering distress symptoms
36 against potential benefits. This staged approach also enables piloting and reflection on the
37 'safety' of the research activities and flexibility to refine research processes. For example, in
38 this project, discussions were first held with a predominantly professional group of 'key
39 stakeholders' in workshop one, then with a group of senior Aboriginal women in a 'pilot'
40 discussion, and then a proposed approach was 'pretested' in a second 'key stakeholder'
41 workshop, prior to submitting the final plans for discussion groups directly with Aboriginal
42 parents. The intent is to ensure our approach and processes maximise safety and minimise
43 the risk of distress for parents, while also gathering the data needed to inform development of
44 awareness, recognition, assessment and support strategies. At the time of submitting this
45 protocol, HREC approval had been granted for phase one (see Figure 2).
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50 The funding proposal for this project was assessed by an Indigenous research panel using the
51 National Health and Medical Research Council Indigenous Research Excellence criteria
52 (Supplementary file 2) developed to promote ethical and culturally appropriate research with
53 Aboriginal communities. In addition, we have developed a conceptual framework (Figure 1)
54 which outlines the ethical and cultural values for this project. A specific safety framework
55 describes how the primary value of safety will be fostered for parents, service providers, key
56 stakeholders and team members, and the broader Aboriginal community.
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59 **Dissemination**

We have developed a research dissemination plan (available on request), in line with the Indigenous Research Excellence criteria (Supplementary file 1) and the value of reciprocity.

The research dissemination plan includes:

- Offering two-way information exchange for all community meetings (i.e. prior to the meeting asking if there are any presentations about topics people would like us to offer to their staff and community members about complex trauma and parenting).
- Publication of articles in open access journals with links to relevant Aboriginal health websites.
- Face to face presentations in national and international conferences.
- Translating all findings into plain language summaries.
- Incorporating art, presentations and other mediums to present information.
- Preparing a video/short YouTube clip with essential information for community members and making this freely available on the project website and sharing at community meetings.
- Ensuring all relevant information is presented on the research website, which is regularly monitored for currency, optimised for search engine performance, and follows accessibility guidelines.

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AUTHOR CONTRIBUTIONS

CC drafted this protocol based on the project proposal and other relevant project documents. All authors are investigators who contributed to the project proposal, project documents and the draft manuscript.

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COMPETING INTERESTS STATEMENT

No competing interests were declared.

REFERENCES

1. McCrory E, De Brito S, Viding E. Research review: The neurobiology and genetics of maltreatment and adversity. *J Child Psychol Psychiatry* 2010;51(10):1079-95.
2. De Bellis MD, Zisk A. The biological effects of childhood trauma. *Child Adolesc Psychiatr Clin N Am* 2014;23(2):185-222.
3. Brent DA, Silverstein M. Shedding light on the long shadow of childhood adversity. *JAMA* 2013;309(17):1777-78.
4. Norman RE, Byambaa M, De R, et al. The long-term health consequences of child physical abuse, emotional abuse, and neglect: A systematic review and meta-analysis. *PLoS Med* 2012;9(11):e1001349. doi: 10.1371/journal.pmed.1001349
5. Sara G, Lappin J. Childhood trauma: Psychiatry's greatest public health challenge? *Lancet Public Health* 2017;2(7):e300-e01. doi: 10.1016/S2468-2667(17)30104-4
6. Bellis MA, Hughes K, Leckenby N, et al. National household survey of adverse childhood experiences and their relationship with resilience to health-harming behaviors in England. *BMC Med Inform Decis Mak* 2014;12(1):72. doi: 10.1186/1741-7015-12-72
7. Felitti VJ, Anda RF, Nordenberg D, et al. Relationship of childhood abuse and household dysfunction to many of the leading causes of death in adults. *Am J Prev Med* 1998;14(4):245-58. doi: 10.1016/S0749-3797(98)00017-8
8. Maercker A, Brewin CR, Bryant RA, et al. Diagnosis and classification of disorders specifically associated with stress: proposals for ICD-11. *World Psychiatry* 2013;12(3):198-206. doi: 10.1002/wps.20057
9. Kezelman C, Stavropoulos P. Practice guidelines for treatment of complex trauma and trauma informed care and service delivery. Sydney: Adults Surviving Child Abuse, 2012.
10. Sotero MA. A conceptual model of historical trauma: Implications for public health practice and research. *J Health Dispar Res Pract* 2006;1(1):93-108.
11. Atkinson J, Nelson J, Atkinson C. Trauma, transgenerational transfer and effects on community wellbeing. In: Purdie N, Dudgeon P, Walker R, eds. Working Together: Aboriginal and Torres Strait Islander mental health and wellbeing practices and principles. Canberra: Department of Health and Ageing 2010:135-44.
12. Violence Prevention Alliance. The ecological framework. Geneva, Switzerland: World Health Organisation; 2016 [Available from: <http://www.who.int/violenceprevention/approach/ecology/en/> accessed 9/9/2016].
13. Lieberman AF, Chu A, Van Horn P, et al. Trauma in early childhood: Empirical evidence and clinical implications. *Dev Psychopathol* 2011;23(2):397-410. doi: 10.1017/s0954579411000137
14. Sperlich M, Seng J, Rowe H, et al. A cycles-breaking framework to disrupt intergenerational patterns of maltreatment and vulnerability during the childbearing year. *J Obstet Gynecol Neonatal Nurs* 2017;46(3):378-89. doi: 10.1016/j.jogn.2016.11.017
15. Stephenson LA, Beck K, Busuulwa P, et al. Perinatal interventions for mothers and fathers who are survivors of childhood sexual abuse. *Child Abuse Negl* 2018;80:9-31. doi: 10.1016/j.chiabu.2018.03.018
16. Amos J, Furber G, Segal L. Understanding maltreating mothers: A synthesis of relational trauma, attachment disorganization, structural dissociation of the personality, and experiential avoidance. *J Trauma Dissociation* 2011;12(5):495-509. doi: 10.1080/15299732.2011.593259
17. Alexander P. Intergenerational cycles of trauma and violence: An attachment and family systems perspective. New York, NY: W W Norton & Co 2015.

18. Bridgett DJ, Burt NM, Edwards ES, et al. Intergenerational transmission of self-regulation: A multidisciplinary review and integrative conceptual framework. *Psychol Bull* 2015;141(3):602-54. doi: 10.1037/a0038662
19. Siegel JP. Breaking the links in intergenerational violence: An emotional regulation perspective. *Family Process* 2013;52(2):163-78.
20. Fava NM, Simon VA, Smith E, et al. Perceptions of general and parenting-specific posttraumatic change among postpartum mothers with histories of childhood maltreatment. *Child Abuse Negl* 2016;56:20-29.
21. Green-Miller SN. Intergenerational parenting experiences and implications for effective interventions of women in recovery. *Dissertation Abstracts International Section A: Humanities and Social Sciences* 2012;73(5-A):1926.
22. Segal L, Dalziel K. Investing to protect our children: Using economics to derive an evidence-based strategy. *Child Abuse Rev* 2011;20(4):274-89. doi: 10.1002/car.1192
23. Richter LM, Daelmans B, Lombardi J, et al. Investing in the foundation of sustainable development: Pathways to scale up for early childhood development. *The Lancet* 2017;389(10064):103-18. doi: 10.1016/S0140-6736(16)31698-1
24. Britto PR, Lye SJ, Proulx K, et al. Nurturing care: promoting early childhood development. *The Lancet* 2016;389(10064):91-102. doi: 10.1016/S0140-6736(16)31390-3
25. Barlow J, MacMillan H, Macdonald G, et al. Psychological interventions to prevent recurrence of emotional abuse of children by their parents. *Cochrane Database Syst Rev* 2013(9):CD010725. doi: 10.1002/14651858.CD010725
26. DeGregorio LJ. Intergenerational transmission of abuse: implications for parenting interventions from a neuropsychological perspective. *Traumatology* 2013;19(2):158-66. doi: 10.1177/1534765612457219
27. Bowes J, Grace R. Review of early childhood parenting, education and health intervention programs for Indigenous children and families in Australia. Issues paper no 8. Produced for the Closing the Gap Clearinghouse. Canberra: Australian Institute of Health and Welfare, and Melbourne: Australian Institute of Family Studies, 2014.
28. Palmer VJ, Weavell W, Callander R, et al. The Participatory Zeitgeist: An explanatory theoretical model of change in an era of coproduction and codesign in healthcare improvement. *Med Humanit* 2018 doi: 10.1136/medhum-2017-011398 [published Online First: 28/6/2018]
29. Haebich A. Broken circles: Fragmenting Indigenous families 1800-2000. Fremantle: Fremantle Arts Centre Press 2000.
30. BigFoot DS, Schmidt SR. Honoring children, mending the circle: Cultural adaptation of trauma-focused cognitive-behavioral therapy for American Indian and Alaska Native children. *J Clin Psychol* 2010;66(8):847-56. doi: doi:10.1002/jclp.20707
31. Gee G, Dudgeon P, Schultz C, et al. Understanding social and emotional wellbeing and mental health from an Aboriginal and Torres Strait Islander perspective. In: Dudgeon P, Milroy H, Walker R, eds. Working Together: Aboriginal and Torres Strait Islander Health and Wellbeing Principles and Practice Second ed. Canberra: Australian Council for Education Research and Telethon Institute for Child Health Research, Office for Aboriginal and Torres Strait Islander Health, Australian Government Department of Health and Ageing 2014.
32. Sexton MB, Davis MT, Menke R, et al. Mother-child interactions at six months postpartum are not predicted by maternal histories of abuse and neglect or maltreatment type. *Psychol Trauma* 2017;9(5):622-26. doi: 10.1037/tra0000272

- 1
- 2
- 3
- 4 33. Thornberry TP, Knight KE, Lovegrove PJ. Does maltreatment beget maltreatment? A
- 5 systematic review of the intergenerational literature. *Trauma Violence Abuse*
- 6 2012;13(3):135-52. doi: 10.1177/1524838012447697
- 7 34. Dudgeon P, Milroy J, Calma T, et al. Aboriginal and Torres Strait Islander Suicide
- 8 Prevention Evaluation Project (ATSISPEP) report. Solutions that work: What the
- 9 evidence and our people tell us. Perth: University of Western Australia, 2016.
- 10 35. Rodriguez CM, Green AJ. Parenting stress and anger expression as predictors of child
- 11 abuse potential. *Child Abuse Negl* 1997;21(4):367-77.
- 12 36. Guarino K, Soares P, Konnath K, et al. Trauma-informed organizational toolkit.
- 13 Rockville, MD: Center for Mental Health Services, Substance Abuse and Mental
- 14 Health Services Administration, the Daniels Fund, the National Child Traumatic
- 15 Stress Network, and the W.K. Kellogg Foundation, 2009.
- 16 37. Denby C, Winslow C, Willette C, et al. The Trauma Toolkit: A resource for service
- 17 organizations and providers to deliver services that are trauma-informed. Winnipeg,
- 18 Canada: Clinic Community Health Centre, 2008.
- 19 38. Atkinson C, Atkinson J, Wrigley B, et al. Aboriginal Family Violence Prevention Legal
- 20 Services: Culturally informed trauma integrated healing approach - A guide for action
- 21 for trauma champions. Canberra: Commonwealth of Australia, 2017.
- 22 39. College of Aboriginal and Torres Strait Islander Nurses and midwives; Australian
- 23 College of Midwives; CRANA Plus. Birthing on Country position statement.
- 24 Canberra: College of Aboriginal and Torres Strait Islander Nurses and midwives,
- 25 Australian College of Midwives and CRANA Plus 2016.
- 26 40. MacDonald C. Understanding participatory action research: A qualitative research
- 27 methodology option. *Canadian Journal of Action Research* 2012;13(2):34-50.
- 28 41. Ivankova NV. Applying mixed methods in community-based participatory action
- 29 research: A framework for engaging stakeholders with research as a means for
- 30 promoting patient-centredness. *J Res Nurs* 2017;22(4):282-94. doi:
- 31 10.1177/1744987117699655
- 32 42. Panaretto KS, Wenitong M, Button S, et al. Aboriginal community controlled health
- 33 services: Leading the way in primary care. *Med J Aust* 2014;200(11):649-52.
- 34 43. Bartholomew Eldridge LK, Markham CM, Ruiter RAC, et al. Planning health promotion
- 35 programs: An Intervention Mapping approach. 4 ed. Hoboken, NJ: Wiley 2016.
- 36 44. Johnstone L, Boyle M, Cromby J, et al. The Power Threat Meaning Framework: Towards
- 37 the identification of patterns in emotional distress, unusual experiences and troubled
- 38 or troubling behaviour, as an alternative to functional psychiatric diagnosis. Leicester:
- 39 British Psychological Society, 2018.
- 40 45. Australian Health Ministers' Advisory Council. Population based screening framework.
- 41 Barton: Commonwealth of Australia, 2008.
- 42 46. Rigney L. Indigenous Australian views on knowledge production and Indigenist research.
- 43 In: Runnie J, Goduka N, eds. Indigenous peoples' wisdom and power: Affirming our
- 44 knowledge. Burlington, USA: Ashgate Publishing 2006:32-48.
- 45 47. Australian Health Ministers' Advisory Council. Aboriginal and Torres Strait Islander
- 46 health performance framework 2017 report. Canberra: Australian Health Ministers'
- 47 Advisory Council, 2017.
- 48 48. Harris P, Taylor R, Thielke R, et al. Research electronic data capture (REDCap) - A
- 49 metadata-driven methodology and workflow process for providing translational
- 50 research informatics support. *J Biomed Inform* 2009;42(2):377-81.
- 51 49. Heale R, Forbes D. Understanding triangulation in research. *Evid Based Nurs*
- 52 2013;16(4):98. doi: 10.1136/eb-2013-101494
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 - 60
50. Chamberlain C, Stansfield C, Sutcliffe K, et al. Perinatal experiences and views of parent's with a history of adverse childhood experiences: A protocol for a systematic review of qualitative studies. *PROSPERO: International prospective register of systematic reviews* 2018;CRD42018102110
51. Ralph N, Clark Y, Gee G, et al. Healing The Past by Nurturing the Future: Perinatal support for Aboriginal and Torres Strait Islander parents who have experienced complex childhood trauma - Workshop one report. Bundoora, Melbourne: Judith Lumley Centre, La Trobe University, 2018.
52. Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol* 2006;3(2):77-101.
53. NPY Womens Council Aboriginal Corporation. Uti Kulintjaku 2018 [Available from: <https://www.npywc.org.au/ngangkari/uti-kulintjaku/> accessed 2/12/2016].
54. Atkinson C. The violence continuum: Aboriginal Australian male violence and generational post-traumatic stress. Charles Darwin University, 2008.
55. Ben-Ezra M, Karatzias T, Hyland P, et al. Posttraumatic stress disorder (PTSD) and complex PTSD (CPTSD) as per ICD-11 proposals: A population study in Israel. *Depress Anxiety* 2018;35(3):264-74. doi: 10.1002/da.22723
56. Hyland P, Shevlin M, Brewin CR, et al. Validation of post-traumatic stress disorder (PTSD) and complex PTSD using the International Trauma Questionnaire. *Acta Psychiatr Scand* 2017;136(3):313-22. doi: 10.1111/acps.12771
57. Muzik M, Morelen D, Hruschak J, et al. Psychopathology and parenting: An examination of perceived and observed parenting in mothers with depression and PTSD. *J Affect Disord* 2017;207:242-50. doi: 10.1016/j.jad.2016.08.035
58. Muzik M, McGinnis EW, Bocknek E, et al. PTSD symptoms across pregnancy and early postpartum among women with lifetime PTSD diagnosis. *Depress Anxiety* 2016;33(7):584-91. doi: 10.1002/da.22465 [published Online First: 2016/01/08]
59. Quispel C, Schneider TA, Hoogendijk WJ, et al. Successful five-item triage for the broad spectrum of mental disorders in pregnancy - A validation study. *BMC Pregnancy Childbirth* 2015;15:51. doi: 10.1186/s12884-015-0480-9
60. Wenz-Gross M, Weinreb L, Upshur C. Screening for post-traumatic stress disorder in prenatal care: Prevalence and characteristics in a low-income population. *Matern Child Health J* 2016;20(10):1995-2002. doi: 10.1007/s10995-016-2073-2
61. Yildiz PD, Ayers S, Phillips L. The prevalence of posttraumatic stress disorder in pregnancy and after birth: A systematic review and meta-analysis. *J Affect Disord* 2017;208:634-45. doi: 10.1016/j.jad.2016.10.009
62. Gee G. Resilience and recovery from trauma among aboriginal help seeking clients in an urban Aboriginal community controlled health organisation. University of Melbourne, 2016.
63. Gartland D, Woolhouse H, Giallo R, et al. Vulnerability to intimate partner violence and poor mental health in the first 4-year postpartum among mothers reporting childhood abuse: An Australian pregnancy cohort study. *Arch Womens Ment Health* 2016;19(6):1091-100. doi: 10.1007/s00737-016-0659-8
64. Kline T. Psychological testing: A practical approach to design and evaluation. Thousand Oaks, CA: Sage Publications Inc 2005.
65. Healing the Past by Nurturing the Future project Melbourne, Australia: La Trobe University; 2018 [Available from: <https://www.latrobe.edu.au/jlc/research/healing-the-past/workshops/past-workshops> accessed 2/12/2018].

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3 **FIGURE CAPTIONS**
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5 **Figure 1: Conceptual framework for co-designing perinatal awareness, recognition,**
6 **assessment and support strategies for Aboriginal parents experiencing complex trauma.**
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9 **Figure 2: ‘Healing the Past by Nurturing the Future’ Research Plan**
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For peer review only

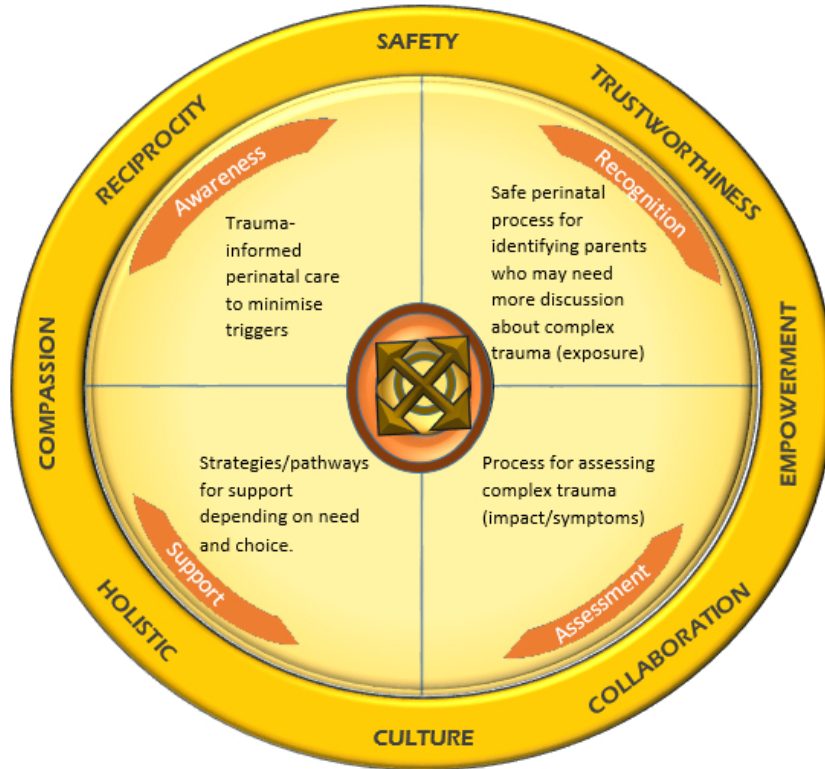


Figure 1: Conceptual framework for co-designing perinatal awareness, recognition, assessment and support strategies for Aboriginal parents experiencing complex trauma.
Artwork by Danielle Dyll.

