Kalyakool Moort – Always Family

Strong culture, strong care, strong families: Codesigning a culturally considered approach to perinatal screening and support for the first 1000 days of parenthood from conception to infancy

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Declaration

I declare that this dissertation is my own account of research that I have conducted. To the best of my knowledge and belief this thesis contains no material previously published by any other person except where due acknowledgement has been made. I have been the primary and main author in all publications and manuscripts contained within.

This thesis contains, as its main content, work which has not previously been submitted for a degree at any university.

The research presented and reported in this thesis was conducted in accordance with the National Health and Medical Research Council National Statement on Ethical Conduct in Human Research (2007) – updated March 2014 and 2018. The proposed research study received ethics approval from the Western Australian Aboriginal Health Ethics Committee (HREC Reference number 553) and Murdoch University Human Research Ethics Committee 2013/202).

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Preface

In the interests of positioning myself transparently, this preface is intended to provide readers with an opportunity to understand influences, and potential bias in, my approach to this research as a non-Indigenous clinician-researcher.

When working in the Kimberly region of Western Australia as a non-Indigenous midwife, nurse practitioner and child health nurse, I observed that perinatal mental health screening with Aboriginal and Torres Strait Islander[1] women was not being facilitated routinely nor well. As I developed relationships with Aboriginal women and their families, they shared that they were struggling silently with their mental health and wellbeing. Within the context of standard antenatal care, challenging circumstances such as family and domestic violence (FDV) and distinctive symptoms of depression and anxiety that many Mothers disclosed, had not been identified. Nor had other health services identified vulnerabilities or flagged them for follow-up or support. Significant time, money and resources were being invested in the few most vulnerable Mothers with open Department of Child Protection (DCP) cases in Western Australia, whilst many others were 'falling though the net'.

Effective screening and early intervention seemed essential if this cycle was to be broken. I brought together some of these Mothers and Elders in the East Kimberley to discuss perinatal mental health screening. This included exploration of screening practices with the gold standard screening perinatal mental health tool, the Edinburgh Postnatal Depression Scale (EPDS). It was clear that women wanted access to effective mental health screening and support

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[1] The term Aboriginal and Torres Strait Islander people is frequently the preferred terminology used when referring to the First Nations people of Australia. They are the two recognised Indigenous Peoples in Australia: Aboriginal Peoples and Torres Strait Islander Peoples and communities. They have their own unique ways of expressing their different values cultural and linguistic diversity. They represent many different clans and nations. In Western Australia, on Nyoongar Boodjar (country), where this research was conducted, the term 'Aboriginal peoples' is often preferred. Hence forth, and in no way to minimise the unique distinctive cultural differences, the term Aboriginal will be used.

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but did not feel that this was available. At the 2009 annual Kimberley Maternal, Child and Family Health Conference, I facilitated a workshop with 15 midwives and child health nurses (CHNs) from across the Kimberley. This revealed at best inconsistent, or otherwise poor screening practices for perinatal depression with Aboriginal women. Feedback from these midwives and CHNs clearly indicated that the language used in the Edinburgh Postnatal Depression Scale (EPDS) was considered too complex and confusing for many Aboriginal women in the Kimberley (Kotz, 2013). Midwives and CHNs wanted an alternative.

Key stakeholder midwives and CHNs working across the Kimberley became engaged and we continued the consultative and iterative work begun in the East Kimberley. After an extensive iterative process, the Kimberley Mums Mood Scale (KMMS) emerged, was piloted and validated for use with Kimberley women (Marley et al, 2017). The KMMS is now being used throughout the Kimberley.