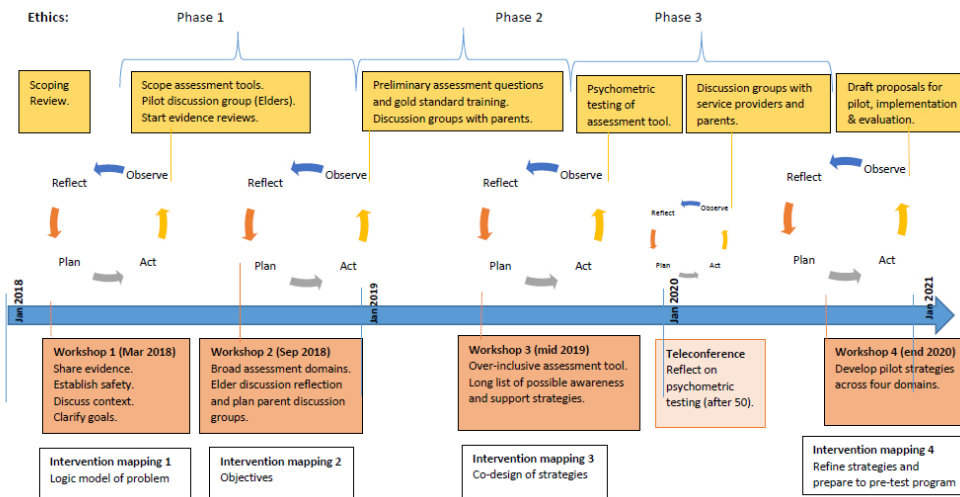


Figure 2: 'Healing the Past by Nurturing the Future' Research Plan

Supplementary file 1: ‘Healing the Past by Nurturing the Future’ conceptual framework values, principles and reflective questions

Value	Value description	Related principles	Reflective questions
<i>Safety*</i>	<p>Safety in the context of trauma refers to efforts to ensure safety for service users, staff, key stakeholders and the broader community. This means reasonable freedom from harm or danger and to prevent further traumas from occurring. Emotional, cultural and physical safety are included in this term, and are defined in the HPNF safety protocol. The importance of ensuring safety in programs is highlighted by being the number one principle in numerous existing guidelines,¹⁻⁵ including the National Trauma Guidelines.¹</p>	<p>The principle of respect and commitment to all forms of diversity and different cultural backgrounds is foundational to trauma-informed care.^{1,3} As safety and trust are established, the two-way dialogue between worker and client enables all voices to be heard and mutual respect in the ongoing maintenance of a culturally safe environment.³ Self-reflection and workplace reflexivity are crucial, and more detailed information about cultural safety are outlined in the safety protocol.</p>	<p>a. To what extent do the project’s activities and settings ensure the physical, cultural and emotional safety of:</p> <ul style="list-style-type: none"> • Parents and community members participating in the research? • Service providers? • Stakeholder and team members involved in the co-design process? • The broader community? <p>b. Are there protocols to protect privacy?³</p> <p>c. Are people approached in a private not public space when asking personal questions?³</p> <p>d. Are questions asked in such a way that people do not feel obliged to answer unless they choose?³</p> <p>e. How can safety be ensured in the asking of such questions?¹– including minimising risks of inappropriate referral to child protection services.</p> <p>f. Are questions that involve disclosure combined with stay/strong plans and support if needed?³</p> <p>g. Is the environment for sensitive discussions inviting and accessible?¹</p> <p>h. Are the first contacts welcoming, respectful and engaging?¹</p> <p>i. Are policies and practices in place to foster cultural safety, self-enquiry and self-reflection in the workplace?³</p>
<i>Trustworthiness*</i>	<p>Fostering trust is another critical principle included in national and other trauma-related guidelines.^{1,6} Trust was also highlighted by project key stakeholders in workshop 1.</p>	<p>Key principles for fostering trust include being honest and transparent⁷ and clear and consistent.¹ Key stakeholders in workshop 1 highlighted the important principle of transparency and demonstrating responsibility, leadership and a commitment to goals to ensure timelines are adhered to and that we do what we say we will. Understanding relatedness (how the person engages in the world which they live and learn) and building authentic and positive relationships³ are central principles to achieving</p>	<p>a. To what extent do the project’s activities and settings maximise trustworthiness by making the tasks involved clear, and by ensuring consistency and transparency?⁷</p> <p>b. Are there processes in place to reflect on commitments made and whether these are being adequately addressed and demonstrated?</p> <p>c. How can the project maximise honesty and transparency?¹</p> <p>d. Are professional boundaries maintained?¹</p> <p>e. Are there processes in place for fostering deep listening and trusting relationships?</p> <p>f. Are services family friendly?³</p> <p>g. Are parents aware of any risks? Including honest and transparent discussions about the risks of being referred to child protection services etc?</p> <p>h. What is involved in the informed consent process?¹</p>

		<p>trustworthiness. In this project we are adopting a strengths-based approach, focusing on capabilities that people bring and we aim to practise deep listening. Facilitating peer-to-peer support across the workplace, families and social groups is also very important.^{3, 5, 6}</p>	<p>i. Does the program provide a clear explanation of what will be done, by whom, when, why, under what circumstances, at what cost and with what goals?¹</p>
<p><i>Empowerment*</i></p>	<p>Fostering empowerment is a critical value for overcoming the transgenerational effects of complex trauma among Aboriginal parents and communities.^{1, 5}</p>	<p>Principles to promote empowerment include maximising choice, control and autonomy and opportunities to actively make decisions.^{1, 3, 5, 6, 8} Using a strengths-based approach to build competencies and recognise the capabilities that individuals bring can help to foster a sense of empowerment and resilience.^{3, 6} Flexibility is also important⁷ and was highlighted by key stakeholders in workshop 1 (being open to change, asking people if they want to be involved and participate even if it means challenging ourselves). Atkinson et al.³ suggest it is important to enable resilience and recovery using a strengths-based approach which focuses on the capabilities that individuals bring to an issue and incorporate a message of hope and optimism.</p>	<p>a) To what extent do the program’s activities and settings maximise choice and control? b) Does the program build in small choices that make a difference?¹ c) Are choices respected? d) Is the need for standardization of screening across sites balanced with the unique needs of each program or setting?¹ e) Are there choices in the way people can identify concerns they wish to discuss? f) Does the parent or service provider have a choice in the way contact is made?¹ g) Does the program work with the community to monitor and proactively respond to changing priorities and needs?⁹ h) Are parents able to choose not to be swept into care pathways they do not wish? i) To what extent do the program’s activities and settings prioritise consumer empowerment and skill-building? j) How can the project be modified to ensure that experiences of empowerment and the development or enhancement of skills are maximised? k) Are the questions strengths-based and ask ‘what’s happened to you?’ and ‘what’s strong in you?’ rather than ‘what’s wrong with you?’ l) Are messages of hope and optimism conveyed? m) Does the program build individual, family and community capabilities to respond to [trauma] and its risk factors?⁹ n) To what extent do the formal policies of the program reflect an understanding of trauma survivors’ needs, strengths, and challenges? Of staff needs? Are these policies monitored and implemented consistently?¹</p>

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<i>Collaboration*</i>	Collaboration and sharing of power is a key value for addressing trauma, and is also included as a core principle for national trauma guidelines. ^{1, 3, 5, 7}	The first key stakeholder workshop highlighted collaboration and unity as of critical value and suggested this could be achieved by communication (listening and considering other people’s views and how they participate) and participation (recognising community expertise and needs). Committing to participation at all levels and facilitating involvement and engagement are also key elements of the vision incorporated in national and other trauma guidelines. ¹⁰	<ul style="list-style-type: none"> a) To what extent do the program’s activities and settings maximise collaboration and sharing of power? How can the project be modified to ensure that collaboration and power-sharing are maximised?¹ b) Are parents with trauma histories involved in design of programs? c) Are their voices elicited and validated in formulating the plan?¹ d) Does the program cultivate a model of doing ‘with’ rather than ‘to’ or ‘for’ consumers?¹ e) Is the community a partner in the process? f) Does the program support communities and families to address the impact of negative social determinants?⁹ g) Is there a consensus this activity is required?⁹ h) How must we adapt project elements for a particular parent/community member etc? Are there other parts of this modality that may dovetail with other work?¹
<i>Culture</i>	Culture is central to the social and emotional wellbeing of Aboriginal people and the complex trauma experienced by Aboriginal people today is a legacy of the destruction of and violence against Aboriginal culture during colonisation.	Aboriginal understandings of relatedness and nurturing relational development with family, community, culture and country are sophisticated and have been passed down for millennia. Therefore, incorporating cultural knowledge and wisdom into our understandings of complex trauma affecting parents and incorporating ‘culturally informed healing elements’ ⁹ is critical to this project.	<ul style="list-style-type: none"> a) Will the program pro-actively engage people with cultural knowledge? b) Are culturally informed healing elements present? And designed by community/credible cultural leaders?⁹ c) What strategies are in place to protect and preserve traditional knowledge and avoid ‘colonising’ it? d) Are Aboriginal and Western knowledge’s equally respected and valued within the project and information?
<i>Holism</i>	Aboriginal understandings of social and emotional wellbeing are holistic and recognise the inherent relatedness to spirit, body, culture, mind, family, community and country. ¹¹	Principles to foster these holistic values include integrating care to bring together all services and supports needed to holistically meet the needs of individuals, families and communities to enhance their physical, emotional, social, cultural and spiritual wellbeing. ^{3, 5} National guideline visions also include promoting collaboration and	<ul style="list-style-type: none"> a) Is the project integrated with other relevant community services and activities?⁹ b) Are the full range of social, education, health and justice systems etc included? c) Is a life-course perspective integrated? d) Does the recognition and assessment processes avoid unnecessary repetition? While there is no need to ask the same questions at multiple points in the intake or assessment process, there is often a good rationale for returning to such questions after some appropriate time interval.¹ e) Are existing services already addressing trauma?⁹

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		coordination across systems of care and include a life-span perspective. ¹	f) How can this program work effectively with existing programs/services?
<i>Compassion</i>	Compassion has been identified as an important value in one existing framework, ⁶ and the importance of empathy and compassion within project was highlighted by key stakeholders in workshop 1.	Compassion and love are critical elements of relational healing. ¹² Strategies include using play, mindfulness and <i>Dadirri</i> or deep listening.	a) Does the project display compassion towards parents and both Aboriginal and non-Aboriginal community members?
<i>Reciprocity</i>	Reciprocity was highlighted by key stakeholders in workshop 1 and is a core value for the Ethical guidelines for working with Aboriginal communities in Australia. ¹³	Ensuring there is resonance with the project aims and activities is an important principle for fostering the sense of reciprocity. ³	a) Are the needs of all stakeholders considered? b) What are the benefits and cost for those involved with the project? What are they contributing and what are they receiving in return? c) Are the project aims and activities recognising and respecting the contributions of all involved and are they resonating?

*National Trauma Guideline Principle¹

Peer review only

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References

1. Kezelman C, Stavropoulos P. Practice guidelines for treatment of complex trauma and trauma informed care and service delivery. Sydney: Adults Surviving Child Abuse, 2012.
2. Guarino K, Soares P, Konnath K, et al. Trauma-informed organizational toolkit. Rockville, MD: Center for Mental Health Services, Substance Abuse and Mental Health Services Administration, the Daniels Fund, the National Child Traumatic Stress Network, and the W.K. Kellogg Foundation, 2009.
3. Atkinson C, Atkinson J, Wrigley B, et al. Aboriginal Family Violence Prevention Legal Services: Culturally informed trauma integrated healing approach - A guide for action for trauma champions. Canberra: Commonwealth of Australia, 2017.
4. Denby RW. Parental incarceration and kinship care: Caregiver experiences, child well-being, and permanency intentions. *Soc Work Public Health* 2012;27(1-2):104-28.
5. Aboriginal Medical Services Alliance of Northern Territory. Core values for trauma-informed care. Darwin: Aboriginal Medical Services Alliance of Northern Territory.
6. Denby C, Winslow C, Willette C, et al. The Trauma Toolkit: A resource for service organizations and providers to deliver services that are trauma-informed. Winnipeg, Canada: Clinic Community Health Centre, 2008.
7. College of Aboriginal and Torres Strait Islander Nurses and midwives; Australian College of Midwives; CRANA Plus. Birthing on Country position statement. Canberra: College of Aboriginal and Torres Strait Islander Nurses and midwives, Australian College of Midwives and CRANA Plus 2016.
8. Congress of Aboriginal and Torres Strait Islander Nurses and Midwives. CATSINaM 2014 Conference: Outcomes of the 'Birthing on Country' Yarning Circles. Perth: CATSINaM, 2014.
9. Dudgeon P, Milroy J, Calma T, et al. Aboriginal and Torres Strait Islander Suicide Prevention Evaluation Project (ATSISPEP) report. Solutions that work: What the evidence and our people tell us. Perth: University of Western Australia, 2016.
10. Abbott J, Johnson R, Koziol-McLain J, et al. Domestic violence against women. Incidence and prevalence in an emergency department population. *JAMA* 1995;273(22):1763-7.
11. Gee G, Dudgeon P, Schultz C, et al. Understanding social and emotional wellbeing and mental health from an Aboriginal and Torres Strait Islander perspective. In: Dudgeon P, Milroy H, Walker R, eds. Working Together: Aboriginal and Torres Strait Islander Health and Wellbeing Principles and Practice Second ed. Canberra: Australian Council for Education Research and Telethon Institute for Child Health Research, Office for Aboriginal and Torres Strait Islander Health, Australian Government Department of Health and Ageing 2014.
12. Early right brain development and relational origins of mutual love and intersubjective play. International Childhood Trauma Conference; 2018; Melbourne Convention Center, Melbourne.
13. National Health and Medical Research Council. Values and ethics - Guidelines for ethical conduct in Aboriginal and Torres Strait Islander health research. Canberra: Commonwealth of Australia, 2003.

Supplementary File 2: Indigenous Research Excellence Criteria

COMMUNITY ENGAGEMENT: This project is led by a majority of Indigenous researchers who have been discussing this proposal regularly with key stakeholders since its inception. The team members identified the issue as a priority through shared experiences working ‘in the real world’ in complementary sectors of Indigenous mental health and reproductive and child health. We have been using a structured plan for communicating with key stakeholders during the scoping stages of developing this proposal, which has formal letters of support from with Australian Medical Services Alliance Northern Territory (AMSANT) and the Aboriginal Family Health Research Partnership Steering Committee (SA) (AIMitchell is CEO) and strong relationships within the Victorian Aboriginal Health Service (VAHS) (CI Gee is research director). We will continue these processes through 2017, including accepting an invitation to present learnings from the scoping review and VAHS ‘breaking the cycle of trauma’ qualitative project in Victoria, South Australia, the Northern Territory and at international and national meetings. The research will be guided by an Advisory Group which builds on existing relationships and includes representatives from community controlled health services, communities, and clinical settings. We will formally engage potential partners by using existing relationships and sending appropriate formal communication to community controlled health service (CCHS) boards and Chief Executive Officers (CEO) and other maternity care sites seeking their formal support and /or discussion on the study. We will also establish a communication strategy with key stakeholders from all Australian jurisdictions, to provide information about the project and to invite participation of nationally representative stakeholders in the workshops. Our team has extensive expertise in community engagement and developing relationships to facilitate an ‘intervention ready’ environment will be a key outcome from this project (supported by AI McLachlan). We recognise strong relationships as a critical foundation necessary for addressing emotionally challenging issues such as complex trauma, which can impact on program staff.³⁸ As partners in research, this project includes funding to support community member involvement, recognising the value of equal contributions and enable ongoing commitment to the research, which can be a major challenge in community-based participatory action research (CBPAR) projects.³⁶ Our team are committed to working collaboratively and CBPAR methods are core to this proposal. CBPAR methods are strongly value orientated³⁶, and provide a vehicle for redressing power imbalances in research and working respectfully with Indigenous communities, de-colonising’ research, building ownership.³⁶ We are conscious of the need to ensure that Indigenous communities are positively represented³⁷ – a critical factor in any research involving discourse about complex trauma, as seen with the responses to the *Little Children are Sacred* report in the Northern Territory. We have extensive expertise in conducting Indigenous health research and we know that genuine community engagement takes time. At all times, the research team will be open to discussing the study with the boards and or CEO and service staff. Many CCHS have developed protocols for working with researchers, and these will be followed by the research team. During the research process, Indigenous researchers will use culturally appropriate methods and tools to facilitate in-depth discussions and generate authentic data which reflects Indigenous perspectives and values.

BENEFIT: Intergenerational trauma is a key priority identified by communities, as evidenced at the 2016 ‘Lowitja conference’ and this study validates community concerns. There is currently limited Indigenous-specific or general evidence about strategies to support prospective and new parents at a critical transitional life-course stage which suggests a critical ‘intervention’ point for prevention where new cycles begin and open up a rare opportunity for ‘healing the past’. Development of culturally acceptable, trauma-informed screening methods is needed to lobby for culturally acceptable feasible support services for families with complex trauma. Development of a screening tool will also help to clarify the true prevalence of complex trauma in this critical population. This project will assess the risks and benefits of universal and targeted screening, which is particularly important in a condition which is expected to have high prevalence (over 50%). Concurrent development of acceptable and

feasible support strategies will ensure that support strategies are ready to be trialled if screening is deemed appropriate, in line with the principles of population-based screening. Indigenous researchers are well-placed to demonstrate leadership in community-led approaches and generate evidence which is of benefit to both Indigenous and non-Indigenous families. We have included activities to ensure this formative research is translatable. This includes using an IM framework, preparing plain language summaries and reports to present the findings of the research in a range accessible formats through a variety of mediums, including face-face meetings, relevant websites and academic journals. This project offers benefits for partner organisations, with an opportunity to demonstrate leadership in trauma-informed and trauma-specific reproductive and child health services. There will be opportunities for shared learning through the partnership approaches inherent in the research plan. There will be benefits for participants in the program, as therapeutic support will be offered in line with the available evidence. We aim to make the experience of participation rewarding and enjoyable, and in line with CBPAR principles, recognise the contributions of participants as partners in the research to the degree they are comfortable with. This project includes plans for supporting the wellbeing of the whole team (including community-based members) through the duration of the project. This will include deliberative strategies for building trust and strengthening relationships, supportive induction and review processes for addressing career and personal needs, active strategies to facilitate capacity exchange between Indigenous and non-Indigenous team members, and clear debriefing/counselling options (where appropriate).

SUSTAINABILITY AND TRANSFERABILITY: Our research team are ideally placed to maximise the sustainability of this research, with links and expertise in community and clinical settings. The research plan is designed using an Intervention Mapping framework which will guide this preliminary systematic process for developing acceptable and feasible interventions, towards the next stages of testing the effectiveness of interventions. Following this developmental work, we have the expertise, community and service linkages across three state and territory jurisdictions to implement and evaluate interventions in a range of settings. Our team brings together expertise in clinical programs, development of resources, training, program implementation, policy and program evaluation necessary for successful translation. Importantly, a major strength of the CBPAR approach is that improves the likelihood that evidence will be transferable, and the engagement of partners maximises the chances of sustainability. We anticipate that any effective interventions are likely to be highly cost-effective, and if this is the case, strong evidence will be needed to ensure sufficient funds are allocated to support prospective and new parents. We have planned this developmental work with this potential endpoint in mind to maximise sustainability and transferability.