Returning to Perth, Western Australia some years later, it seemed these clinical perinatal challenges remained, and the stubbornly resistant perinatal outcome data seemed to be calling out for a program of research to support innovation. Where to start? Aboriginal Australians have been exposed to the damaging effects of unethical research over the last 200 years and are rightly wary. As a non-Indigenous midwife, nurse practitioner and child health nurse I have worked with First Nations peoples in Tanzania, Vanuatu, Victoria, the Northern Territory (NT) and Western Australia (WA). Whilst working in clinical practice, always in community and alongside families, I witnessed firsthand how frequently First Nations peoples' hopes and expectations are raised when PhD students and researchers come into communities and the disappointment when these same researchers leave nothing behind but dashed hopes. Those coming from strongly dominant cultures (European ethnocentric, privileged dominant cultures of research and medicalised healthcare), can be unaware of the debilitating effects of time-focused research agendas. I discovered that working with First Nations people requires critical self-reflection and recognition of the privilege we have as health professionals and researchers.

As health professionals and researchers, our privilege includes most SES markers. Guided by a dual commitment as a clinician and researcher I committed to undertake this doctoral project and began to explore translational research methodologies where the control and accountability balance is shifted towards the needs of those being researched. This decision was swayed by (i) the wisdom of two of my supervisors highly experienced in the ethical research with Aboriginal communities, one of whom is an Aboriginal nurse and midwife (Professor Rhonda Marriott) and (ii) the support of local Aboriginal communities.

Undertaking research with Aboriginal communities in this project has been a privilege. Undertaking a decolonising approach to research has been important to me and, I believe is essential to ensuring authentic outcomes for participants. Adopting a community participatory action research (CPAR) framework gave impetus and veracity to the conceptualisation, formulation, data collection, analysis and ultimately to the clinical translation of findings. Looking back, I do not think this project would have been successful any other way. Securing strong partnerships took 18-months of snowballing collaborative engagement with Aboriginal communities and organisations invested in perinatal outcomes for Aboriginal families. This strong Aboriginal and organisational engagement has continued throughout the research process.

Overall, this PhD research has taken five-years. In addition to reflecting the needs of my personal journey as a working student, an active parent and grandparent, it also reflects the time required to ensure that each stage of the research was strongly anchored in Aboriginal knowledge and ways of knowing and doing. Getting this process right was key to the likelihood of future success, and the sustainability of resultant perinatal screening tool for Aboriginal families and perinatal healthcare professionals.

Personally, and professionally, it was critical that this project extend beyond theory-advancement to tangible, clinically relevant outcomes. This was essential to honour the many hours, days, weeks and months of contribution of my Aboriginal colleagues and participants who were equally invested in this research. I look forward to embarking on the next part of this journey together as we work to apply the evidence-base gathered in this dissertation to re-defining gold standard perinatal mental health care for Aboriginal families.

Abstract

Background: Indigenous maternal and child health and wellbeing outcomes remain unacceptably poor and is reflected in low participation in Edinburgh Postnatal Depression Scale (EPDS) screening. Evidence shows that early exposure to maternal anxiety and depression is a strong predictor of maternal, infant, child and adolescent health and wellbeing outcomes. Critical consideration should also be given to whether current screening is culturally safe, effective and responsive and/or further colonising.

Assessing mental health needs is critical for prevention and care during the critical 1000 days from conception to the early years of parenthood. Psychometric properties of mental health screens are important. However, critical consideration should also be given to whether current screening is culturally safe, effective and responsive.

Aim: This program of work investigated the barriers to successful perinatal screening for Aboriginal Mothers and developed a culturally secure evidence-base to support the formulation of a new gold standard for perinatal care for Aboriginal Australians.

Methodology: A decolonising approach using community participatory action research (CPAR) methods was operationally centred around guidance from an Aboriginal leadership and governance collective. It was a shared view of all groups in this collective that the EPDS has significant limitations in an Australian Aboriginal context, and that there was an urgent need to find culturally stronger ways of supporting families during the perinatal period. This consensus provided the starting point for this program of translational research. Noongar Elders gifted the name, Kalyakool Moort, meaning Always Family in Nyoongar language. The Kalyakool Moort project explored the a) current context of assessing the mental health and wellbeing of Aboriginal and Torres Strait Islander parents in the perinatal period, and b) enablers and barriers to strong parenting practices.

Two systematic literature reviews were undertaken. The first explored use of the EPDS with Aboriginal women. No evidence was found that the EPDS is suitable for screening Aboriginal women, nor that its adapted versions were widely applicable. The second, a psychometric review of Aboriginal symptom and risk measures found some progress toward culturally relevant mental health screening measures. This review was complemented by a cultural review of each measure undertaken by members of the Aboriginal leadership and governance collective. However, no single tool was found that had generalised transferability to Aboriginal women perinatally.

With the need for a new approach to perinatal mental health screening established, a mixed methods approach was adopted to gather data from experts with lived experience. Aboriginal parents and health professionals provided rich qualitative data through semi-structured interviews, 'yarn' sessions and focus groups. Quantitative data were derived from an anonymous practitioner questionnaire, two systematic literature reviews, and analysis of current screening tools. Initially drawing on a grounded theory, thematic analysis and Nvivo-12 were ultimately used for coding qualitative data. Findings from complementary data sources were triangulated, compared and contrasted through a cultural lens eliciting points of difference and congruence. Emergent data were used to prepare an evidence-base to inform a new gold standard in clinical perinatal practice, including providing impetus for the development of a new screening tool.

Results: Aboriginal parents frequently feel marginalised and disempowered by perinatal assessments and care, yet no evidence supports the validity of using existing screening tools with this population – a new framework is needed. Developing a culturally valid screening process is predicated on utilising a culturally sound research methodology. The emerging evidence-base from this series of studies suggests that perinatal screening for Aboriginal parents should be Family-centred (rather than singularly Mother-centred), strengths-based (rather than pathology-based) and culturally sound (rather than based on Western models). An innovative approach to perinatal screening is a translational outcome and will be the subject of a series of studies over the coming year.

Keywords: Indigenous; First Nation; Aboriginal; Wellbeing; Decolonising; Perinatal; Mental Health; Screening; Antenatal

Table of Contents

List of Tables

List of Figures

Abbreviations

AAG	Aboriginal Advisory Groups
AHW	Aboriginal Health Worker
ALO	Aboriginal Liaison Officer
AMHS	Aboriginal Mental Health Subgroup
ANRQ	Antenatal Risk Questionnaire
AoD	Alcohol or Other Drugs
ARA	Aboriginal Research Assistants
AWP	Aboriginal Working Party
BCYR	Baby Coming You Ready
CAHS	Child and Adolescent Health Service
CEO	Chief Executive Officer
CHN	Child Health Nurse
COPE	Centre of Perinatal Excellence
CPAR	Community Participatory Action Research
CRT	Critical Race Theory
DCP	Department of Child Protection
DCSG	Data Coding Subgroup
DSM 1V	Diagnostic Statistical Manual version 5
DV	Domestic Violence
EPDS	Edinburgh Postnatal Depression Scale
FDV	Family and Domestic Violence
GAD	General Anxiety Disorder
GEM	Growth and Empower Measure
GP	General Practitioner
HANAA	Here and Now Aboriginal Assessment
HRECs	Human Research Ethics Committees
K10	Kessler
KICA	Kimberley Indigenous Cognitive Assessment
KMMS	Kimberley Mums Mood Scale
LRAG	Lead Research Advisory Group
MSE	Mental State Examinations

NT	Northern Territory
PFB	Performance Based Funding
PHQ	Patient Health Questionnaire
PND	Postnatal Depression
PND/A	Perinatal Depression and/or Anxiety
SCRGSP	Steering Committee for the Review of Government Service Provision
SEWB	Social and Emotional Well-Being
SJOG	St John of God Health Care
TKI	Telethon Kids Institute
UWA	University of Western Australia
WA	Western Australia
WAACHS	Western Australia Aboriginal Child Health Survey
WASC-Y	Westerman Aboriginal Symptom Checklist Youth
SAMHS	Specialist Aboriginal Mental Health Service
KEMH	King Edwards Memorial Hospital