BUILDING CAPACITY: This project offers substantial capacity-building opportunities at all levels of research and for knowledge exchange between Indigenous and non-Indigenous researchers. The team includes highly experienced Indigenous and non-Indigenous researchers in mental health and trauma (CI Herrman, CI Atkinson), family health (CI Brown, AI Andrews), social work and systems (CI Arabena) and parenting research (CI Nicholson, AI McLachlan); who are well placed to support early-mid career researchers in family health (CI Chamberlain, CI Glover, AI Andrews) and psychology (CI Gee, CI Gartland, CI Clark, AI Atkinson). We will also discuss capacity-building needs with partner organisations, and how we can support skill development of staff in this research project. The project also includes opportunities for postgraduate research (PhD) and other Indigenous research staff to develop skills in research (project coordinator and research assistant) and we will ensure the best possible support for all project members, including appraisal processes to support career goals.

Supplementary file 3: Perinatal strategies to support parents who have experienced maltreatment in their own childhoods: Evidence synthesis plan

	Phase 1: Mapping	Phase 2: In-depth reviews				Phase 3: Overview
Population	Parents planning pregnancy, during pregnancy or first two years postpartum					
Primary review question	What evidence is available regarding child maltreatment/complex childhood trauma during the perinatal period?	1. What are the intergenerational pathways from parental maltreatment in the perinatal period? What factors mediate/moderate these outcomes? What theories help to explain these pathways (mechanisms)? And what aspects are supported or contradicted by the epidemiological evidence?	2. What are perinatal experiences for parents who have experienced maltreatment in their own childhood? What strategies do parents use to heal and/or discontinue cycles of complex trauma?	3. What is the effectiveness and cost of perinatal interventions for parents who have experienced maltreatment in their own childhood? Are there any differential effects of interventions in different subpopulations?	4. What is the sensitivity, specificity and utility of screening tools used in the perinatal period for identifying parents who have experienced maltreatment in their own childhood (exposure) and/or trauma symptoms (effects)?	What works? For whom? In what circumstances? Are the most effective interventions also acceptable? What are the costs?
Review type	Scoping review	Systematic Review (epidemiological)	Systematic Review (qualitative)	Systematic review (quantitative)	Diagnostic/test accuracy review	Realist review
Search	'parent' AND 'childhood trauma' AND 'intergenerational' AND 'prevention'	'parent' AND 'childhood trauma' AND 'intergenerational' (based on revised terms from mapping phase)				In-depth reviews, excluded reviews from previous search, integration with co-design workshops
Study type	Any primary study related to (theories; mediators/moderators; parents' experiences; interventions; screening tools)	Theoretical and epidemiological studies (observational).	Qualitative studies.	RCTs, CCTs, ITS (Descriptive studies).	Screening test accuracy studies	Systematic reviews, co-design discussions
Data extraction	Microsoft Excel	Eppi-reviewer or NVivo				
Synthesis	Narrative synthesis	Narrative synthesis using socioecological model and integration with co-design workshop/qual studies with Elders.	Meta-synthesis of parents' experiences (1 st level) and author conclusions (2 nd level) to generate unique review themes across studies (3 rd level).	Meta-analysis, meta-regression and narrative synthesis. Sensitivity analysis for major intervention components, study quality, implementation/process measures, and PROGRESS + characteristics (Age; Place; Race; education; social capital (partner/other); mental illness; SES; other risk factors).	HSR/HC analysis	Narrative synthesis
Outcomes	Evidence map	Diagram/illustration of resilience, protective and risk factors that mediate or moderate relationship between childhood trauma and behavioural & health outcomes for parents and infants.	Review level synthesis with GRADE-CERQual assessment of confidence in evidence.	Impact of interventions on process (acceptability/cost/implementation); parental behavioural and health outcomes; and infant behavioural and health outcomes.	Sensitivity and specificity of existing screening tools.	Recommendations for perinatal screening and support strategies are likely to support resilience and healing for parents.

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Supplementary file 4: Workshop 1 facilitators guide

Time		Facilitation Guide
9.30am	Registration and tea/coffee/fruit platter	Greet participants/Elders/dancers etc
10.00	START Welcome/Acknowledgement to country	Welcome
10.15	Creating our safe space	<ul style="list-style-type: none"> • Acknowledgement of what we are talking about is hard • Importance of listening • Ask group to contribute to collective agreement on 'principles of participation' and then put them up on butchers paper. • Reiterate no-one will be asked or expected to share personal experiences (not purpose of workshop) • Absolutely ok to leave at any time if uncomfortable & to play on phone (nb smiling mind app) • Introduce trauma response factsheet (We Al-li Pty Ltd) and card with Psychologist contact. • Some diversionary activities on tables (mindfulness colouring/drawing). • Rocks on table for people to choose - one to paint as a symbol of 'hopes/dreams aspirations for project'. Write brief description on sticky notes. At end of day we will place these in the coolamon as a symbol of our aspirations, and also leaving the 'weight' of discussions here as we go back to our families.
10.30	Introductions	<p>Ask people to form a big circle.</p> <ol style="list-style-type: none"> 1. Say your name and where you're from. 2. Ask people to form groups of 3. 3. Assistant hands each group of 3 x 6 strengths cards. Pick a strength/picture card (or choose each if you don't like it) And share a little story what that means to you or your family (from selection on table). Do this for a few minutes until about 10.55. 4. Circle up and thank everyone for sharing (remind people to chat to those they didn't meet at lunchtime).
11.00	Sharing research knowledge	<ul style="list-style-type: none"> • Clarify purpose of this session • Very simple overview of evidence, including from scoping review (remind sent out earlier), • Outline of project plan (team, approach, major activities and timelines) • Questions • Ask people to spend 10 min's in table to write down why are we here? what's brought you to this project?

		<ul style="list-style-type: none"> – brightly coloured postit notes and large poster (words to go with images on rocks) • 5 mins feedback on group discussions
12.00	LUNCH	Stick words up on posters
12.30	Working together safely	<ul style="list-style-type: none"> • Clarify purpose of this session • Brief discussion of importance of cultural/emotional safety – particularly in context of this project • Group experiential activity to understand lateral violence • Small group questions to generate protocol for cultural and emotional safety (1) for participants (families, community members, service providers); (2) among each other (3) with the broader society (e.g. ensuring anything coming out of project is not damaging to the broader community) and (4) between Indigenous and non-Indigenous peoples.
2.00	AFTERNOON TEA	
2.15	Sharing community and service knowledge	<ul style="list-style-type: none"> • Clarify purpose of this session • Brief recap on evidence specific for Aboriginal communities • Group activity to understand: • How do you/services/communities currently recognise if a parent is experiencing trauma? (screening) • What assessment processes are currently used? • What support strategies are currently used?
3.30	Reflections and next steps	<ul style="list-style-type: none"> • Overview of day (5 mins) • Evaluation forms for feedback and suggestions for next workshop (10 mins) • Reminder to take care and be kind to themselves tonight (eat well, exercise etc important too) • Reflective activity with holding stone with aspirations and drop into coolamon (15 mins). People can share if they want with group. Sticky notes/record on butchers paper.
4.00	THANK YOU AND CLOSE	Thank you and close

Supplementary file 5: Preliminary areas of distress synthesized from scoping of assessment tools

Discussion Part 2: Domains
1 Intrusions (DSMV/ICD/AAVHTQ) e.g. nightmares, flashbacks
2 Avoidance (DSMV/ICD/AAVHTQ) e.g., avoiding people, places that are reminders, dissociation
3 Negative alterations in mood and cognitions (DSMV) e.g., beliefs about self/others/world i.e., 'always dangerous'
4 Alterations in arousal and reactivity (DSMV/ICD-AAVHTQ) e.g., heightened anxiety, irritability, aggression
5 Emotion dysregulation (ICD/AAVHTQ) e.g., unable to regulate/manage heightened emotion (anger) or emotional numbness
6 Negative self-concept (ICD/AAVHTQ) e.g., guilt, shame, worthlessness, altered meaning/beliefs
7 Disturbed Relationships (ICD/AAVHTQ) e.g., difficulty developing/maintaining close relationships, feeling isolated/disconnected
8 Community Disconnection (AVHTQ) e.g., feeling isolated/disconnected from one's community/mob, may be due to conflict, D&A
9 Identity loss/fragmentation (AVHTQ) e.g., impacted cultural identity due to interpersonal trauma
10 Grief and loss (AVHTQ) e.g., unresolved or unintegrated grief and loss from interpersonal trauma
11 Other cultural idioms distress (AVHTQ) e.g., harm against self or others, D & A abuse, suicidality
12 Depression
13 Psychosocial risks (if so, which ones? Social determinants, parenting and family factors)
14 Strengths (if so, which ones? personal, relational, cultural e.g., spirituality, connection to county, coping skills etc.)
15 Duration
16 Functional impact
17 Attribution (not due to medical or other)
18 Exposure (if so, what language/events?)

Supplementary file 6: Workshop 2 facilitators guide

Time		Facilitation Guide
8.45am	Registration and tea/coffee	Greet participants/Elders/dancers etc
		Attendees set up tables/poster
9.15	START	Welcome
	Welcome/ Acknowledgement to country	
9.30	Creating our safe space	<ul style="list-style-type: none"> • Statement of purpose and what stage we are at. • Check-in if using own family clap sticks is ok. • Acknowledgement of what we are talking about is hard. • 65 people is a lot to be discussing this sensitive issue • Importance of listening. • This is not the place to be sharing trauma stories. Reiterate no-one will be asked or expected to share personal experiences (not purpose of workshop). • Will be using scenarios that may remind people of their own trauma histories. • Demonstrating recognising different types of wisdom with Ngangkere (traditional healer) and psychologist available today. • Value everybody's contribution and acknowledge breadth of expertise is the strength, welcome non-Indigenous people. • Clarify this is a co-design and experts are within the room not on the stadium. • Millennia of wisdom and new scientific knowledge. • Absolutely ok to leave at any time if uncomfortable & to play on phone. • Introduce trauma response factsheet (We Al-li Pty Ltd) and card with contacts etc. • Some diversionary activities on tables -mindfulness colouring/mini clay coolamons (optional only). • At end of day we will place these in the coolamon as a symbol of our aspirations, and also leaving the 'weight' of discussions here as we go back to our families. • Post-it notes/coloured circles on tables to jot down anything you don't get a chance to say. • Introduce draft safety protocol from W1 for info and to ask questions (may send copy before) and acknowledge that W1 have contributed this. (5 mins)
9.45	Introductions	<ul style="list-style-type: none"> • Ask people to form a big circle. • Walking around in circle and clap stick sounds and you introduce yourself to the nearest person. Introduce yourself and random item e.g. 'first car'.

		<ul style="list-style-type: none"> Pick someone and guide them without touching them through the group.
10.00	Brief overview of project and recap of workshop 1	<ul style="list-style-type: none"> Clarify purpose of this session: (1) to provide a very quick overview of the project and where we are on that journey today to help orientate ourselves; and (2) to present the conceptual framework/plan. 10 min presentation: Conceptual framework for project Outline of project plan (diagram in folders) and have had workshop1 (acknowledge people who were at that, main themes and refer to report and safety protocol based on those discussions. 10 mins for questions and discussion about the plan (leave up on screen). And remind people that they can provide any confidential questions or things we don't have time for as a note in the basket or give to us.
10.20	Tjulpa and Walpa	Start today's session with NPY Women's council presentation of the book Tjulpu and Walpa: Two Children Two Roads see http://www.worldcat.org/title/tjulpu-and-walpu-two-children-two-roads/oclc/1002311301
10.50	MORNING TEA	Set up stations for Assessment session
11.10	Modified Delphi discussion of assessment domains	<p>Clarify purpose of this session: Introduction of Walpa and 12 areas of distress and reference CPTSD. Note that the Walpa story is about a woman but we are also wanting to include men (or both parents). Introduce participants to their information sheets with these areas of distress. Acknowledge strengths will be discussed later (10 mins). Explain process:</p> <ul style="list-style-type: none"> Go to one of 12 stations and form groups of 5-6 (one investigator to go with each station/group and take notes). At each station spend 3 mins (clap sticks) talking together about their thoughts of the area of distress and how that might be asked in a safe manner. On each piece of paper (anonymous) circle the word that reflects their rating of what they think and make comments over page (2 mins) Any thoughts about who or why it would be really helpful for us to jot this down. Then ask whole group to move to the next station. <p>11.20-12.00 (6 stations) 12.10-12.50 (6 stations) Debrief with whole group (10 mins).</p>
12.00-12.10 mini break		
1 pm	LUNCH	Set up tables: butchers paper, texta's with colour mix, sticky notes, sticky tape to hold together.
1.40	Reflect on findings of pilot discussions with	<ul style="list-style-type: none"> Clarify purpose of session: (1) To briefly outline the themes emerging from the Deadly Nannas discussion group (2) to

	Grannies group and Tree of Life exercise	<p>discuss the process (including in context of the safety protocol) and proposed modifications for discussion group with parents - ?tree or image to work with (see discussions from Assessment working group meeting)</p> <ul style="list-style-type: none"> • 2 slides from Deadly Nannas –what their program is about (10 mins) • Talk about why asked to conduct the pilot discussion group with Deadly Nannas group, the process, and main themes (8) (15 mins) • Tree of life exercise to briefly pilot test the proposed process with parents and ask tables to have a short discussion about the issues for parents but also to provide feedback on the process and any further suggestions? • Tom and Mary scenario – different from Walpa story but many of same issues come up • Outline safety issues (3rd person scenario (self-care)) • Ask each table to draw a tree and briefly outline below: and reassure people no right or wrong so doesn't matter if you get the leaves mixed up with fruits etc. <ul style="list-style-type: none"> Roots: historical aspects and how past has impacted on them (5 mins) Ground: Now – what's happening now? (5 mins) Trunk: Parent strengths and what holds them up? What are they capable of together and individually (5 mins) Branches and twigs: Reaching up to sky – hopes and dreams and desires (5 mins) Leaves: convert sunlight to energy – changing process – actions in changing. What changes could happen? Who do they ask to help them? (5 mins) Flowers/fruits: Form the seeds/fruits protective part of seeds – what are the things that protect them? (5 mins) <p>Trees part of a community of trees/forrest – share information about trees (1 min each - 10 mins)</p> <p>Many hazards that can wreck trees – fires/droughts etc. (5 mins) – what are some of the hazards here.</p> <p>Then discussion about how the exercise is and how safe? (10 mins)</p> <p>Remind people if they haven't had time to discuss everything to leave suggestions/comments on the coloured circles.</p> <p>Flag that next workshop will be focussing on the feedback of these discussions with parents so will be more time to discuss.</p>
3.00	AFTERNOON TEA	Set up sessions/tables and handouts
3.15	Presentations on programs	<ul style="list-style-type: none"> • Purpose of session: (1) to share innovative ideas in an interactive format for building on in later workshops. • Tables/poster boards set up at the start of the day. • Each station to have an A4 handout – brief description and main contact. • Notetaker at each poster – and set up notes/pens for people to report notes.

		<ul style="list-style-type: none"> • Free moving around with clapping sticks every 10 mins to remind people to change over – ask people flag other programs. 1 group outside.
4.15	Debrief and reflection/evaluations	<ul style="list-style-type: none"> • Overview of day (5 mins). • Circle up. • Reflective activity with coolamon (traditional baby carrier)/drawing with aspirations and drop into coolamon (15 mins). People can share if they want with group. • Evaluation forms for feedback and suggestions for next workshop (10 mins) (will also be sent online). • Performance by Drum Atweme, part of the Tangentyere Aboriginal Council Drum Atweme Program. • Reminder to take care and be kind to themselves tonight (eat well, exercise etc important too).
5.00	THANK YOU AND CLOSE	Thank you and close.



On the day Time (est) -to be adapted to the need and preferences of local groups.	Segment	Purpose	Activity	Materials/notes
9.00am 60 mins	Setting up the focus group environment	Creating a safe environment	Set up: <ul style="list-style-type: none"> • furniture to make a talking circle • Table to one side to draw on • art and other materials, including cards on a sideboard with cues from other research • information and consent forms • tea/coffee/water/ milk • signage • safe break out area • mindfulness colouring books (pens, rocks etc) • newsletters for project • something to look at (poster/artwork on A3) – laminated • Set up activities for children 	Recorder (use audio pen to write notes/observations (including related to images) at the same time) Name badges (if required)
10am- 15 mins (or longer if needed/preferred)	Greeting participants as they arrive and going through consent process	Make participants feel welcome Obtain signed consent	<ul style="list-style-type: none"> • Talking participants through the information sheet and consent forms • Offer people a cup of tea/coffee and refreshments • Housekeeping- let people know where toilets are/ break out rooms • Brief facilitator introductions • Childcare arrangements 	Information sheets Consent forms Name tags
10.15am 15 mins (longer if needed to assure group safety and comfort)	Welcome/introductions	Introduce participants to each other (if necessary) and introduce selves Create a safe space	<ul style="list-style-type: none"> • Circle up first/ can sit if around table • Introductions and activity to help people feel safe and welcome- using strength cards- to share their inspirations or why they were drawn to that card. • Brief reflective activity (e.g. holding a rock, leaf (paint if wanted to leave behind at end of day). Eg “We know that parenting can be hard, particularly if parents have difficulties in their own childhood. We all bring our own experiences to these discussions today. We pass these rocks/leaves for you to hold during these discussions, and then at the end of the session we can have a little reflection and either leave any heaviness behind’ or return the leaf to the ground to enrich the soil, as a symbol of your rich contributions today. To help us 	



			<p><i>leave this behind as we go back to care for our own precious children and families.”</i></p> <ul style="list-style-type: none"> • Acknowledge potential for triggering (and explain normal responses) and suggest strategies to minimise symptoms (including breakout/mindfulness and tip sheet). • Psychological support available and card and mobile number. • Opportunity to ask questions. • Ground rules for safety (respect what other people say, can leave if feeling uncomfortable, psychological support available and distress protocol, everything said is confidential, will not be asked about own experiences – will use a ‘story’ of Walpa (scenario)) 	
<p>10.30</p>	<p>Pre-discussion and Discussion for activity 2</p>	<p>Facilitate discussion about key issues for parents (barriers and enablers)</p>	<ul style="list-style-type: none"> • Explain purpose of the discussion group and how it will work (brief consent recap), what we mean by complex trauma. <i>“We know parenting can be hard, especially for parents who have had a challenging childhood themselves. We also know that children bring a lot of love and joy into the world with them, which needs to be nurtured, and this can help parents to heal. The purpose of the discussion today is to learn how we can support parents who have had difficult childhood themselves to heal and nurture their children. We will do this by sharing the story of Tjulpa and Walpa, and creating a ‘tree’ which shows how we can best support Walpa”</i> • Give out Tjulpa and Walpa books and read aloud • Turn on recorder <p>Participants draw a tree and then use sticky notes to create discussion around: (5mins)</p> <ul style="list-style-type: none"> • The roots /ground– what are the things from there past that may be impacting on Walpa [and her partner] now (5 mins) • Trunk – strengths – what’s helping to keep them strong? (5) • Branches – what are the hopes and dreams for these parents? (5) • Leaves etc – what are the things that are going to help them to get there? (individual (flowers)/family & community(leaves)/services (butterflies)/society (fruit) (10) • Clouds – what are the challenges? and (rainbows) what might help them to overcome these challenges? (5) 	

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11.30			Show cards with information on strategies from other parents discussions [represents 'forest' of many trees'] - key issues of working together	
11.50			Show draft questions to ask parents about areas of distress and strengths?	
12.20			<p>Final reflection (leaves/rock) and finish up</p> <ul style="list-style-type: none"> • Acknowledge difficulty of this discussions and ask people to think of how they are feeling (grounding exercise). • Invite people to have a quiet minute or so for reflection and then to drop the leaf/stone into the coolamon to symbolise leaving any stressful feelings behind and how what they are contributing is for our future generations. • Invite people to share with the group as they do this if they wish – but no obligation. If they want they can discuss the symbolism of any painting on rocks etc. • Give thankyou cards with contact details for any support services if needed. • How to get information back • Reinforce how important their wisdom is and that they are contributing to something much bigger than all of us that we hope will help parents to heal and be strong and able to experience and nurture the joy and love that children bring into the world with them. • Explain what we will do with the information shared now and how we will discuss to check we have understood correctly first and then give that information back in written form (or visit if needed). • Give gift vouchers/funds and ensured everyone able to get home ok, etc. 	
12.30	LUNCH			

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BMJ Open

Healing the Past by Nurturing the Future – co-designing perinatal strategies for Aboriginal and Torres Strait Islander parents experiencing complex trauma: framework and protocol for a community-based participatory action research study

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TITLE PAGE

Title: Healing the Past by Nurturing the Future – co-designing perinatal strategies for Aboriginal and Torres Strait Islander parents experiencing complex trauma: framework and protocol for a community-based participatory action research study

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ABSTRACT

Introduction

Child maltreatment and other traumatic events can have serious long-term physical, social and emotional effects, including a cluster of distress symptoms recognised as ‘complex trauma’. Aboriginal and Torres Strait Islander (Aboriginal) peoples are also affected by legacies of historical trauma and loss. Trauma responses may be triggered during the transition to parenting in the perinatal period. Conversely, becoming a parent offers a unique life-course opportunity for healing and prevention of intergenerational transmission of trauma. This paper outlines a conceptual framework and protocol for an Aboriginal-led, community-based participatory action research (action research) project which aims to co-design safe, acceptable and feasible perinatal *awareness, recognition, assessment and support* strategies for Aboriginal parents experiencing complex trauma.