Glossary of Terms

Aboriginal and Torres Strait Islander people	Are the First Nation people of Australia. Aboriginal peoples live and maintained the continent of Australia.
Indigenous	This term is frequently interchangeable with First Nations people in Australia. Where the term Indigenous has been used it is to reference those Australians who are not of Aboriginal or Torres Strait Islander descent: non-Indigenous.
Aboriginal people/s	In Western Australia (WA), the term Aboriginal is used in preference to Aboriginal and Torres Strait Islander peoples, in recognition that Aboriginal people are the original inhabitants of WA. The use of the word peoples with an 's' is intended to recognise cultural diversity within and across all Aboriginal communities.
Boodjar	The Nyoongar[1] term for Country is "Mother"
Boodjari	The Nyoongar term for a Mother who has conceived and is pregnant.
Complex trauma	Refers to multiple, repeated forms of interpersonal victimisation and the resulting traumatic health problems and psychosocial challenges.
Context	Context is the term used throughout this thesis to describe the setting, background, perspective, and circumstances explored and understood.
Country	Aboriginal peoples have deep interconnected and intimate relationship with country, that is sacred and unique. Country is considered "Mother"; or in Nyoongar language 'boodjar'.
CRT	Critical race theory (CRT), is based on the premise that race is socially constructed category.
Cultural Safety / Culturally Safe	An environment where it is culturally, psychologically, spiritually, physically and emotionally safe for Aboriginal peoples: shared respect, shared meaning, shared knowledge and experience, and where dignity is supported.
Decolonisation	In a personal and cultural sense, the term refers to a lifelong process that commences when an individual recognises that they have been colonised. It requires ongoing reflective thinking and an appreciation of multiple worldviews and their respective truths are required. On a cultural level in Australia, it necessitates a contextualised discussion

	and re-claiming of knowledge informed through a balance of truths and histories. Decolonisation refers to a comprehensive approach to resisting and preventing further impacts of colonisation. These colonial ideological constructs are embedded in dominant culture (politics, law, education, media, health-care) and require constant unpacking to prevent ongoing systemic and institutionalised racism and further indoctrination.
Deep Listening	This refers to a conscious and active process of listening with ears, eyes, heart and mind. It requires the temporary suspension of judgment, emotional intelligence and a willingness to receive new information.
Elders	Aboriginal Elders are normally the older people in families and communities who are deemed to be the most knowledgeable and wise. They are deferred to by their community for the provision of support in the form of guidance, counselling, advice and knowledge. They assist in tackling problems of health, education, unemployment and racism. Elders have developed their knowledge through both lived and learnt experiences and have always been considered the custodians of cultural knowledge and protocols.
Imperialism	Imperialism and colonialism are crucial terms used across a range of disciplines, often with meanings which are taken for granted. The two terms are interconnected. Colonialism is directly connected and results from imperialism. Imperialism is the policy of extending a country's power and influence (economic, knowledge, exploitation), frequently through colonisation, which meant securing and subjugating Indigenous populations.
Indigenous ways of knowing, being and doing	This embodies the holistic philosophy of Aboriginal peoples' belief systems passed down through Lore and the Dreaming for generations. It is supported and taught by Elders. It is the application of knowledge, Lore and the Dreaming (Martin & Mirraboopa, 2003).
Kalyakool Moort	This means *Always Family* in Nyoongar language. This name was afforded this research by Nyoongar Elders in respect for the importance that Family plays in the health and wellbeing of Aboriginal Mother.
Methodologies	The term methodologies rather than methodology are used to acknowledge that many philosophical backgrounds and worldviews have informed.
Perinatal years	The perinatal period, in this context encompasses the time frame from conception to 24 months after the birth of the child. Also known as the first 1000 days, this period of time is tremendously influential in the developing