Methods and Analysis

This formative research project is being conducted in three Australian jurisdictions (Northern Territory, South Australia and Victoria) with key stakeholders from all national jurisdictions. Four action research cycles incorporate mixed methods research activities including evidence reviews, parent and service provider discussion groups, development and psychometric evaluation of a recognition and assessment process and drafting proposals for pilot, implementation and evaluation. Reflection and planning stages of four action research cycles will be undertaken in four key stakeholder workshops aligned with the first four Intervention Mapping steps to prepare program plans.

Ethics and dissemination

Ethics and dissemination protocols are consistent with the National Health and Medical Research Council Indigenous Research Excellence criteria of engagement, benefit, transferability and capacity-building. A conceptual framework has been developed to promote the application of core values of safety, trustworthiness, empowerment, collaboration, culture, holism, compassion and reciprocity. These include related principles and accompanying reflective questions to guide research decisions.

ARTICLE SUMMARY

Strengths and limitations of this study

- Demonstrates a comprehensive formative action research process to co-design acceptable and feasible perinatal awareness, recognition, assessment and support strategies for Aboriginal parents experiencing complex trauma.
- A conceptual framework to guide this project includes core values of safety, trustworthiness, empowerment, collaboration, culture, holism, compassion and reciprocity.
- Indigenous Research Excellence criteria influence ethics and dissemination protocols.
- Assessment of safety, acceptability and feasibility of an awareness, recognition and assessment process for Aboriginal parents experiencing complex trauma in three Australian jurisdictions.

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- Formative study to set the foundation for implementation and evaluation of the co-designed support strategies.

For peer review only

INTRODUCTION

Child maltreatment and other adverse childhood experiences (ACEs) are an international health priority,[1] contributing to a wide range of long-lasting physical, social and emotional health issues.[1-7] There is growing international consensus to recognise a cluster of distress symptoms people may experience following childhood exposure to severe threats, called complex post-traumatic stress disorder (complex trauma). This classification describes a symptom profile that typically follows traumatic experiences of a prolonged nature or repeated adverse events from which separation is not possible.[8] These symptoms include ‘affect/emotional dysregulation’, ‘negative self-concept’ and ‘relational disturbances’, in addition to previously recognised Posttraumatic Stress Disorder (PTSD) symptoms of ‘Re-experiencing the events (triggers), Avoidance, and a ‘Sense of threat’.[8] These traumatic experiences often involve interpersonal violation and occur within childhood family or institutional care giving systems[9] (e.g. childhood abuse, severe domestic violence, torture, or slavery).[8] Broader societal factors can amplify or counteract the impact of potentially traumatic experiences. Aboriginal and Torres Strait Islander (Aboriginal¹) peoples in Australia are particularly affected by complex trauma, following a legacy of historical trauma[10, 11] which includes state-sanctioned systematic removal of Aboriginal children from their families and ongoing discrimination.[12] While community cohesion, access to services and cultural continuity have been shown to have a protective effect for some trauma related outcomes among Aboriginal peoples,[13] within the context of colonisation socio-ecological risk factors experienced by many Aboriginal communities are likely to amplify rather than counteract the effects of complex trauma originating from childhood experiences.[14, 15] There are strong associations between child maltreatment and a wide range of physical and psychological morbidities[16] and risk factors, including smoking, eating disorders, unplanned pregnancies[17, 18] and adverse birth outcomes.[19] Critically, these long-lasting relational effects can impede the capacity to nurture and care for children, leading to ‘intergenerational cycles’ of trauma.[20] Experiences of child maltreatment are not equally distributed across general populations and the World Health Organization (WHO) use a socio-ecological framework[21] to highlight the links between higher levels of social adversity and increased rates of child maltreatment experienced in some communities worldwide. These factors also interact and create a ‘compounding intergenerational effect’ on health inequities. As such, this is a crucial issue for improving health equity worldwide. ‘Life course approaches’ are central to understanding complex intergenerational causal pathways and also for identifying critical ‘intervention points’ for prevention and support to improve health equity.[22]

The transition to parenting during the perinatal period (pregnancy to two years after birth) is a critical ‘life course’ transition for parents who have experienced complex trauma.[23] Trauma responses may be triggered by the intimate nature of experiences associated with pregnancy, birth and breastfeeding;[24] and the attachment needs of the infant.[25] The long-lasting relational effects can impede the capacity of parents to nurture and care for their children, and may contribute to ‘intergenerational cycles’ of trauma.[20, 26, 27]

Conversely, the transition to parenthood offers a unique life-course opportunity for emotional healing and development.[28, 29] A positive strengths-based focus during this often-

¹ We use the term ‘Aboriginal’ to refer to both Aboriginal and Torres Strait Islander peoples’ in Australia, and the term ‘Indigenous’ to collectively refer to Indigenous people’s internationally. We respectfully acknowledge the diversity and autonomy of Torres Strait Islander and Indigenous people’s encompassed within these inclusive terms.

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3 optimistic period has the potential to transform the ‘vicious cycle’ of intergenerational trauma
4 into a ‘virtuous cycle’ that contains positively reinforcing elements. When parents can
5 manage trauma responses and provide love and nurturing care, this love is returned by
6 children, and trauma responses can be relearnt, promoting healing in the parent,[30] and
7 optimal development for the infant.[31, 32] It is this concept which has inspired the title for
8 this project - ‘*Healing the Past by Nurturing the Future*’.

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11 Frequent scheduled contacts with perinatal care providers before and after childbirth and
12 across the first two years offer an opportunity for providing comprehensive system-based
13 supports for people experiencing complex trauma during this period. This is particularly
14 important because it may be the first time many of this predominantly young childbearing
15 population have had contact with universal health services since childhood. Despite these
16 clear risks and opportunities, few interventions are available for parents with specific
17 histories of maltreatment,[24, 33, 34] and there are no systematic, culturally informed
18 processes or evidence of effective strategies to identify and support Aboriginal parents
19 experiencing complex trauma.[35]

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22 The benefits of involving communities in co-designing health-care strategies are increasingly
23 recognised.[36, 37] This is critical in the perinatal period for Aboriginal families
24 experiencing complex trauma for several reasons. First, there is very limited evidence of
25 effective interventions internationally. Australian guidelines for the treatment of complex
26 trauma and trauma-informed care emphasise the need for complex trauma to be understood
27 within relational networks and social environments if it is to be adequately addressed.[9]
28 Aboriginal Australians, despite suffering great disadvantage and adversity, demonstrate
29 strong resistance to those actions that are foreign to Aboriginal culture, including separation
30 from families, discrimination and removal from Country. Thus, we will engage in respectful
31 collaborative research with and alongside Aboriginal peoples and keep Aboriginal peoples’
32 strengths and protective factors to the fore. These strengths include rich cultural relationship
33 and kinship networks that foster relatedness and connectedness for children.[38]

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36 Collaboration with local Aboriginal leaders and Aboriginal organisations has been shown to
37 be critical in adapting child trauma therapies among other Indigenous communities.[39]

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40 Second, Aboriginal conceptualisations of social and emotional wellbeing are holistic and
41 incorporate connection to land, culture, spirituality, family, and community; all of which are
42 impacted by complex trauma, which is sometimes referred to as ‘relational trauma’.[40] The
43 rich relational understandings of wellbeing may offer important insights for other Indigenous
44 and non-Indigenous communities.

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47 Third, there are risks associated with identifying parents with complex trauma. Labelling
48 individuals as ‘at risk’ has the potential to undermine parents’ existing resilience and coping
49 skills, and trigger inappropriate notifications to a potentially punitive child protection system.
50 These concerns are particularly salient for Aboriginal communities, with the history of
51 colonisation and forced child removals from families, and ongoing high rates of infants being
52 removed from Aboriginal families,[41] which have had devastating ongoing intergenerational
53 impacts. Finally, despite a history of childhood adversity, most parents are able to nurture and
54 care for their children.[42] Evidence suggests that examining these ‘cycles of discontinuity’
55 are an important place to start to illuminate innovative strategies for support.[43]

56 **Aims and objectives**

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59 *Healing the Past by Nurturing the Future* is a formative Aboriginal-led, community-based
60 participatory action research (action research) project, which aims to co-design perinatal
strategies to support Aboriginal parents experiencing complex trauma. There is currently

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3 insufficient evidence to identify potentially acceptable, feasible and effective strategies to
4 support Aboriginal parents experiencing complex trauma, hence the focus of this project is
5 formative research.
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7 The expected outcomes of the project are to identify strategies that are considered acceptable
8 to Aboriginal parents and feasible for service providers. Piloting, implementation and
9 evaluation of the effectiveness of these perinatal strategies will be the subject of a sequential
10 project following this formative design stage.
11

12 The co-design strategies aim to improve four key domains of perinatal care:

- 14 • **Awareness** of the impact of trauma on parents or ‘trauma-informed’ perinatal care
15 to minimise the risks of triggering and compounding trauma responses.
- 16 • Safe **recognition** of parents who may benefit from assessment and support, with
17 processes to reduce risk of harm.
- 18 • **Assessment** of complex trauma symptoms, to accurately identify parents
19 experiencing distress.
- 20 • **Support** strategies for parents to heal, including psychological/emotional, social,
21 cultural and physical strategies.
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25 The purpose of this protocol paper is to illustrate the processes, frameworks and methods
26 utilised by an Aboriginal-led research team to generate rigorous context-relevant strategies,
27 while also fostering cultural and emotional safety for participants, partners, research staff and
28 the broader Aboriginal community. This paper includes an outline of the following elements:
29

- 30 • Community involvement in the project.
- 31 • Conceptual framework for developing safe research processes.
- 32 • Research activities within the four action research cycles and Intervention Mapping
33 (IM) steps.
- 34 • Ethical considerations and research dissemination plans.
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37 Due to the evolving nature of action research and co-design research, submissions for Human
38 Research Ethics Committee (HREC) approval are planned in three distinct ‘ethics phases’,
39 following key stakeholder co-design workshops one, two and three. At the time of submitting
40 this protocol, phase one and two HREC approval had been granted, and HREC submission is
41 planned for phase three in late 2019. Therefore, this protocol includes a detailed description
42 of ‘phase one and two’ activities, with a brief outline only of anticipated phase three
43 activities (highlighted in text).
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46 **METHODS AND ANALYSIS**

47 **Patient and public (community) involvement**

48 This project involves Aboriginal people at every level, and a detailed description is outlined
49 in the National Health and Medical Research Council (NHMRC) Indigenous Research
50 Excellence Criteria (Supplementary file 1). In summary, the majority of the investigator team
51 are Aboriginal with extensive expertise in this area. The need for this research has been
52 identified in national Aboriginal conferences and formally supported by three Aboriginal
53 community controlled ‘peak bodies’, who play a leading role in Aboriginal health
54 initiatives:[44] the Aboriginal Medical Services Alliance of Northern Territory; the
55 Aboriginal Health Council of South Australia; and the Victorian Aboriginal Community
56 Controlled Health Organisation.
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We are using an **action research model** to ensure ongoing community involvement is built into the research plan, including refinement of the research questions. Action research draws on phenomenology and critical theory to generate constructivist grounded theory using mixed methods.[45] It involves a practical community based focus and collaboration for action.[46] The focus of the first year has been meaningful *community engagement* to enable action research. We have established formal partnerships and recognise the leadership of five partner service organisations with this project, including: Central Australian Aboriginal Congress (Northern Territory); Nunkuwarrin Yunti of South Australia Inc. and Women's and Children's Health Network (South Australia); the Royal Women's Hospital (Victoria), and the Bouverie Family Healing Centre (Victoria).

Participants in this study include Aboriginal parents, perinatal service providers, Aboriginal Elders and key stakeholders (service providers, researchers, policy-makers and community leaders working to address complex trauma). Participants are required to provide informed consent prior to participating in study activities, and draft findings of each activity are provided to participants for feedback, prior to broader community dissemination. We invite key stakeholders from all Australian jurisdictions to participate in the four co-design workshops to enable broader national collaboration in planning for subsequent program pilot, implementation and evaluation.

Conceptual framework: developing safe research processes

To articulate the values for the project and address risks and contextual complexities, we have developed a Conceptual Framework (Figure 1) drawing on holistic Aboriginal constructs of social and emotional wellbeing. Protocols that have been critical for informing this conceptual framework include:

- *Power Threat Meaning Framework (PTMF)*,[47] “an over-arching structure for identifying patterns in emotional distress, unusual experiences and troubling behaviour, as an alternative to psychiatric diagnosis and classification”.[47, p 5] We will incorporate the PTMF by reframing behaviours related to complex trauma as normal self-protective responses to threatening situations rather than pathological deficits.
- *Principles for population-based screening*[48] to assess the benefits, risks, costs, acceptability, accuracy and potential risk of harms resulting from recognising and assessing parents experiencing complex trauma.
- *Indigenous research methodologies*[49] that involve privileging Aboriginal worldviews, self-determination and Aboriginal community control.

The conceptual framework incorporates two elements:

- a) Four main domains of awareness, recognition, assessment, and support.
- b) Eight core values with related principles and questions.

<<insert Figure 1 about here>>

a) *Four main domains of recognition, assessment, awareness and support*

The four main domains were developed during the early community engagement stages of the project which revealed concerns about the use of language such as ‘screening’ and ‘intervention’, which implies ‘something is wrong’ with a person, and is not consistent with PTMF framing of trauma to ask ‘what has happened to you’.[47] There are also sensitivities in the context of Aboriginal communities in Australia, with controversial Government ‘interventions’ imposed on Aboriginal communities. The domains of ‘recognition’ and

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3 ‘assessment’ broadly align with ‘screening’ strategies that incorporate a safe and feasible
4 two-tiered process for care providers to *recognise* parents who may require more in-depth
5 *assessment* for complex trauma; and ‘intervention’ approaches to improve trauma-informed
6 perinatal care and minimise the risks of re-traumatising parents (*awareness*), and provide
7 trauma-specific *support*.

8
9
10 *b) Eight core values with related principles and questions*

11 Utilising online searches and team members’ clinical and knowledge, we identified seven
12 frameworks that included trauma-informed values and principles[9, 50-55]. These values and
13 principles were mapped and consensus was reached by the project team for eight core **values**:
14 *safety, trustworthiness, empowerment, collaboration, culture, holism, compassion and*
15 *reciprocity*. Each contains action-oriented **principles** that enable the core values to be
16 realised, and are accompanied by **questions** developed to aid reflection on whether the
17 activity under consideration is consistent with the core value (Supplementary file 2).
18
19

20
21 **Setting**

22 Research activities will be conducted in three of seven Australian jurisdictions selected on the
23 basis of existing research relationships and expressed interest by key stakeholders: Northern
24 Territory, South Australia and Victoria. Approximately 23% of Australian Aboriginal people
25 live in these three jurisdictions across mixed urban, rural and remote demographic
26 contexts.[56]
27

28
29 **Data storage and triangulation**

30 All data will be securely stored using REDCap software,[57] and accessible only to members
31 of the project team. Wherever possible, data will be stored in de-identified form. However,
32 where concerns exist about the health of a participant, the safety plans and responses relating
33 to that participant will be stored to enable appropriate follow-up by healthcare professionals.
34

35 Multiple data sources will be triangulated within this project (as described below), which will
36 increase confidence in the findings through the confirmation of proposed ideas from two or
37 more independent sources.[58] Data collection tools are designed to progressively inform the
38 co-design of safe, acceptable and feasible perinatal awareness, recognition, assessment and
39 support strategies.
40
41

42
43 **Research approaches**

44 An **Intervention Mapping** (IM) approach,[59] is used in this project to frame the co-design
45 process. IM uses “theory and evidence as foundations for taking an ecological approach to
46 assessing and intervening in health problems and engendering community participation”. [59,
47 p 7] This formative research project addresses IM steps one to four, which are aligned with
48 four key stakeholder workshops (see Figure 2). IM steps five and six (implementation and
49 evaluation) will form the basis of a subsequent project.
50

51 **Action research** processes will be used to foster an iterative co-design process comprising
52 four ‘plan-act-observe-reflect’ cycles. The ‘*reflect*’ and ‘*plan*’ action research stages will be
53 conducted in four key stakeholder workshops which align with the first four steps of IM.[59]
54 The ‘*act*’ and ‘*observe*’ stages of the action research cycles involve a series of mixed method
55 ‘research activities’ that will be refined in each ‘*reflect*’ and ‘*plan*’ stage within the
56 workshops. We outline research activities within each of the IM steps and action research
57 cycles below. We note that HREC approval has been received for ‘phase one and two’, but
58
59
60

1
2
3 that activities planned for a 'phase three' HREC submission have not been approved and are
4 subject to review (thus briefly outlined here).
5

6 <<Insert Figure 2 about here>>
7
8
9

10 **1. Action research cycle and IM step 1: Developing relationships and** 11 **understanding the problem**

12 This first action research cycle includes: (1a) evidence reviews, (1b) the first key stakeholder
13 workshop, aligned with IM step 1, (1c) mapping domains included within existing assessment
14 tools, and (d) a pilot discussion group with senior Aboriginal women. Each of these activities
15 is described further below:
16

17
18 *1a: Evidence reviews: Scoping review and evidence map of studies involving parents in the*
19 *perinatal period with a history of childhood maltreatment; and comprehensive systematic*
20 *reviews*
21

22 The purpose of the scoping review and evidence map was to identify preliminary evidence,
23 and enable development of protocols for a series of comprehensive systematic reviews
24 (Supplementary file 3). The scoping review findings have been incorporated into subsequent
25 research activities, including: presentation at workshop 1; generating 'cards' of key issues
26 described by parents elsewhere in discussion groups with senior Aboriginal women and
27 parents; and scoping 'strengths' to be included in an assessment tool. The scoping review has
28 also been critical to refine the search strategy for a series of comprehensive reviews.[60]
29
30

31 *1b: Key stakeholder workshop 1*
32

33 The purpose of workshop 1, aligned with IM step 1 (understanding the problem and
34 developing a logic model), was to provide a forum for preliminary engagement with key
35 stakeholders to:
36

- 37 • Introduce the rationale for the project and share preliminary evidence from the
- 38 scoping review to enable informed discussion and clarification of goals (logic model).
- 39 • Establish safety protocols for working with parents, service providers, key
- 40 stakeholders, team members, and the wider Aboriginal community.
- 41 • Understand the context and issues for key stakeholders regarding identifying and
- 42 supporting Aboriginal parents experiencing complex trauma.
43

44 Recruitment and sample: Key stakeholders were identified through consultation and using a
45 snowballing recruitment process of advertising about the project through Aboriginal and
46 academic health networks, professional meetings and conferences. People expressing interest
47 in the project were included in a key stakeholder email list, and received updates about the
48 project and invitations to the workshops which were cost-free to enable attendance.
49 Approximately 40 people participated in workshop 1.
50

51
52 Data collection and analysis: A facilitation guide was developed to address the aims of the
53 workshop (Supplementary file 4) and promote a culturally and emotionally safe environment.
54 Strategies to support any participants who may experience 'triggers' themselves (i.e. trauma
55 responses) during the workshop and psychological support were provided.
56

57 Data were collected in the form of workshop materials developed by participants (butchers
58 paper notes) and observer notetakers. Data were collated into themes and circulated to
59 workshop participants to check the accuracy of the interpretations. A summary of the
60

workshop is available on the project website.[61] In keeping with the action research process, findings were reflected on and used for planning workshop 2 (2a) and developing the conceptual framework and a detailed safety protocol.

1c: Scoping assessment tools

The purpose of scoping existing assessment tools for complex trauma and/or a parental history of child maltreatment, and for assessing resilience and strengths was to:

- Map the range of areas of distress included within existing assessment tools.
- Enable informed consultation with key stakeholders about each of the main areas of distress and if all important areas were considered.
- Map domains of resilience and strengths.

Data collection and analysis: Distress assessment tools were identified through the scoping review and consultation. For each tool, data were extracted on: description of the tool; key references; validation information; symptoms of distress and/or trauma exposures measured. Data were synthesised into summary ‘areas of distress’ (Supplementary file 5), and further refined by the research team for presentation to key stakeholders at workshop 2.

Strengths domains were mapped from existing resilience tools, mediating/moderating factors and ‘strategies parents use’ in the scoping review, and data generated from a discussion group with senior Aboriginal women and in key stakeholder workshop 2.

1d: Pilot discussion group with senior Aboriginal women

The purpose of this discussion group was to:

1. Consult with community leaders about the effects of complex trauma during the perinatal period for Aboriginal parents, and what might help or hinder the parenting transition.
2. Pilot qualitative methods proposed for use with parents, and gather feedback on the safety and appropriateness of these approaches and tools.

Recruitment and sample: A convenience sample of six to eight senior Aboriginal members of a community group that had expressed interest in the project.

Data collection and analysis: A facilitation plan was developed that included use of: visual tools and natural materials to facilitate discussions; cards illustrating the main themes from the scoping review to build on existing research; third person scenarios to increase safety and minimise the ‘directness’ of sensitive discussions so they were not intrusive; use of metaphors and symbolism; and a ‘strengths-based’ focus on ‘healing’ rather than ‘trauma’. The discussion group was facilitated by an Aboriginal psychologist (YC) and Aboriginal midwife (CC) with expertise in conducting discussion groups with Aboriginal people. Additional psychological support was available in line with the detailed safety plan.

A detailed discussion group protocol was developed (available on request). Data were collected in the form of visual notes and images provided by group participants, observer notes and a recording of the discussion which was transcribed verbatim. Two Aboriginal researchers (YC, CC) independently coded data into themes (thematic analysis)[62] and these were discussed with participants to check the interpretation of the data accurately reflected both what was said as well as the intent. Themes were shared with key stakeholders at workshop 2 for reflection and planning of subsequent parent discussion groups.

2. Action research cycle and IM step 2: Scoping assessment domains with a focus on research evidence and community knowledge, and developing objectives

The second action research cycle includes: (2a) a second key stakeholder workshop, aligned with IM step 2, (2b) refining the assessment tool domains and preliminary questions for parents, (2c) identifying ‘gold standard’ assessment for comparison in psychometric testing, training and cultural adaptation (if required), and (2d) first round of discussion groups with parents who have experienced complex childhood trauma.

2a: Key stakeholder workshop 2

The purpose of workshop 2 was to reflect on the activities from action research cycle 1 and plan for ethics phase 2. This is aligned with IM step 2, which involves refining the project objectives and consulting with key stakeholders regarding:

- The areas of distress to be included in an assessment tool.
- Reflection on pilot discussions with senior Aboriginal women regarding areas of strengths and pre-testing the proposed approach for working with parents.

Recruitment and sample: Key stakeholders were identified as described in 1b, with approximately 60 participants attending.

Data collection and analysis: A facilitation guide was developed to address the aims of the workshop (Supplementary file 6) and promote a culturally and emotionally safe environment. A traditional healer (*Ngangkerre*) worked alongside the registered psychologist to cater for different support needs and recognise the equal value of respective expertise.

Data regarding the 12 summary areas of distress were gathered using a modified Delphi approach. Each area of distress was allocated to a table and facilitator. Participants gathered in groups of six to eight at one table and were given individual forms (non-identified) with a description of the area of distress, with additional information provided by the facilitator. They were asked to indicate the degree of ‘importance’ (1-5) of the area of distress, and discuss and/or document any comments about why, who, where and how questions regarding this area of distress should be asked. These discussions will be central for informing co-design of safe ‘recognition’ strategies in workshop 3. Participants rotated around all 12 tables. Data were transcribed and imported into NVivo for thematic analysis and future triangulation with data to be collected at workshops 3 and 4.

Reflections regarding the discussion group with senior Aboriginal women and pre-testing the discussion group ‘Tree of life’[63] approach for use with parents were recorded by participants pictorially using sticky notes on butchers paper. The ‘Tree of Life’[63] was used as it provides a hopeful and inspiring approach to talking about challenging issues and generates visual images to promote shared understanding, and had been used by effectively by an Investigator in other settings (JA). This positive ‘tree of life’ tool aligned with the ‘strengths-based’ focus on parents hopes and dreams and the support parents need moving forward, rather than dwelling on past experiences. These images were photographed, data were coded into themes and imported into NVivo for thematic analysis and future triangulation with other data sources to inform co-design of awareness and support strategies.

2b: Developing assessment tool areas of distress and strength questions for parents

The purpose of refining the areas of distress and strength questions that may be included in an assessment tool is to enable initial evaluation of ‘face validity’ of the questions with parents and identify any important issues requiring direct discussion with parents.

1
2
3 Data collection and analysis: Data collected in key stakeholder workshop 1 (1b), scoping
4 assessment tools (1c) and workshop 2 (2a) will be collated in NVivo for thematic analysis.
5 These themes and issues will be refined in consultation with the research team to propose
6 questions related to ‘areas of distress’ to be included in an assessment tool. Questions for
7 assessing each of these areas of distress will be drafted, based on questions validated in
8 existing tools (International Trauma Questionnaire and a version of the Harvard Trauma
9 Questionnaire adapted for Aboriginal people and cultural resources regarding mental health
10 literacy).[64, 65]
11
12

13 Strengths questions will be developed by the research team, based on strength themes
14 identified from the scoping review, workshop activities, pilot discussion group and other
15 strength-based tools. The core values from the conceptual framework will be applied to
16 assess the degree to which each of the proposed questions is consistent with the values and
17 principles of the project, and discussed in relation to key issues raised in the thematic
18 analysis. The preliminary over-inclusive question list will be discussed with the research
19 team, and ‘pretested’ in a convenience sample of Aboriginal colleagues. The proposed
20 questions will be incorporated into the first round of discussion groups with parents to
21 evaluate preliminary ‘face validity’ of the proposed questions.
22
23

24 *2c: Identifying ‘gold standard’ assessment for comparison in psychometric testing, training
25 and cultural adaptation (if required)*
26

27 The purpose of this activity is to identify the best possible ‘gold standard’ for comparison
28 with our proposed assessment tool.
29

30 Data collection and analysis: A preliminary list of suitable tools for use as a ‘gold standard’
31 was generated by consensus within the research team following a systematic and transparent
32 process of consideration. From this, the trauma section of the WHO World Mental health
33 Composite International Diagnostic Interview (CIDI) has been proposed. Consultation about
34 the proposed ‘gold standard’ will also be conducted with three or four additional key external
35 psychiatric and psychological experts.
36

37 Up to six Aboriginal psychologists will train together in the use of the ‘gold standard’
38 structured clinical interview to enable them to reflect and use their cultural and clinical
39 expertise. They will advise whether any aspects need adaptation for use with Aboriginal
40 parents.
41
42

43 *2d: First round of discussion groups with Aboriginal parents*
44

45 The purpose of the first round of discussion groups with Aboriginal parents is to:

- 46 • Understand key perinatal experiences affecting Aboriginal parents and what kinds of
47 awareness (trauma-informed care) and support strategies might help or hinder the
48 transition to parenting for parents experiencing complex trauma; and
- 49 • Evaluate the ‘face validity’ of draft questions in a preliminary assessment tool.
50
51

52 Recruitment and sample: Approximately 24 Aboriginal parents will be invited to participate
53 in discussion groups, one to three groups per participating jurisdiction with up to eight
54 parents in each. The size of the group will be determined by the study coordinator in
55 consultation with service provider staff regarding the most appropriate mix of: gender, the
56 level of comfort of participants in group discussion and language. We estimate that this will
57 be sufficient to produce theoretical saturation of thematic categories, particularly when
58 triangulated with data from the pilot discussion group and key stakeholder workshops.
59
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3 However, if saturation of themes is not reached we will consider further discussion groups as
4 needed.
5

6 Individual parents will be recruited through the services they attend for perinatal care using
7 direct and indirect methods. Service providers will be given written and verbal information
8 about the study by the research team. Service providers will then ask potentially eligible
9 parents if they give consent to be contacted by the research team to discuss the study in more
10 detail and consider if they would like to consent to participate in the discussion group.
11 Parents may be asked if they would like to be contacted by the research team in a private area
12 while waiting to attend for services, after a consultation, or during other community
13 activities. Additionally, flyers will be displayed describing the purpose of the study and
14 providing contact details for parents to contact the research team directly.
15
16

17 Inclusion criteria: Participants will be eligible to participate if they identify as Aboriginal
18 and/or Torres Strait Islander, are aged 16 years or older, and they or their partner are
19 currently pregnant or have a child less than two years of age.
20

21 Exclusion criteria: Parents experiencing current serious mental illness (e.g. acute psychoses
22 or other mental health difficulties that may affect their capacity to provide informed consent
23 and/or pose a risk to the safety of the parent and other participants in the discussion group).
24 This will be assessed by service staff prior to asking for consent to be contacted, and by the
25 research team prior to asking for consent to participate in the discussion group.
26
27

28 Data collection and analysis: A facilitation plan has been refined based on feedback from the
29 pilot discussion group (1d) and workshop 2 (2a). The discussion group will be facilitated by
30 an Aboriginal researcher with expertise in conducting discussion groups with Aboriginal
31 peoples. Psychological support will be provided. The facilitation plan (Supplementary file 7)
32 includes use of: visual tools and natural materials to facilitate discussions; cards illustrating
33 the main themes from the scoping review to build on existing research; third person scenarios
34 to increase safety and minimise the 'directness' of sensitive discussions so they are not
35 intrusive; use of metaphors and symbolism to explain complex phenomena; and a 'strengths-
36 based' focus. Data will be collected using visual notes prepared by participants in a 'tree of
37 life' activity to frame discussions about the needs for Aboriginal parents experiencing
38 complex trauma, and transcribed audio recordings of the discussions.
39
40

41 Two researchers will independently conduct thematic analysis and discuss draft themes with
42 participants to check the interpretation of the data. The themes from this discussion group
43 will be triangulated with data from previous project activities and shared with key
44 stakeholders participating in workshop 3 to inform co-design of a preliminary awareness and
45 support strategies.
46

47 Additional face to face interviews will be conducted with up to nine parents to assess the
48 'face validity' of a preliminary list of distress and strengths questions. These will be further
49 refined in workshop 3.
50

51 **3. Action research cycle and IM step 3: Developing acceptable and feasible** 52 **perinatal awareness, recognition, assessment and support strategies** 53

54 The third action research cycle includes: (3a) key stakeholder co-design workshop 3, aligned
55 with IM step 3, (3b) psychometric evaluation of assessment tool, (3c) a second round of
56 discussion groups with parents, and (3d) discussion groups with service providers.
57

58 *3a: Key stakeholder co-design workshop 3*
59
60

1
2
3 The purpose of workshop 3, aligned with IM step 3, is to co-design the preliminary
4 recognition and assessment process and possible awareness and support strategies.
5

6 Recruitment and sample: Key stakeholders will be identified as previously described, with up
7 to 60 participants anticipated.
8

9 Data collection and analysis: A facilitation guide will be developed to address the aims of the
10 workshop and promote a culturally and emotionally safe environment as per previous
11 workshop. The workshop will incorporate triangulated data from previous action research
12 cycles to foster informed co-design of for preliminary:
13

- 14 • **awareness** and **support** strategies, informed by scoping review, qualitative
15 systematic review of parents views, intervention review, and relevant data from
16 discussion groups and key stakeholder workshops. The purpose is to generate an
17 over-inclusive range of options, for further refinement in parent discussion groups to
18 rank and assess acceptability, and service provider discussion groups to assess
19 feasibility.
20
- 21 • **recognition** and **assessment** strategies, informed by data from the scoping review,
22 scoping of assessment tools, key stakeholder workshop 2 exercise, and the face
23 validity assessments in parent discussion groups. The purpose is to develop
24 processes to foster safe **recognition** of parents who may benefit from further
25 assessment, to be further refined following parent and service provider discussion
26 groups, and an overinclusive list of **assessment** items for psychometric evaluation
27 and refinement.
28
29

30 **Summary of proposed activities to be submitted for ‘phase three’ HREC approval**

31
32 The detailed methods for the following activities will be refined based on feedback from
33 ‘reflection’ and ‘planning’ from activities described in ‘ethics phase one and two’ in
34 consultation with partner organisation staff, and submitted for ethical approval. A brief
35 outline of main activities, aims and sample size estimates are included below.
36

37 *3b: Psychometric evaluation of assessment tool*, which aims to develop a valid assessment
38 tool that enables perinatal care providers to accurately identify strengths, as well as complex
39 trauma symptoms (measurement sensitivity) whilst minimising the erroneous identification of
40 parents who are not experiencing complex trauma symptoms (measurement specificity).
41

42 The sensitivity of a complex trauma assessment will need to be high for the inventory to be
43 effective and appropriate for use in practice, where our priority would be that all parents who
44 could benefit from further assessment and support are recognised. Based on previous
45 estimates of Post Traumatic Stress Disorder (PTSD) and complex trauma,[65-75] we
46 conservatively estimate that 20% of Aboriginal parents will meet sub-threshold criteria of at
47 least two symptoms. Identifying parents meeting sub-threshold criteria will maximise the
48 sensitivity of the instrument to identify PTSD and complex trauma and we estimate that a
49 sensitivity of 90% would be achieved. Thus, a sample size of 173 participants will be
50 required to yield an estimate of the instrument sensitivity with a 2-sided 95% confidence
51 interval with a width of 10% of the estimate. This sample size will also enable estimation of
52 the specificity of the instrument to correctly identify participants who had not experienced
53 complex trauma.
54
55

56
57 *3c: Second round of discussion groups with parents*, which aims to assess the *acceptability* of
58 the proposed recognition and assessment process; and awareness and support strategies.
59
60

1
2
3 Approximately 24 Aboriginal parents will be recruited to participate in discussion groups,
4 one to three groups per participating jurisdiction with up to eight parents in each.
5

6 *3d: Discussion groups with service providers*, which aim to assess the *feasibility* of the
7 proposed recognition and assessment process; and awareness and support strategies.
8 Approximately 24 service providers will be recruited to participate in discussion groups, one
9 to two groups per participating jurisdiction with up to eight service providers in each.
10

11 **4. Action research cycle 4: Planning for pilot, implementation and evaluation**

12
13 The fourth and final action research cycle includes a fourth key stakeholder workshop and
14 drafting plans with perinatal service providers to pilot, implement and evaluate safe
15 acceptable and feasible perinatal awareness, recognition, assessment and support strategies
16 for Aboriginal parents experiencing complex trauma.
17

18
19 *4a: Key stakeholder workshop 4*, aligned with IM step 4 to ‘refine strategies and prepare to
20 pre-test’, aims to reflect on the research findings with service providers and develop plans
21 for seeking funding to pilot, implement (IM step 5) and evaluate (IM step 6) perinatal
22 awareness, recognition, assessment and support strategies.
23

24 **ETHICS AND DISSEMINATION**

25 **Ethics**

26
27 Action research poses unique challenges for seeking HREC approval. While there is an
28 overarching structure and an outline of main activities, the detail required for ethical approval
29 evolves during the action research process. In this project, submissions for HREC approval
30 are being submitted to relevant jurisdictional authorities in three phases, with HREC approval
31 for phases 1 and 2 granted at the time of submission. This is particularly important in a
32 project involving sensitive content such as complex trauma, where the HREC need to
33 examine draft tools and resources to consider risks for triggering distress symptoms against
34 potential benefits.
35

36
37 This staged approach also enables piloting and reflection on the ‘safety’ of the research
38 activities and flexibility to refine research processes. For example, in this project, discussions
39 were first held with a predominantly professional group of ‘key stakeholders’ in workshop
40 one, then with a group of senior Aboriginal women in a ‘pilot’ discussion, and then a
41 proposed approach was ‘pretested’ in a second ‘key stakeholder’ workshop, prior to
42 submitting the final plans for discussion groups directly with Aboriginal parents. The intent is
43 to ensure our approach and processes maximise safety and minimise the risk of distress for
44 parents, while also gathering the data needed to inform iterative development of awareness,
45 recognition, assessment and support strategies. At the time of submitting this protocol, HREC
46 approval had been granted for phase one and two (see Figure 2).
47

48
49 The funding proposal for this project was assessed by an Indigenous research panel using the
50 NHMRC Indigenous Research Excellence criteria (Supplementary file 1) developed to
51 promote ethical and culturally appropriate research with Aboriginal communities. In addition,
52 we have developed a conceptual framework (Figure 1) which outlines the ethical and cultural
53 values for this project. A specific safety framework describes how the primary value of
54 safety will be fostered for parents, service providers, key stakeholders and team members,
55 and the broader Aboriginal community.
56

57 **Dissemination**

We have developed a research dissemination plan (available on request), in line with the NHMRC Indigenous Research Excellence criteria (Supplementary file 1) and the value of reciprocity.

The research dissemination plan includes:

- Offering two-way information exchange for all community meetings (i.e. prior to the meeting asking if there are any presentations about topics people would like us to offer to their staff and community members about complex trauma and parenting).
- Publication of articles in open access journals with links to relevant Aboriginal health websites.
- Face to face presentations in national and international conferences.
- Translating all findings into plain language summaries.
- Incorporating art, presentations and other mediums to present information.
- Preparing a video/short YouTube clip with essential information for community members and making this freely available on the project website and sharing at community meetings.
- Ensuring all relevant information is presented on the research website, which is regularly monitored for currency, optimised for search engine performance, and follows accessibility guidelines.

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AUTHOR CONTRIBUTIONS

CC is the study Principal Investigator and drafted this protocol based on the project proposal and other relevant project planning documents involving many people as outlined in acknowledgements and author contribution statements. GG, SJB, JA, DG, HH, KG, YC, SC, FM, CA, SB, HM, TH and JNM are study investigators who contributed to development of the project proposal, project planning and drafting the manuscript. FM conducted sample size estimate calculations for psychometric evaluation of the assessment tool. DD assisted with development of the conceptual framework, study planning and drafting the manuscript. NR, SH and YC are employed on the project and have contributed to development of planning documents, conceptual framework, ethics submissions which involved many considerations outlined in this protocol, and drafting the manuscript. All authors read and approved the final manuscript.