	infant’s life.
Reciprocity	This refers to a way ‘doing’ where there is mutual exchange for mutual benefit. Relationships define obligations. They are fundamental with Aboriginal peoples, they are multidimensional and must be balanced.
Rubric	Here the term ‘refers to and assessment that is shared between client and clinician. It integrates process and outcome indicators to bring clarity to complex situations through integrated consideration of multiple features. This encourages self-evaluation, reflection and fosters joint understanding.
Trauma informed care	Strengths-based framework grounded in understanding of and responsiveness to the impact of trauma, emphasising physical, psychological and emotional safety for survivors as well as providers of care. From an Indigenous perspective, this starts with healing from the past and present impacts colonialism through wholistic cultural, and strength-based process of wellness and health care (Fayed et al., (2018)
Social determinants	The non-medical factors that influence health outcomes. These forces and systems include economic policies and systems, social norms, social policies and political systems eg: income and social protection, education, job insecurity, food insecurity, housing, basic amenities, environmental factors, early childhood development, social inclusion and non-discrimination, structural conflict, access to affordable quality health services. Indigenous social determinants additionally include systemic racism, cultural bias, lack of cultural safety and an incapacity to meet cultural needs. Indigenous social determinants are fundamentally linked to and perpetuated by colonization.
Reductionist biomedical approach	Medical thinking was revolutionised by cell theory, germ theory of disease and bacteriology: all disease can be reduced to biological cause at an organisms simplest structural and functional level. This reductionist view led to surgical and pharmaceutical interventions. Contemporary medicine now proports to recognise the understanding that human beings are significantly more than the sum of their parts (Humanism). However, it remains heavily influenced by the reductionist view which fails appreciate the extent of factors influencing the human condition.

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[1] Occasionally there are multiple spellings for Aboriginal names which stems from Aboriginals peoples history being an oral not written tradition. For example, the word Noongar/Nyoongar. This document uses Nyoongar to preference traditional custodians desire that spelling includes the local *word* and its' *spelling* and *pronunciation*. Here 'ng' is *one* sound in Aboriginal languages and is different to the 'n'.

List of Publications

This thesis contains published works, all of which have been co-authored. The bibliographical details and descriptions of the works, and the contributions of each author are listed below. The papers are documented in order of their placement within the thesis chapters.

Paper 1

Kotz, J., Marriott, R., & Reid, C. (2021). The EPDS and Australian Indigenous women: A systematic review of the literature. *Women and Birth*, 34(2), e128-e134. https://doi.org/10.1016/j.wombi.2020.02.007

Jayne Kotz conducted the literature review, developed the protocol and drafted the manuscript. Rhonda Marriot and Corinne Reid critically reviewed the manuscript.

Paper 2

Currently in review for publication in: Primary Health Care Research & Development. Cambridge University Press.

Kotz, J., Robinson, M., Gibson, A., Marriott, R., Reid, C., & Reibel, T. Decolonising the exploration of perinatal mental health screening with Indigenous Australian parents in primary care.

Jayne Kotz developed the paper. Alison Gibson and Melanie Robinson were members of the Aboriginal Advisory Group. Rhonda Marriott, Corinne Reid, Tracy Reibel, Melanie Robinson and Alison Gibson critically reviewed the manuscript.

Statement of Permission of Contributors

We confirm author contributions for all papers and that permission has been obtained from all authors to include the manuscripts in this PhD thesis.

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Conference Presentations

WHA Aboriginal & Torres Strait Islander Women's & Children's Health Web Conference 11th February 2020

Women's Health Care Australia Conference (Web Conference)

AIDH Seminar BCYR Presentation 23 February 2021

PSANZ Conference: Bridging Gaps in Perinatal Care – 29 March 2021

Midwifery Seminar – Midwifery in the Margins – 5 May 2021

Radiance South West Perinatal and Infant Mental Health 20 February 2021

Perinatal Mental Health Symposium 7 May 2021

Kimberley Maternal and Child Health Conference 29th October 2019

Marcé Conference 10th October 2019

Women's Health Care Australia 2nd May 2019

Perinatal Infant Mental Health Symposium 29th March 2019

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Dedication

I want to acknowledge the Aboriginal Elders past and present as the Traditional Owners of this beautiful Country, Nyoongar Boodjar, where I work and play.