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COMPETING INTERESTS STATEMENT

No competing interests were declared.

REFERENCES

1. Sara G, Lappin J. Childhood trauma: psychiatry's greatest public health challenge? *Lancet Public Health* 2017;2(7):e300-e01. doi: 10.1016/S2468-2667(17)30104-4
2. McCrory E, De Brito S, Viding E. Research review: The neurobiology and genetics of maltreatment and adversity. *J Child Psychol Psychiatry* 2010;51(10):1079-95.
3. De Bellis MD, Zisk A. The biological effects of childhood trauma. *Child Adolesc Psychiatr Clin N Am* 2014;23(2):185-222.
4. Brent DA, Silverstein M. Shedding light on the long shadow of childhood adversity. *JAMA* 2013;309(17):1777-78.
5. Norman RE, Byambaa M, De R, et al. The long-term health consequences of child physical abuse, emotional abuse, and neglect: a systematic review and meta-analysis. *PLoS Med* 2012;9(11):e1001349. doi: 10.1371/journal.pmed.1001349
6. Bellis MA, Hughes K, Leckenby N, et al. National household survey of adverse childhood experiences and their relationship with resilience to health-harming behaviors in England. *BMC Med Inform Decis Mak* 2014;12(1):72. doi: 10.1186/1741-7015-12-72
7. Felitti VJ, Anda RF, Nordenberg D, et al. Relationship of Childhood Abuse and Household Dysfunction to Many of the Leading Causes of Death in Adults. *Am J Prev Med* 1998;14(4):245-58. doi: 10.1016/S0749-3797(98)00017-8
8. Maercker A, Brewin CR, Bryant RA, et al. Diagnosis and classification of disorders specifically associated with stress: proposals for ICD-11. *World Psychiatry* 2013;12(3):198-206. doi: 10.1002/wps.20057
9. Kezelman C, Stavropoulos P. Practice Guidelines for Treatment of Complex Trauma and Trauma Informed Care and Service Delivery. Sydney: Adults Surviving Child Abuse, 2012.
10. Sotero MA. A Conceptual Model of Historical Trauma: Implications for Public Health Practice and Research *Journal of Health Disparities Research and Practice* 2006;1(1):93-108.
11. Evans-Campbell T, Walters KL. Catching our breath: A decolonization framework for healing indigenous families. *Intersecting Child Welfare, Substance Abuse, and Family Violence: Culturally Competent Approaches Alexandria, VA, CSWE Publications* 2006:266-92.
12. Atkinson J, Nelson J, Atkinson C. Trauma, transgenerational transfer and effects on community wellbeing. In: Purdie N, Dudgeon P, Walker R, eds. Working together: Aboriginal and Torres Strait Islander mental health and wellbeing practices and principles. Canberra: Department of Health and Ageing 2010.
13. Chandler MJ, Lalonde CE. Cultural Continuity as a Protective Factor against Suicide in First Nations Youth. *Horizons --A Special Issue on Aboriginal Youth, Hope or Heartbreak: Aboriginal Youth and Canada's Future* 2008;10(1):68-72.

14. Violence Prevention Alliance. The ecological framework Geneva, Switzerland: World Health Organisation; 2016 [Available from: <http://www.who.int/violenceprevention/approach/ecology/en/> accessed 9/9/2016.
15. Lieberman AF, Chu A, Van Horn P, et al. Trauma in early childhood: empirical evidence and clinical implications. *Dev Psychopathol* 2011;23(2):397-410. doi: 10.1017/s0954579411000137
16. Font SA, Maguire-Jack K. Pathways from childhood abuse and other adversities to adult health risks: The role of adult socioeconomic conditions. *Child Abuse Negl* 2015;No Pagination Specified.
17. Bellis MA, Hughes K, Leckenby N, et al. National household survey of adverse childhood experiences and their relationship with resilience to health-harming behaviors in England. *BMC Med* 2014;12:72.
18. McCrory C, Dooley C, Layte R, et al. The Lasting Legacy of Childhood Adversity for Disease Risk in Later Life. *Health Psychol* 2015;34(7):687-96.
19. Blackmore ER, Putnam FW, Pressman EK, et al. The effects of trauma history and prenatal affective symptoms on obstetric outcomes. *J Trauma Stress* 2016;29(3):245-52.
20. Alexander PC. Intergenerational cycles of trauma and violence: An attachment and family systems perspective. (2015) *Intergenerational cycles of trauma and violence: An attachment and family systems perspective xi, 370 pp New York, NY, US: W W Norton & Co; US* 2015
21. Dahlberg L, Krug E. Violence—a global public health problem Geneva, Switzerland: World Health Organization; 2002 [1–56]. Available from: http://www.who.int/violence_injury_prevention/violence/world_report/en/chap1.pdf accessed 10/10/2018.
22. Marmot M, Allen J, Bell R, et al. WHO European review of social determinants of health and the health divide. *The Lancet* 2012;380(9846):1011-29.
23. Sperlich M, Seng J, Rowe H, et al. A Cycles-Breaking Framework to Disrupt Intergenerational Patterns of Maltreatment and Vulnerability During the Childbearing Year. *Journal of obstetric, gynecologic, and neonatal nursing : JOGNN* 2017;46(3):378-89. doi: 10.1016/j.jogn.2016.11.017
24. Stephenson LA, Beck K, Busuulwa P, et al. Perinatal interventions for mothers and fathers who are survivors of childhood sexual abuse. *Child Abuse Negl* 2018;80:9-31. doi: 10.1016/j.chiabu.2018.03.018
25. Amos J, Furber G, Segal L. Understanding maltreating mothers: a synthesis of relational trauma, attachment disorganization, structural dissociation of the personality, and experiential avoidance. *J Trauma Dissociation* 2011;12(5):495-509. doi: 10.1080/15299732.2011.593259
26. Bridgett DJ, Burt NM, Edwards ES, et al. Intergenerational transmission of self-regulation: A multidisciplinary review and integrative conceptual framework. *Psychological bulletin* 2015;141(3):602-54. doi: 10.1037/a0038662
27. Siegel JP. Breaking the links in intergenerational violence: An emotional regulation perspective. *Family Process* 2013;52(2):163-78.
28. Fava NM, Simon VA, Smith E, et al. Perceptions of general and parenting-specific posttraumatic change among postpartum mothers with histories of childhood maltreatment. *Child Abuse Negl* 2016;56:20-29.
29. Green-Miller SN. Intergenerational parenting experiences and implications for effective interventions of women in recovery. *Dissertation Abstracts International Section A: Humanities and Social Sciences* 2012;73(5-A):1926.
30. Segal L, Dalziel K. Investing to protect our children: Using economics to derive an evidence-based strategy. *Child Abuse Rev* 2011;20(4):274-89. doi: 10.1002/car.1192
31. Richter LM, Daelmans B, Lombardi J, et al. Investing in the foundation of sustainable development: pathways to scale up for early childhood development. *Lancet (London, England)* 2017;389(10064):103-18. doi: 10.1016/S0140-6736(16)31698-1

- 1
- 2
- 3
- 4 32. Britto PR, Lye SJ, Proulx K, et al. Nurturing care: promoting early childhood development. *The Lancet* 2016 doi: 10.1016/S0140-6736(16)31390-3
- 5
- 6 33. Barlow J, MacMillan H, Macdonald G, et al. Psychological interventions to prevent recurrence of
- 7 emotional abuse of children by their parents. *Cochrane Database Syst Rev* 2013(9) doi:
- 8 10.1002/14651858.CD010725
- 9 34. DeGregorio LJ. Intergenerational transmission of abuse: implications for parenting interventions
- 10 from a neuropsychological perspective. *Traumatology* 2013;19(2):158-66. doi:
- 11 10.1177/1534765612457219
- 12 35. Bowes J, Grace R. Review of early childhood parenting, education and health intervention
- 13 programs for Indigenous children and families in Australia. Issues paper no 8 Australian
- 14 Institute of Family Studies for the Closing the Gap Clearinghouse, 2014.
- 15 36. Palmer VJ, Weavell W, Callander R, et al. The Participatory Zeitgeist: an explanatory theoretical
- 16 model of change in an era of coproduction and codesign in healthcare improvement. *Medical*
- 17 *Humanities* 2018 doi: 10.1136/medhum-2017-011398
- 18 37. Gonzales KL, Jacob MM, Mercier A, et al. An indigenous framework of the cycle of fetal alcohol
- 19 spectrum disorder risk and prevention across the generations: historical trauma, harm and
- 20 healing. *Ethn Health* 2018;1-19. doi: 10.1080/13557858.2018.1495320
- 21 38. Haebich A. Broken Circles: Fragmenting Indigenous families 1800-2000. Fremantle, Western
- 22 Australia: Fremantle Arts Centre Press 2000.
- 23 39. BigFoot DS, Schmidt SR. Honoring children, mending the circle: cultural adaptation of trauma-
- 24 focused cognitive-behavioral therapy for American Indian and Alaska Native children. *J Clin*
- 25 *Psychol* 2010;66(8):847-56. doi: doi:10.1002/jclp.20707
- 26 40. Gee G, Dudgeon P, Schultz C, et al. Understanding Social and Emotional Wellbeing and Mental
- 27 Health from an Aboriginal and Torres Strait Islander perspective. In: Dudgeon P, Milroy H,
- 28 Walker R, eds. Working Together: Aboriginal and Torres Strait Islander Health and Wellbeing
- 29 Principles and Practice Second ed. Canberra: Australian Council for Education Research and
- 30 Telethon Institute for Child Health Research, Office for Aboriginal and Torres Strait Islander
- 31 Health, Australian Government Department of Health and Ageing 2014.
- 32 41. O'Donnell M, Taplin S, Marriott R, et al. Infant removals: The need to address the over-
- 33 representation of Aboriginal infants and community concerns of another 'stolen generation'.
- 34 *Child Abuse Negl* 2019;90:88-98. doi: 10.1016/j.chiabu.2019.01.017
- 35 42. Sexton MB, Davis MT, Menke R, et al. Mother-child interactions at six months postpartum are not
- 36 predicted by maternal histories of abuse and neglect or maltreatment type. *Psychological*
- 37 *trauma : theory, research, practice and policy* 2017;9(5):622-26. doi: 10.1037/tra0000272
- 38 43. Thornberry TP, Knight KE, Lovegrove PJ. Does Maltreatment Beget Maltreatment? A Systematic
- 39 Review of the Intergenerational Literature. *Trauma, violence & abuse* 2012;13(3):135-52. doi:
- 40 10.1177/1524838012447697
- 41 44. Panaretto KS, Wenitong M, Button S, et al. Aboriginal community controlled health services:
- 42 leading the way in primary care. *Med J Aust* 2014;200(11):649-52.
- 43 45. MacDonald C. Understanding participatory action research: A qualitative research methodology
- 44 option. *Canadian Journal of Action Research* 2012;13(2):34-50.
- 45 46. Ivankova NV. Applying mixed methods in community-based participatory action research: a
- 46 framework for engaging stakeholders with research as a means for promoting patient-
- 47 centredness. *Journal of Research in Nursing* 2017;22(4):282-94. doi:
- 48 10.1177/1744987117699655
- 49 47. Johnstone L, Boyle M, Cromby J, et al. The Power Threat Meaning Framework: Towards the
- 50 identification of patterns in emotional distress, unusual experiences and troubled or troubling
- 51 behaviour, as an alternative to functional psychiatric diagnosis Leicester: British Psychological
- 52 Society, 2018.
- 53 48. Australian Health Ministers' Advisory Council. Population Based Screening Framework. Barton:
- 54 Commonwealth of Australia, 2008.
- 55
- 56
- 57
- 58
- 59
- 60

- 1
- 2
- 3
- 4 49. Rigney L. Indigenous Australian views on Knowledge Production and Indigenist Research. In:
5 Runnie J, Goduka N, eds. Indigenous Peoples' Wisdom and Power: Affirming our Knowledge.
6 Burlington, USA: Ashgate Publishing 2006:32-48.
- 7 50. Dudgeon P, Milroy J, Calma T, et al. Aboriginal and Torres Strait Islander Suicide Prevention
8 Evaluation Project (ATSISPEP) report. Solutions that Work: What the Evidence and Our People
9 Tell Us. Perth: University of WA, 2016.
- 10 51. Rodriguez CM, Green AJ. Parenting stress and anger expression as predictors of child abuse
11 potential. *Child Abuse Negl* 1997;21(4):367-77.
- 12 52. Guarino K, Soares P, Konnath K, et al. Trauma-Informed Organizational Toolkit. Rockville, MD:
13 Center for Mental Health Services, Substance Abuse and Mental Health Services
14 Administration, and the Daniels Fund, the National Child Traumatic Stress Network, and the
15 W.K. Kellogg Foundation, 2009.
- 16 53. Denby C, Winslow C, Willette C, et al. The Trauma Toolkit: a resource for service organizations and
17 providers to deliver services that are trauma-informed. Winnipeg, Canada: Clinic Community
18 Health Centre, 2008.
- 19 54. Atkinson C, Atkinson J, Wrigley B, et al. Aboriginal Family Violence Prevention Legal Services:
20 Culturally informed trauma integrated healing approach - a guide for action for trauma
21 champions. Canberra: Commonwealth of Australia, 2017.
- 22 55. CATSINAM, ACM, CRANAPlus. Birthing on country position statement. Canberra: College of
23 Aboriginal and Torres Strait Islander Nurses and midwives, Australian College of Midwives,
24 CRANA Plus 2016.
- 25 56. Australian Health Ministers' Advisory Council. Aboriginal and Torres Strait Islander Health
26 Performance Framework 2017 Report. Canberra: AHMAC, 2017.
- 27 57. Harris P, Taylor R, Thielke R, et al. Research electronic data capture (REDCap) - A metadata-driven
28 methodology and workflow process for providing translational research informatics support.
29 *J Biomed Inform* 2009;42(2):377-81.
- 30 58. Heale R, Forbes D. Understanding triangulation in research. *Evidence Based Nursing* 2013 doi:
31 10.1136/eb-2013-101494
- 32 59. Bartholomew Eldridge LK, Markham CM, Ruiters RAC, et al. Planning health promotion programs:
33 An Intervention Mapping approach (4th ed.). Hoboken, NJ: Wiley 2016.
- 34 60. Chamberlain C, Stansfield C, Sutcliffe K, et al. Perinatal experiences and views of parent's with a
35 history of adverse childhood experiences: a protocol for a systematic review of qualitative
36 studies. *PROSPERO: International prospective register of systematic reviews*
37 2018;CRD42018102110
- 38 61. Ralph N, Clark Y, Gee G, et al. Healing The Past by Nurturing the Future: Perinatal support for
39 Aboriginal and Torres Strait Islander Parents who have experienced Complex Childhood
40 Trauma - Workshop One Report. Bundoora, Melbourne: Judith Lumley Centre, La Trobe
41 University, 2018.
- 42 62. Braun V, Clarke V. Using thematic analysis in psychology. *Qualitative Research in Psychology*
43 2006;3(2):77-101.
- 44 63. Dulwich Centre. The Tree of Life Adelaide, Australia.2019 [Available from:
45 <https://dulwichcentre.com.au/the-tree-of-life/> accessed 23/3/2019.
- 46 64. NPY Womens Council Aboriginal Corporation. Uti Kulintjaku 2018 [Available from:
47 <https://www.npywc.org.au/ngangkari/uti-kulintjaku/>.
- 48 65. Atkinson C. The violence continuum: Aboriginal Australian male violence and generational post-
49 traumatic stress. Charles Darwin University, 2008.
- 50 66. Ben-Ezra M, Karatzias T, Hyland P, et al. Posttraumatic stress disorder (PTSD) and complex PTSD
51 (CPTSD) as per ICD-11 proposals: A population study in Israel. *Depress Anxiety* 2018;35(3):264-
52 74. doi: 10.1002/da.22723
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58
59
60
67. Hyland P, Shevlin M, Brewin CR, et al. Validation of post-traumatic stress disorder (PTSD) and complex PTSD using the International Trauma Questionnaire. *Acta Psychiatr Scand* 2017;136(3):313-22. doi: 10.1111/acps.12771
 68. Muzik M, Morelen D, Hruschak J, et al. Psychopathology and parenting: An examination of perceived and observed parenting in mothers with depression and PTSD. *Journal of affective disorders* 2017;207:242-50. doi: 10.1016/j.jad.2016.08.035
 69. Muzik M, McGinnis EW, Bocknek E, et al. PTSD symptoms across pregnancy and early postpartum among women with lifetime PTSD diagnosis. *Depression and anxiety* 2016;33(7):584-91. doi: 10.1002/da.22465
 70. Quispel C, Schneider TA, Hoogendijk WJ, et al. Successful five-item triage for the broad spectrum of mental disorders in pregnancy - a validation study. *BMC pregnancy and childbirth* 2015;15:51. doi: 10.1186/s12884-015-0480-9
 71. Wenz-Gross M, Weinreb L, Upshur C. Screening for Post-traumatic Stress Disorder in Prenatal Care: Prevalence and Characteristics in a Low-Income Population. *Maternal and child health journal* 2016;20(10):1995-2002. doi: 10.1007/s10995-016-2073-2
 72. Yildiz PD, Ayers S, Phillips L. The prevalence of posttraumatic stress disorder in pregnancy and after birth: A systematic review and meta-analysis. *Journal of affective disorders* 2017;208:634-45. doi: 10.1016/j.jad.2016.10.009
 73. Gee G. Resilience and Recovery from Trauma among Aboriginal Help Seeking Clients in an Urban Aboriginal Community Controlled Health Organisation. . University of Melbourne, 2016.
 74. Gartland D, Woolhouse H, Giallo R, et al. Vulnerability to intimate partner violence and poor mental health in the first 4-year postpartum among mothers reporting childhood abuse: an Australian pregnancy cohort study. *Arch Womens Ment Health* 2016;19(6):1091-100. doi: 10.1007/s00737-016-0659-8
 75. Healing the past by nurturing the future project Melbourne, Australia: La Trobe University; 2018 [Available from: <https://www.latrobe.edu.au/jlc/research/healing-the-past/workshops/past-workshops> accessed 2/12/2018.

FIGURE CAPTIONS

Figure 1: Conceptual framework for co-designing perinatal awareness, recognition, assessment and support strategies for Aboriginal parents experiencing complex trauma.

Figure 2: 'Healing the Past by Nurturing the Future' Research Plan



Figure 1: Conceptual framework for co-designing perinatal awareness, recognition, assessment and support strategies for Aboriginal parents experiencing complex trauma. Artwork by Danielle Dyll.