This thesis was made possible through the significant support and assistance of many remarkable people. I want to acknowledge and thank the many Nyoongar people, the Elders, the women and the men and all the Aboriginal peoples who have made Nyoongar boodjar their home and have generously afforded their time, energy, commitment, and passion to this research program. We all shared the same vision. Thank you for sharing this journey with me.

To my colleagues at Ngangk Yira, thank you all for your unfailing support, encouragement humour and kindness. You are a fabulous team, and it is a privilege to work with you all.

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And last but by no means least I want to thank my extraordinary partner Denise, my two beautiful daughters Genevieve and Vashti and their husbands Shawn and Graeme. Thank you, *each* of you, for your patience, support, and encouragement, and for believing in me particularly when I lost belief in myself.

> *"Real change, enduring change happens one step at a time"* RBG

Chapter 1. Setting the scene
The first 1000 days for Aboriginal Australian parents

1.1 Backdrop

The perinatal mental health and wellbeing of Australian Aboriginal women is poor compared to non-Indigenous counterparts. It continues to decline despite the intention behind rollout of universal perinatal mental health screening throughout all Australian states and Territories for more than a decade (Steering Committee for the Review of Government Service Provision, 2020). Aboriginal women report 'high' to 'very high' levels of psychological distress, measured using the Kessler-5 tool, in the first 12 months postpartum (Weetra et al., 2016). In 2020 the rate of Aboriginal women reporting 'high' to 'very high' levels of psychological distress was 35% (the Australian Bureau of Statistics, 2020). The rate of Aboriginal women being hospitalised due to intentional self-harm increased by 120% between 2004/5 and 2016/7 (Australian Institute of Health and Welfare (AIHW), 2020a). Between 1997 and 2013 in Western Australia (WA), over one in three of 43,383 Aboriginal babies were born to Mothers who had a hospital contact for mental illness in the five years prior, or the first-year post birth (Lima et al., 2019). The most common presentations were substance related or depression and anxiety.

Maternal distress increases risks of preterm, stillbirth and small birthweight (Adane et al., 2021; Lui et al., 2016 Alhusen et al., 2016). There has been limited improvement in Aboriginal infant outcomes against preterm, stillbirth and birthweight parameters since the national Closing the Gap initiative began in 2007 (Mah et al., 2019; (AIHWa), 2020). The gap between Aboriginal infant outcomes against each parameter remains twice that of their non-Indigenous counterparts (AIHW, 2020d).

Rapidly advancing science continues to provide compelling evidence that the foundations of lifelong health and wellbeing are laid down in the first 1000 days (conception to

2-years) of infant development (Moore et al., 2017). Maternal distress during this time can have short and long-term impacts on the developing infant's neurodevelopmental and physical, behavioural, and mental health. These effects can continue into adulthood, causing behavioural, cognitive and emotional dysregulation and life-long risks for chronic diseases (Galbally et al., 2021; Adane, 2021; NSCDC, 2020; Atkar et al., 2019; Mah et al., 2019; Glover, 2019; Moore et al., 2017; Posner et al., 2016; Seth et al., 2015; Hay et al., 2014; Oberlander, 2012; David and Sandman, 2012). Indeed, epigenetic studies indicate that these risk factors can be transmitted intergenerationally further highlighting the critical importance of prevention and early intervention (Scorza et al., 20919; Roubinov et al., 2021; Monaco, 2021).

Routine maternity care includes both clinical measures and risk screening for mental health, smoking, alcohol and other drugs (AoD) and family and domestic violence (FDV) exposure. Screening is intended to identify a disease or risk marker to help services best target limited intervention resources and reduce the burden of that disease, including incidence, morbidity and mortality – in all instances, the benefit of screening should outweigh any harms (Department of Health, 2018). Perinatal mental health screening is intended to be a means of understanding the supports, education or interventions women may need to achieve or maintain social, emotional and spiritual wellbeing during and beyond pregnancy. Standard risk screening tools such as the Edinburgh Postnatal Depression Scale (EPDS) (Cox et al., 1987) and the four-question FDV screening (AIHW, 2015) have been developed for mainstream populations. Both maternal and infant outcomes and research suggests these standard tools are at best ineffective and at worst harmful for Aboriginal women (Chan et al., 2020; Marely et al., 2017; Gausia et al., 2015).

In summary, improving the mental health and wellbeing of Aboriginal Mothers is a matter of urgency with intergenerational consequences for individuals, families and communities. The aim of this program of research was to develop an evidence-base to inform improved clinical perinatal screening and care of Aboriginal women. More specifically, to work closely with Aboriginal communities to better understand current challenges to effective screening and to identify axial elements for developing more effective perinatal screening processes. This commitment provided the impetus for the current series of studies.

1.2 Impacts of colonisation

It is proposed that the deep roots of this seemingly intractable health system failure can only be understood by considering key historical and contextual factors. Perinatal mental health screening and health care with Aboriginal families cannot be viewed outside the present-day impacts of colonisation and the Stolen Generation[3]. Colonisation has precipitated many dehumanising strategies impact Aboriginal Australians. Two such strategies, the 1937 Aborigines Protection Board and Assimilation Policy and the subsequent ‘Stolen Generations’ (McGregor, 1997), had devastating domino effects that resulted in dispossession and intergenerational trauma. Early Australian thinking and research practices included scientific racism (Williams, 2014) and eugenics. The Eugenics movement proposed to ensure that those with “superior natural endowments” had high birth rates while those with “gross defects of mind or body” were prevented from producing children; Australian Aboriginal people were placed into the latter category (Lemieaux, 2017). Melbourne University’s Professor Richard Berry, the founder of the Victorian Eugenics Society researched over 400 Aboriginal corpses. He supported the establishment of a “lethal chamber” to euthanise those who evolved from “rotten heredity”, which included Australia’s First Nations people (cited in Lemieaux, 2017, pp47). The Eugenics Society of Victoria hosted the who’s who of Melbourne, with partnerships between health, research and legislators. Their power and influence were such that their thinking was used to justify aspects of policy leading to the Stolen Generation (Jones, 1999).

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[3] *Since colonisation, numerous government laws, policies and practices resulted in the removal of across generations of Aboriginal and Torres Strait Islander children from their families and communities across Australia. Thousands of children were removed by governments, churches and welfare bodies to be raised in institutions, fostered out or adopted by non-Indigenous families, nationally and internationally. They are known as the Stolen Generations* (The Australian Institute of Aboriginal and Torres Strait Islander Studies).

The toxic history of racism in Australian society, both learned and intergenerational, is insidious and has infiltrated our educational, legal and health systems (Griffiths et al., 2016). Recently the Australian Senate rejected a motion to introduce ‘Critical Race Theory’ (CRT) into Australian school’s curricula (Anderson and Gatwiri, 2021). CRT upholds that “systemic racism” (Firth et al., 2021) is present in social institutions and unconscious bias perpetuates racial inequity in health, in education and the law. The Senate rejection came shortly after powerful elements of mainstream media claimed it was “preoccupied with the oppression, discrimination and struggles of Indigenous Australians” (Connick, 2021)

In this body of research, priority was given to adopting a decolonising approach to research to ensure that the cascading effects of colonisation on health practices, was disrupted.

1.3 Reductionist health system

Legacies of historical government policies effect current policies and also effect health, health service provision (Griffiths et al., 2016) and contribute to poorer health outcomes for Aboriginal Australians. The importance of addressing the resulting social determinants of Aboriginal peoples’ health, has been stressed by successive governments (AIHW, 2020a); Australian Health Ministers’ Advisory Council, (2017) and by Aboriginal Mothers (Reibel et al., 2016). However, the direct links between these social determinants and the effects of colonisation itself are rarely addressed.