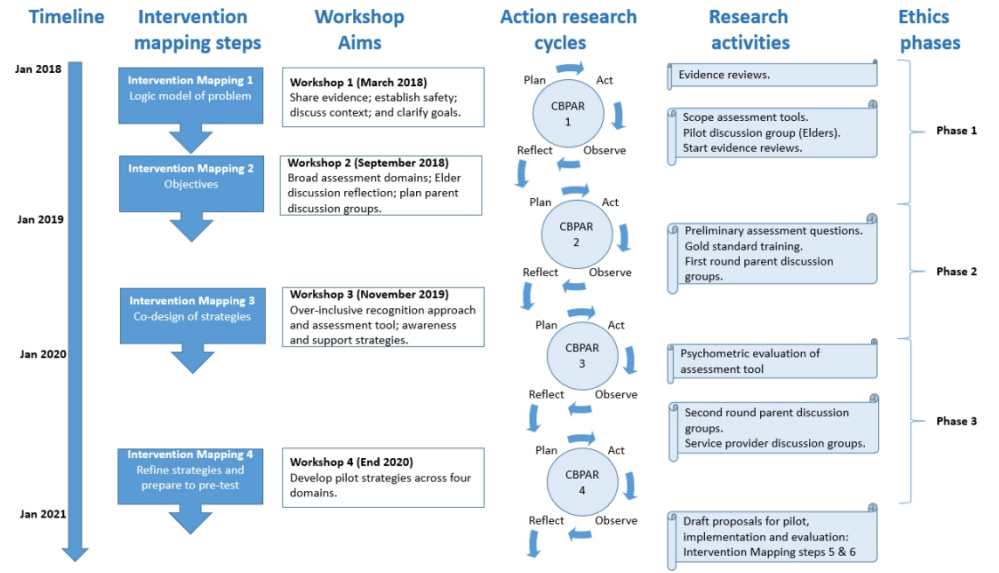


Figure 2: 'Healing the Past by Nurturing the Future' Research Plan

Supplementary File 1: Indigenous Research Excellence Criteria

COMMUNITY ENGAGEMENT: This project is led by a majority of Indigenous researchers who have been discussing this proposal regularly with key stakeholders since its inception. The team members identified the issue as a priority through shared experiences working ‘in the real world’ in complementary sectors of Indigenous mental health and reproductive and child health. We have been using a structured plan for communicating with key stakeholders during the scoping stages of developing this proposal, which has formal letters of support from with Australian Medical Services Alliance Northern Territory (AMSANT) and the Aboriginal Family Health Research Partnership Steering Committee (SA) (AIMitchell is CEO) and strong relationships within the Victorian Aboriginal Health Service (VAHS) (CI Gee is research director). We will continue these processes through 2017, including accepting an invitation to present learnings from the scoping review and VAHS ‘breaking the cycle of trauma’ qualitative project in Victoria, South Australia, the Northern Territory and at international and national meetings. The research will be guided by an Advisory Group which builds on existing relationships and includes representatives from community controlled health services, communities, and clinical settings. We will formally engage potential partners by using existing relationships and sending appropriate formal communication to community controlled health service (CCHS) boards and Chief Executive Officers (CEO) and other maternity care sites seeking their formal support and /or discussion on the study. We will also establish a communication strategy with key stakeholders from all Australian jurisdictions, to provide information about the project and to invite participation of nationally representative stakeholders in the workshops. Our team has extensive expertise in community engagement and developing relationships to facilitate an ‘intervention ready’ environment will be a key outcome from this project (supported by AI McLachlan). We recognise strong relationships as a critical foundation necessary for addressing emotionally challenging issues such as complex trauma, which can impact on program staff.³⁸ As partners in research, this project includes funding to support community member involvement, recognising the value of equal contributions and enable ongoing commitment to the research, which can be a major challenge in community-based participatory action research (CBPAR) projects.³⁶ Our team are committed to working collaboratively and CBPAR methods are core to this proposal. CBPAR methods are strongly value orientated³⁶, and provide a vehicle for redressing power imbalances in research and working respectfully with Indigenous communities, de-colonising’ research, building ownership.³⁶ We are conscious of the need to ensure that Indigenous communities are positively represented³⁷ – a critical factor in any research involving discourse about complex trauma, as seen with the responses to the *Little Children are Sacred* report in the Northern Territory. We have extensive expertise in conducting Indigenous health research and we know that genuine community engagement takes time. At all times, the research team will be open to discussing the study with the boards and or CEO and service staff. Many CCHS have developed protocols for working with researchers, and these will be followed by the research team. During the research process, Indigenous researchers will use culturally appropriate methods and tools to facilitate in-depth discussions and generate authentic data which reflects Indigenous perspectives and values.

BENEFIT: Intergenerational trauma is a key priority identified by communities, as evidenced at the 2016 ‘Lowitja conference’ and this study validates community concerns. There is currently limited Indigenous-specific or general evidence about strategies to support prospective and new parents at a critical transitional life-course stage which suggests a critical ‘intervention’ point for prevention where new cycles begin and open up a rare opportunity for ‘healing the past’. Development of culturally acceptable, trauma-informed screening methods is needed to lobby for culturally acceptable feasible support services for families with complex trauma. This project will assess the risks and benefits of universal and targeted screening, which is particularly important in a condition which is expected to have high prevalence (over 50%). Concurrent development of acceptable and feasible support strategies will ensure that support strategies are ready to be trialled if screening is deemed appropriate, in line

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3 with the principles of population-based screening. Indigenous researchers are well-placed to
4 demonstrate leadership in community-led approaches and generate evidence which is of benefit to both
5 Indigenous and non-Indigenous families. We have included activities to ensure this formative research
6 is translatable. This includes using an IM framework, preparing plain language summaries and reports
7 to present the findings of the research in a range accessible formats through a variety of mediums,
8 including face-face meetings, relevant websites and academic journals. This project offers benefits for
9 partner organisations, with an opportunity to demonstrate leadership in trauma-informed and trauma-
10 specific reproductive and child health services. There will be opportunities for shared learning through
11 the partnership approaches inherent in the research plan. There will be benefits for participants in the
12 program, as therapeutic support will be offered in line with the available evidence. We aim to make
13 the experience of participation rewarding and enjoyable, and in line with CBPAR principles, recognise
14 the contributions of participants as partners in the research to the degree they are comfortable with.
15 This project includes plans for supporting the wellbeing of the whole team (including community-based
16 members) through the duration of the project. This will include deliberative strategies for building trust
17 and strengthening relationships, supportive induction and review processes for addressing career and
18 personal needs, active strategies to facilitate capacity exchange between Indigenous and non-Indigenous
19 team members, and clear debriefing/counselling options (where appropriate).

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23 **SUSTAINABILITY AND TRANSFERABILITY:** Our research team are ideally placed to maximise
24 the sustainability of this research, with links and expertise in community and clinical settings. The
25 research plan is designed using an Intervention Mapping framework which will guide this preliminary
26 systematic process for developing acceptable and feasible interventions, towards the next stages of
27 testing the effectiveness of interventions. Following this developmental work, we have the expertise,
28 community and service linkages across three state and territory jurisdictions to implement and evaluate
29 interventions in a range of settings. Our team brings together expertise in clinical programs,
30 development of resources, training, program implementation, policy and program evaluation necessary
31 for successful translation. Importantly, a major strength of the CBPAR approach is that improves the
32 likelihood that evidence will be transferable, and the engagement of partners maximises the chances of
33 sustainability. We anticipate that any effective interventions are likely to be highly cost-effective, and
34 if this is the case, strong evidence will be needed to ensure sufficient funds are allocated to support
35 prospective and new parents. We have planned this developmental work with this potential endpoint in
36 mind to maximise sustainability and transferability.

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40 **BUILDING CAPACITY:** This project offers substantial capacity-building opportunities at all levels
41 of research and for knowledge exchange between Indigenous and non-Indigenous researchers. The team
42 includes highly experienced Indigenous and non-Indigenous researchers in mental health and trauma
43 (CI Herrman, CI Atkinson), family health (CI Brown, AI Andrews), social work and systems (CI
44 Arabena) and parenting research (CI Nicholson, AI McLachlan); who are well placed to support early-
45 mid career researchers in family health (CI Chamberlain, CI Glover, AI Andrews) and psychology (CI
46 Gee, CI Gartland, CI Clark, AI Atkinson). We will also discuss capacity-building needs with partner
47 organisations, and how we can support skill development of staff in this research project. The project
48 also includes opportunities for postgraduate research (PhD) and other Indigenous research staff to
49 develop skills in research (project coordinator and research assistant) and we will ensure the best
50 possible support for all project members, including appraisal processes to support career goals.
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Supplementary file 2: 'Healing the Past by Nurturing the Future' conceptual framework values, principles and reflective questions

Value	Value description	Related principles	Reflective questions
<i>Safety*</i>	Safety in the context of trauma refers to efforts to ensure safety for service users, staff, key stakeholders and the broader community. This means reasonable freedom from harm or danger and to prevent further traumas from occurring. Emotional, cultural and physical safety are included in this term, and are defined in the HPNF safety protocol. The importance of ensuring safety in programs is highlighted by being the number one principle in numerous existing guidelines, ¹⁻⁵ including the National Trauma Guidelines. ¹	The principle of respect and commitment to all forms of diversity and different cultural backgrounds is foundational to trauma-informed care. ^{1,3} As safety and trust are established, the two-way dialogue between worker and client enables all voices to be heard and mutual respect in the ongoing maintenance of a culturally safe environment. ³ Self-reflection and workplace reflexivity are crucial, and more detailed information about cultural safety are outlined in the safety protocol.	<p>a. To what extent do the project's activities and settings ensure the physical, cultural and emotional safety of:</p> <ul style="list-style-type: none"> • Parents and community members participating in the research? • Service providers? • Stakeholder and team members involved in the co-design process? • The broader community? <p>b. Are there protocols to protect privacy?³</p> <p>c. Are people approached in a private not public space when asking personal questions?³</p> <p>d. Are questions asked in such a way that people do not feel obliged to answer unless they choose?³</p> <p>e. How can safety be ensured in the asking of such questions?¹ – including minimising risks of inappropriate referral to child protection services.</p> <p>f. Are questions that involve disclosure combined with stay/strong plans and support if needed?³</p> <p>g. Is the environment for sensitive discussions inviting and accessible?¹</p> <p>h. Are the first contacts welcoming, respectful and engaging?¹</p> <p>i. Are policies and practices in place to foster cultural safety, self-enquiry and self-reflection in the workplace?³</p>
<i>Trustworthiness*</i>	Fostering trust is another critical principle included in national and other trauma-related guidelines. ^{1,6} Trust was also highlighted by project key stakeholders in workshop 1.	Key principles for fostering trust include being honest and transparent ⁷ and clear and consistent . ¹ Key stakeholders in workshop 1 highlighted the important principle of transparency and demonstrating responsibility , leadership and a commitment to goals to ensure timelines are adhered to and that we do what we say we will. Understanding relatedness (how the person engages in the world which they live and learn) and building authentic and positive relationships ³ are central principles to achieving	<p>a. To what extent do the project's activities and settings maximise trustworthiness by making the tasks involved clear, and by ensuring consistency and transparency?⁷</p> <p>b. Are there processes in place to reflect on commitments made and whether these are being adequately addressed and demonstrated?</p> <p>c. How can the project maximise honesty and transparency?¹</p> <p>d. Are professional boundaries maintained?¹</p> <p>e. Are there processes in place for fostering deep listening and trusting relationships?</p> <p>f. Are services family friendly?³</p> <p>g. Are parents aware of any risks? Including honest and transparent discussions about the risks of being referred to child protection services etc?</p> <p>h. What is involved in the informed consent process?¹</p>

		trustworthiness. In this project we are adopting a strengths-based approach, focusing on capabilities that people bring and we aim to practise deep listening. Facilitating peer-to-peer support across the workplace, families and social groups is also very important. ^{3, 5, 6}	i. Does the program provide a clear explanation of what will be done, by whom, when, why, under what circumstances, at what cost and with what goals? ¹
<i>Empowerment*</i>	Fostering empowerment is a critical value for overcoming the transgenerational effects of complex trauma among Aboriginal parents and communities. ^{1, 5}	Principles to promote empowerment include maximising choice, control and autonomy and opportunities to actively make decisions. ^{1, 3, 5, 6, 8} Using a strengths-based approach to build competencies and recognise the capabilities that individuals bring can help to foster a sense of empowerment and resilience. ^{3, 6} Flexibility is also important ⁷ and was highlighted by key stakeholders in workshop 1 (being open to change, asking people if they want to be involved and participate even if it means challenging ourselves). Atkinson et al. ³ suggest it is important to enable resilience and recovery using a strengths-based approach which focuses on the capabilities that individuals bring to an issue and incorporate a message of hope and optimism.	a) To what extent do the program's activities and settings maximise choice and control? b) Does the program build in small choices that make a difference? ¹ c) Are choices respected? d) Is the need for standardization of screening across sites balanced with the unique needs of each program or setting? ¹ e) Are there choices in the way people can identify concerns they wish to discuss? f) Does the parent or service provider have a choice in the way contact is made? ¹ g) Does the program work with the community to monitor and proactively respond to changing priorities and needs? ⁹ h) Are parents able to choose not to be swept into care pathways they do not wish? i) To what extent do the program's activities and settings prioritise consumer empowerment and skill-building? j) How can the project be modified to ensure that experiences of empowerment and the development or enhancement of skills are maximised? k) Are the questions strengths-based and ask 'what's happened to you?' and 'what's strong in you?' rather than 'what's wrong with you?' l) Are messages of hope and optimism conveyed? m) Does the program build individual, family and community capabilities to respond to [trauma] and its risk factors? ⁹ n) To what extent do the formal policies of the program reflect an understanding of trauma survivors' needs, strengths, and challenges? Of staff needs? Are these policies monitored and implemented consistently? ¹

<p><i>Collaboration*</i></p>	<p>Collaboration and sharing of power is a key value for addressing trauma, and is also included as a core principle for national trauma guidelines.^{1, 3, 5, 7}</p>	<p>The first key stakeholder workshop highlighted collaboration and unity as of critical value and suggested this could be achieved by communication (listening and considering other people’s views and how they participate) and participation (recognising community expertise and needs). Committing to participation at all levels and facilitating involvement and engagement are also key elements of the vision incorporated in national and other trauma guidelines.¹⁰</p>	<ul style="list-style-type: none"> a) To what extent do the program’s activities and settings maximise collaboration and sharing of power? How can the project be modified to ensure that collaboration and power-sharing are maximised?¹ b) Are parents with trauma histories involved in design of programs? c) Are their voices elicited and validated in formulating the plan?¹ d) Does the program cultivate a model of doing ‘with’ rather than ‘to’ or ‘for’ consumers?¹ e) Is the community a partner in the process? f) Does the program support communities and families to address the impact of negative social determinants?⁹ g) Is there a consensus this activity is required?⁹ h) How must we adapt project elements for a particular parent/community member etc? Are there other parts of this modality that may dovetail with other work?¹
<p><i>Culture</i></p>	<p>Culture is central to the social and emotional wellbeing of Aboriginal people and the complex trauma experienced by Aboriginal people today is a legacy of the destruction of and violence against Aboriginal culture during colonisation.</p>	<p>Aboriginal understandings of relatedness and nurturing relational development with family, community, culture and country are sophisticated and have been passed down for millennia. Therefore, incorporating cultural knowledge and wisdom into our understandings of complex trauma affecting parents and incorporating ‘culturally informed healing elements’⁹ is critical to this project.</p>	<ul style="list-style-type: none"> a) Will the program pro-actively engage people with cultural knowledge? b) Are culturally informed healing elements present? And designed by community/credible cultural leaders?⁹ c) What strategies are in place to protect and preserve traditional knowledge and avoid ‘colonising’ it? d) Are Aboriginal and Western knowledge’s equally respected and valued within the project and information?
<p><i>Holism</i></p>	<p>Aboriginal understandings of social and emotional wellbeing are holistic and recognise the inherent relatedness to spirit, body, culture, mind, family, community and country.¹¹</p>	<p>Principles to foster these holistic values include integrating care to bring together all services and supports needed to holistically meet the needs of individuals, families and communities to enhance their physical, emotional, social, cultural and spiritual wellbeing.^{3, 5} National guideline visions also include promoting collaboration and</p>	<ul style="list-style-type: none"> a) Is the project integrated with other relevant community services and activities?⁹ b) Are the full range of social, education, health and justice systems etc included? c) Is a life-course perspective integrated? d) Does the recognition and assessment processes avoid unnecessary repetition? While there is no need to ask the same questions at multiple points in the intake or assessment process, there is often a good rationale for returning to such questions after some appropriate time interval.¹ e) Are existing services already addressing trauma?⁹

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		coordination across systems of care and include a life-span perspective. ¹	f) How can this program work effectively with existing programs/services?
<i>Compassion</i>	Compassion has been identified as an important value in one existing framework, ⁶ and the importance of empathy and compassion within project was highlighted by key stakeholders in workshop 1.	Compassion and love are critical elements of relational healing. ¹² Strategies include using play, mindfulness and <i>Dadirri</i> or deep listening.	a) Does the project display compassion towards parents and both Aboriginal and non-Aboriginal community members?
<i>Reciprocity</i>	Reciprocity was highlighted by key stakeholders in workshop 1 and is a core value for the Ethical guidelines for working with Aboriginal communities in Australia. ¹³	Ensuring there is resonance with the project aims and activities is an important principle for fostering the sense of reciprocity. ³	a) Are the needs of all stakeholders considered? b) What are the benefits and cost for those involved with the project? What are they contributing and what are they receiving in return? c) Are the project aims and activities recognising and respecting the contributions of all involved and are they resonating?

*National Trauma Guideline Principle¹

References

1. Kezelman C, Stavropoulos P. Practice guidelines for treatment of complex trauma and trauma informed care and service delivery. Sydney: Adults Surviving Child Abuse, 2012.
2. Guarino K, Soares P, Konnath K, et al. Trauma-informed organizational toolkit. Rockville, MD: Center for Mental Health Services, Substance Abuse and Mental Health Services Administration, the Daniels Fund, the National Child Traumatic Stress Network, and the W.K. Kellogg Foundation, 2009.
3. Atkinson C, Atkinson J, Wrigley B, et al. Aboriginal Family Violence Prevention Legal Services: Culturally informed trauma integrated healing approach - A guide for action for trauma champions. Canberra: Commonwealth of Australia, 2017.
4. Denby RW. Parental incarceration and kinship care: Caregiver experiences, child well-being, and permanency intentions. *Soc Work Public Health* 2012;27(1-2):104-28.
5. Aboriginal Medical Services Alliance of Northern Territory. Core values for trauma-informed care. Darwin: Aboriginal Medical Services Alliance of Northern Territory.
6. Denby C, Winslow C, Willette C, et al. The Trauma Toolkit: A resource for service organizations and providers to deliver services that are trauma-informed. Winnipeg, Canada: Klinik Community Health Centre, 2008.
7. College of Aboriginal and Torres Strait Islander Nurses and midwives; Australian College of Midwives; CRANA Plus. Birthing on Country position statement. Canberra: College of Aboriginal and Torres Strait Islander Nurses and midwives, Australian College of Midwives and CRANA Plus 2016.
8. Congress of Aboriginal and Torres Strait Islander Nurses and Midwives. CATSINaM 2014 Conference: Outcomes of the 'Birthing on Country' Yarning Circles. Perth: CATSINaM, 2014.
9. Dudgeon P, Milroy J, Calma T, et al. Aboriginal and Torres Strait Islander Suicide Prevention Evaluation Project (ATSISPEP) report. Solutions that work: What the evidence and our people tell us. Perth: University of Western Australia, 2016.
10. Abbott J, Johnson R, Koziol-McLain J, et al. Domestic violence against women. Incidence and prevalence in an emergency department population. *JAMA* 1995;273(22):1763-7.
11. Gee G, Dudgeon P, Schultz C, et al. Understanding social and emotional wellbeing and mental health from an Aboriginal and Torres Strait Islander perspective. In: Dudgeon P, Milroy H, Walker R, eds. Working Together: Aboriginal and Torres Strait Islander Health and Wellbeing Principles and Practice Second ed. Canberra: Australian Council for Education Research and Telethon Institute for Child Health Research, Office for Aboriginal and Torres Strait Islander Health, Australian Government Department of Health and Ageing 2014.
12. Early right brain development and relational origins of mutual love and intersubjective play. International Childhood Trauma Conference; 2018; Melbourne Convention Center, Melbourne.
13. National Health and Medical Research Council. Values and ethics - Guidelines for ethical conduct in Aboriginal and Torres Strait Islander health research. Canberra: Commonwealth of Australia, 2003.

Supplementary file 3: Perinatal strategies to support parents who have experienced maltreatment in their own childhoods: Evidence synthesis plan

	Phase 1: Mapping	Phase 2: In-depth reviews				Phase 3: Overview
Population	Parents planning pregnancy, during pregnancy or first two years postpartum					
Primary review question	What evidence is available regarding child maltreatment/complex childhood trauma during the perinatal period?	1. What are the intergenerational pathways from parental maltreatment in the perinatal period? What factors mediate/moderate these outcomes? What theories help to explain these pathways (mechanisms)? And what aspects are supported or contradicted by the epidemiological evidence?	2. What are perinatal experiences for parents who have experienced maltreatment in their own childhood? What strategies do parents use to heal and/or discontinue cycles of complex trauma?	3. What is the effectiveness and cost of perinatal interventions for parents who have experienced maltreatment in their own childhood? Are there any differential effects of interventions in different subpopulations?	4. What is the sensitivity, specificity and utility of screening tools used in the perinatal period for identifying parents who have experienced maltreatment in their own childhood (exposure) and/or trauma symptoms (effects)?	What works? For whom? In what circumstances? Are the most effective interventions also acceptable? What are the costs?
Review type	Scoping review	Systematic Review (epidemiological)	Systematic Review (qualitative)	Systematic review (quantitative)	Diagnostic/test accuracy review	Realist review
Search	'parent' AND 'childhood trauma' AND 'intergenerational' AND 'prevention'	'parent' AND 'childhood trauma' AND 'intergenerational' (based on revised terms from mapping phase)				In-depth reviews, excluded reviews from previous search, integration with co-design workshops
Study type	Any primary study related to (theories; mediators/moderators; parents' experiences; interventions; screening tools)	Theoretical and epidemiological studies (observational).	Qualitative studies.	RCTs, CCTs, ITS (Descriptive studies).	Screening test accuracy studies	Systematic reviews, co-design discussions
Data extraction	Microsoft Excel	Eppi-reviewer or NVivo				
Synthesis	Narrative synthesis	Narrative synthesis using socioecological model and integration with co-design workshop/qual studies with Elders.	Meta-synthesis of parents' experiences (1 st level) and author conclusions (2 nd level) to generate unique review themes across studies (3 rd level).	Meta-analysis, meta-regression and narrative synthesis. Sensitivity analysis for major intervention components, study quality, implementation/process measures, and PROGRESS + characteristics (Age; Place; Race; education; social capital (partner/other); mental illness; SES; other risk factors).	HSR/CA analysis	Narrative synthesis
Outcomes	Evidence map	Diagram/illustration of resilience, protective and risk factors that mediate or moderate relationship between childhood trauma and behavioural & health outcomes for parents and infants.	Review level synthesis with GRADE-CERQual assessment of confidence in evidence.	Impact of interventions on process (acceptability/cost/implementation); parental behavioural and health outcomes; and infant behavioural and health outcomes.	Sensitivity and specificity of existing screening tools.	Recommendations for perinatal screening and support strategies are likely to support resilience and healing for parents.

Supplementary file 4: Workshop 1 facilitators guide

Time		Facilitation Guide
9.30am	Registration and tea/coffee/fruit platter	Greet participants/Elders/dancers etc
10.00	START	Welcome
	Welcome/Acknowledgement to country	
10.15	Creating our safe space	<ul style="list-style-type: none"> • Acknowledgement of what we are talking about is hard • Importance of listening • Ask group to contribute to collective agreement on ‘principles of participation’ and then put them up on butchers paper. • Reiterate no-one will be asked or expected to share personal experiences (not purpose of workshop) • Absolutely ok to leave at any time if uncomfortable & to play on phone (nb smiling mind app) • Introduce trauma response factsheet (We Al-li Pty Ltd) and card with Psychologist contact. • Some diversionary activities on tables (mindfulness colouring/drawing). • Rocks on table for people to choose - one to paint as a symbol of ‘hopes/dreams aspirations for project’. Write brief description on sticky notes. At end of day we will place these in the coolamon as a symbol of our aspirations, and also leaving the ‘weight’ of discussions here as we go back to our families.
10.30	Introductions	<p>Ask people to form a big circle.</p> <ol style="list-style-type: none"> 1. Say your name and where you’re from. 2. Ask people to form groups of 3. 3. Assistant hands each group of 3 x 6 strengths cards. Pick a strength/picture card (or choose each if you don’t like it) And share a little story what that means to you or your family (from selection on table). Do this for a few minutes until about 10.55. 4. Circle up and thank everyone for sharing (remind people to chat to those they didn’t meet at lunchtime).
11.00	Sharing research knowledge	<ul style="list-style-type: none"> • Clarify purpose of this session • Very simple overview of evidence, including from scoping review (remind sent out earlier), • Outline of project plan (team, approach, major activities and timelines) • Questions • Ask people to spend 10 min’s in table to write down why are we here? what’s brought you to this project?

		<ul style="list-style-type: none"> – brightly coloured postit notes and large poster (words to go with images on rocks) • 5 mins feedback on group discussions
12.00	LUNCH	Stick words up on posters
12.30	Working together safely	<ul style="list-style-type: none"> • Clarify purpose of this session • Brief discussion of importance of cultural/emotional safety – particularly in context of this project • Group experiential activity to understand lateral violence • Small group questions to generate protocol for cultural and emotional safety (1) for participants (families, community members, service providers); (2) among each other (3) with the broader society (e.g. ensuring anything coming out of project is not damaging to the broader community) and (4) between Indigenous and non-Indigenous peoples.
2.00	AFTERNOON TEA	
2.15	Sharing community and service knowledge	<ul style="list-style-type: none"> • Clarify purpose of this session • Brief recap on evidence specific for Aboriginal communities • Group activity to understand: • How do you/services/communities currently recognise if a parent is experiencing trauma? (screening) • What assessment processes are currently used? • What support strategies are currently used?
3.30	Reflections and next steps	<ul style="list-style-type: none"> • Overview of day (5 mins) • Evaluation forms for feedback and suggestions for next workshop (10 mins) • Reminder to take care and be kind to themselves tonight (eat well, exercise etc important too) • Reflective activity with holding stone with aspirations and drop into coolamon (15 mins). People can share if they want with group. Sticky notes/record on butchers paper.
4.00	THANK YOU AND CLOSE	Thank you and close

Supplementary file 5: Preliminary areas of distress synthesized from scoping of assessment tools

Discussion Part 2: Domains
1 Intrusions (DSMV/ICD/AAVHTQ) e.g. nightmares, flashbacks
2 Avoidance (DSMV/ICD/AAVHTQ) e.g., avoiding people, places that are reminders, dissociation
3 Negative alterations in mood and cognitions (DSMV) e.g., beliefs about self/others/world i.e., ‘always dangerous’
4 Alterations in arousal and reactivity (DSMV/ICD-AAVHTQ) e.g., heightened anxiety, irritability, aggression
5 Emotion dysregulation (ICD/AAVHTQ) e.g., unable to regulate/manage heightened emotion (anger) or emotional numbness
6 Negative self-concept (ICD/AAVHTQ) e.g., guilt, shame, worthlessness, altered meaning/beliefs
7 Disturbed Relationships (ICD/AAVHTQ) e.g., difficulty developing/maintaining close relationships, feeling isolated/disconnected
8 Community Disconnection (AVHTQ) e.g., feeling isolated/disconnected from one’s community/mob, may be due to conflict, D&A
9 Identity loss/fragmentation (AVHTQ) e.g., impacted cultural identity due to interpersonal trauma
10 Grief and loss (AVHTQ) e.g., unresolved or unintegrated grief and loss from interpersonal trauma
11 Other cultural idioms distress (AVHTQ) e.g., harm against self or others, D & A abuse, suicidality
12 Depression
13 Psychosocial risks (if so, which ones? Social determinants, parenting and family factors)
14 Strengths (if so, which ones? personal, relational, cultural e.g., spirituality, connection to county, coping skills etc.)
15 Duration
16 Functional impact
17 Attribution (not due to medical or other)
18 Exposure (if so, what language/events?)

Supplementary file 6: Workshop 2 facilitators guide

Time		Facilitation Guide
8.45am	Registration and tea/coffee	Greet participants/Elders/dancers etc
		Attendees set up tables/poster
9.15	START	Welcome
	Welcome/ Acknowledgement to country	
9.30	Creating our safe space	<ul style="list-style-type: none"> • Statement of purpose and what stage we are at. • Check-in if using own family clap sticks is ok. • Acknowledgement of what we are talking about is hard. • 65 people is a lot to be discussing this sensitive issue • Importance of listening. • This is not the place to be sharing trauma stories. Reiterate no-one will be asked or expected to share personal experiences (not purpose of workshop). • Will be using scenarios that may remind people of their own trauma histories. • Demonstrating recognising different types of wisdom with Ngangkere (traditional healer) and psychologist available today. • Value everybody's contribution and acknowledge breadth of expertise is the strength, welcome non-Indigenous people. • Clarify this is a co-design and experts are within the room not on the stadium. • Millennia of wisdom and new scientific knowledge. • Absolutely ok to leave at any time if uncomfortable & to play on phone. • Introduce trauma response factsheet (We Al-li Pty Ltd) and card with contacts etc. • Some diversionary activities on tables -mindfulness colouring/mini clay coolamons (optional only). • At end of day we will place these in the coolamon as a symbol of our aspirations, and also leaving the 'weight' of discussions here as we go back to our families. • Post-it notes/coloured circles on tables to jot down anything you don't get a chance to say. • Introduce draft safety protocol from W1 for info and to ask questions (may send copy before) and acknowledge that W1 have contributed this. (5 mins)
9.45	Introductions	<ul style="list-style-type: none"> • Ask people to form a big circle. • Walking around in circle and clap stick sounds and you introduce yourself to the nearest person. Introduce yourself and random item e.g. 'first car'.

		<ul style="list-style-type: none"> Pick someone and guide them without touching them through the group.
10.00	Brief overview of project and recap of workshop 1	<ul style="list-style-type: none"> Clarify purpose of this session: (1) to provide a very quick overview of the project and where we are on that journey today to help orientate ourselves; and (2) to present the conceptual framework/plan. 10 min presentation: Conceptual framework for project Outline of project plan (diagram in folders) and have had workshop1 (acknowledge people who were at that, main themes and refer to report and safety protocol based on those discussions. 10 mins for questions and discussion about the plan (leave up on screen). And remind people that they can provide any confidential questions or things we don't have time for as a note in the basket or give to us.
10.20	Tjulpa and Walpa	Start today's session with NPY Women's council presentation of the book Tjulpu and Walpa: Two Children Two Roads see http://www.worldcat.org/title/tjulpu-and-walpu-two-children-two-roads/oclc/1002311301
10.50	MORNING TEA	Set up stations for Assessment session
11.10	Modified Delphi discussion of assessment domains	<p>Clarify purpose of this session: Introduction of Walpa and 12 areas of distress and reference CPTSD. Note that the Walpa story is about a woman but we are also wanting to include men (or both parents). Introduce participants to their information sheets with these areas of distress. Acknowledge strengths will be discussed later (10 mins). Explain process:</p> <ul style="list-style-type: none"> Go to one of 12 stations and form groups of 5-6 (one investigator to go with each station/group and take notes). At each station spend 3 mins (clap sticks) talking together about their thoughts of the area of distress and how that might be asked in a safe manner. On each piece of paper (anonymous) circle the word that reflects their rating of what they think and make comments over page (2 mins) Any thoughts about who or why it would be really helpful for us to jot this down. Then ask whole group to move to the next station. <p>11.20-12.00 (6 stations) 12.10-12.50 (6 stations) Debrief with whole group (10 mins).</p>
12.00-12.10 mini break		
1 pm	LUNCH	Set up tables: butchers paper, texta's with colour mix, sticky notes, sticky tape to hold together.
1.40	Reflect on findings of pilot discussions with	<ul style="list-style-type: none"> Clarify purpose of session: (1) To briefly outline the themes emerging from the Deadly Nannas discussion group (2) to

	Grannies group and Tree of Life exercise	<p>discuss the process (including in context of the safety protocol) and proposed modifications for discussion group with parents - ?tree or image to work with (see discussions from Assessment working group meeting)</p> <ul style="list-style-type: none"> • 2 slides from Deadly Nannas –what their program is about (10 mins) • Talk about why asked to conduct the pilot discussion group with Deadly Nannas group, the process, and main themes (8) (15 mins) • Tree of life exercise to briefly pilot test the proposed process with parents and ask tables to have a short discussion about the issues for parents but also to provide feedback on the process and any further suggestions? • Tom and Mary scenario – different from Walpa story but many of same issues come up • Outline safety issues (3rd person scenario (self-care)) • Ask each table to draw a tree and briefly outline below: and reassure people no right or wrong so doesn't matter if you get the leaves mixed up with fruits etc. <ul style="list-style-type: none"> Roots: historical aspects and how past has impacted on them (5 mins) Ground: Now – what's happening now? (5 mins) Trunk: Parent strengths and what holds them up? What are they capable of together and individually (5 mins) Branches and twigs: Reaching up to sky – hopes and dreams and desires (5 mins) Leaves: convert sunlight to energy – changing process – actions in changing. What changes could happen? Who do they ask to help them? (5 mins) Flowers/fruits: Form the seeds/fruits protective part of seeds – what are the things that protect them? (5 mins) <p>Trees part of a community of trees/forrest – share information about trees (1 min each - 10 mins)</p> <p>Many hazards that can wreck trees – fires/droughts etc. (5 mins) – what are some of the hazards here.</p> <p>Then discussion about how the exercise is and how safe? (10 mins)</p> <p>Remind people if they haven't had time to discuss everything to leave suggestions/comments on the coloured circles.</p> <p>Flag that next workshop will be focussing on the feedback of these discussions with parents so will be more time to discuss.</p>
3.00	AFTERNOON TEA	Set up sessions/tables and handouts
3.15	Presentations on programs	<ul style="list-style-type: none"> • Purpose of session: (1) to share innovative ideas in an interactive format for building on in later workshops. • Tables/poster boards set up at the start of the day. • Each station to have an A4 handout – brief description and main contact. • Notetaker at each poster – and set up notes/pens for people to report notes.

		<ul style="list-style-type: none"> • Free moving around with clapping sticks every 10 mins to remind people to change over – ask people flag other programs. 1 group outside.
4.15	Debrief and reflection/evaluations	<ul style="list-style-type: none"> • Overview of day (5 mins). • Circle up. • Reflective activity with coolamon (traditional baby carrier)/drawing with aspirations and drop into coolamon (15 mins). People can share if they want with group. • Evaluation forms for feedback and suggestions for next workshop (10 mins) (will also be sent online). • Performance by Drum Atweme, part of the Tangentyere Aboriginal Council Drum Atweme Program. • Reminder to take care and be kind to themselves tonight (eat well, exercise etc important too).
5.00	THANK YOU AND CLOSE	Thank you and close.



On the day Time (est) -to be adapted to the need and preferences of local groups.	Segment	Purpose	Activity	Materials/notes
9.00am 60 mins	Setting up the focus group environment	Creating a safe environment	Set up: <ul style="list-style-type: none"> • furniture to make a talking circle • Table to one side to draw on • art and other materials, including cards on a sideboard with cues from other research • information and consent forms • tea/coffee/water/ milk • signage • safe break out area • mindfulness colouring books (pens, rocks etc) • newsletters for project • something to look at (poster/artwork on A3) – laminated • Set up activities for children 	Recorder (use audio pen to write notes/observations (including related to images) at the same time) Name badges (if required)
10am- 15 mins (or longer if needed/preferred)	Greeting participants as they arrive and going through consent process	Make participants feel welcome Obtain signed consent	<ul style="list-style-type: none"> • Talking participants through the information sheet and consent forms • Offer people a cup of tea/coffee and refreshments • Housekeeping- let people know where toilets are/ break out rooms • Brief facilitator introductions • Childcare arrangements 	Information sheets Consent forms Name tags
10.15am 15 mins (longer if needed to assure group safety and comfort)	Welcome/introductions	Introduce participants to each other (if necessary) and introduce selves Create a safe space	<ul style="list-style-type: none"> • Circle up first/ can sit if around table • Introductions and activity to help people feel safe and welcome- using strength cards- to share their inspirations or why they were drawn to that card. • Brief reflective activity (e.g. holding a rock, leaf (paint if wanted to leave behind at end of day). Eg <i>“We know that parenting can be hard, particularly if parents have difficulties in their own childhood. We all bring our own experiences to these discussions today. We pass these rocks/leaves for you to hold during these discussions, and then at the end of the session we can have a little reflection and either leave any heaviness behind’ or return the leaf to the ground to enrich the soil, as a symbol of your rich contributions today. To help us</i> 	

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			<p><i>leave this behind as we go back to care for our own precious children and families.”</i></p> <ul style="list-style-type: none"> • Acknowledge potential for triggering (and explain normal responses) and suggest strategies to minimise symptoms (including breakout/mindfulness and tip sheet). • Psychological support available and card and mobile number. • Opportunity to ask questions. • Ground rules for safety (respect what other people say, can leave if feeling uncomfortable, psychological support available and distress protocol, everything said is confidential, will not be asked about own experiences – will use a ‘story’ of Walpa (scenario)) 	
10.30	Pre-discussion and Discussion for activity 2	Facilitate discussion about key issues for parents (barriers and enablers)	<ul style="list-style-type: none"> • Explain purpose of the discussion group and how it will work (brief consent recap), what we mean by complex trauma. <i>“We know parenting can be hard, especially for parents who have had a challenging childhood themselves. We also know that children bring a lot of love and joy into the world with them, which needs to be nurtured, and this can help parents to heal. The purpose of the discussion today is to learn how we can support parents who have had difficult childhood themselves to heal and nurture their children. We will do this by sharing the story of Tjulpa and Walpa, and creating a ‘tree’ which shows how we can best support Walpa”</i> • Give out Tjulpa and Walpa books and read aloud • Turn on recorder <p>Participants draw a tree and then use sticky notes to create discussion around: (5mins)</p> <ul style="list-style-type: none"> • The roots /ground– what are the things from there past that may be impacting on Walpa [and her partner] now (5 mins) • Trunk – strengths – what’s helping to keep them strong? (5) • Branches – what are the hopes and dreams for these parents? (5) • Leaves etc – what are the things that are going to help them to get there? (individual (flowers)/family & community(leaves)/services (butterflies)/society (fruit) (10) • Clouds – what are the challenges? and (rainbows) what might help them to overcome these challenges? (5) 	

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11.30			Show cards with information on strategies from other parents discussions [represents 'forest' of many trees'] - key issues of working together	
11.50			Show draft questions to ask parents about areas of distress and strengths?	
12.20			<p>Final reflection (leaves/rock) and finish up</p> <ul style="list-style-type: none"> • Acknowledge difficulty of this discussions and ask people to think of how they are feeling (grounding exercise). • Invite people to have a quiet minute or so for reflection and then to drop the leaf/stone into the coolamon to symbolise leaving any stressful feelings behind and how what they are contributing is for our future generations. • Invite people to share with the group as they do this if they wish – but no obligation. If they want they can discuss the symbolism of any painting on rocks etc. • Give thankyou cards with contact details for any support services if needed. • How to get information back • Reinforce how important their wisdom is and that they are contributing to something much bigger than all of us that we hope will help parents to heal and be strong and able to experience and nurture the joy and love that children bring into the world with them. • Explain what we will do with the information shared now and how we will discuss to check we have understood correctly first and then give that information back in written form (or visit if needed). • Give gift vouchers/funds and ensured everyone able to get home ok, etc. 	
12.30	LUNCH			

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