Further, the national guidelines for perinatal clinical practice (Department of Health, 2018b) recommend that health professionals who screen Aboriginal women, should receive training in the importance and use of psychosocial assessments. This would assist in addressing relevant social determinants within the perinatal context. The guidelines also state that language and cultural appropriateness of the tool are key considerations (Department of Health, 2018b). In practice, these recommendations rarely happen.

The reductionist biomedical health system approach continues to focus on assessing de-contextualised health behaviours and lays responsibility at the feet of the individual. This fails to prioritise the social determinants that are within the capacity of antenatal care providers to address, including systemic racism, cultural bias, lack of cultural safety and an incapacity to meet Aboriginal women's cultural needs (Marriott et al., 2020). Failing to address them further perpetuates the impacts of colonisation.

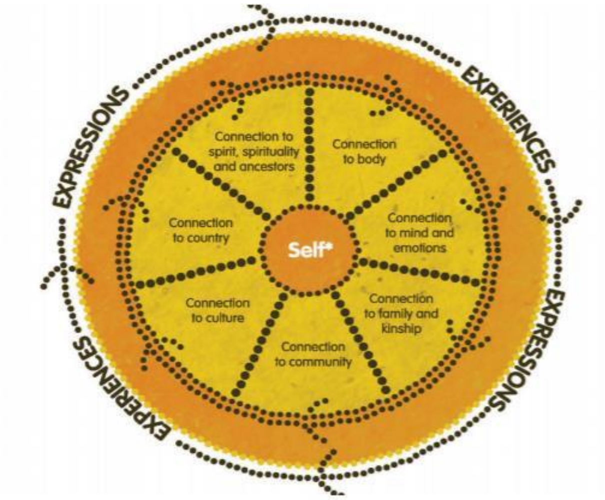
The poorer health outcomes and risk behaviours of Aboriginal Australians are widely reported in health publications. These reflect the aftermath of dispossession and complex trauma. However, the resultant thinking among the majority of health professionals is that Aboriginality itself is a risk factor. This entrenches the ‘colonial’ thinking that there is something intrinsically wrong with Aboriginal people. Perhaps unsurprisingly, Aboriginal people have adopted reduced health care-seeking behaviour, increasingly high hospital discharge rates against medical advice and inadequate perinatal care attendance rates (AIHW, 2020). In short, cultural bias and racism are making Australia’s First Nation people sick (Cave at al., 2019; Williams et al., 2019; Ferdinand et al., 2015).

In this series of studies, a contextual rather than reductionist approach to investigation was critical to disrupting ineffective perinatal practices for Aboriginal women.

1.4 Aboriginal resilience

Despite the impact of these historical and contemporary forces, Aboriginal women and their families demonstrate remarkable resilience. This resilience is anchored in cultural identity and interconnectedness to Family, Kinship ties, cultural beliefs, knowledge and practices, in cultural responsibilities and obligations and to the land (country) (Dudgeon et al., 2017; Usher et al., 2021). Cultural identity remains a source of power and strength to not only to deal with challenges and adversity but to flourish in daily lives. Many Aboriginal women experience healthy pregnancies, births and enjoy positive journeys into ‘Motherhood’ and beyond. Many of these women, including teenage Mothers, become strong protective Mothers despite significant adversities. For others, the stigmatisation associated with young or single parenthood, culturally unsafe services and service providers, combined with inadequate social and emotional supports and compromised social and emotional wellbeing (SEWB), make the transition into Motherhood particularly challenging and precarious – and this can undermine resilience.

Strengthening SEWB supports resilience: It is increasingly recognised that providing culturally safe and woman/Family centered maternity services is critical to improving health for Aboriginal Mothers and babies (Kildea et al 2016; Reibel et al., 2016). Such services are underpinned by health professionals combining greater cultural sensitivity, flexibility and awareness (Marriott et al. 2021; Department of Health, 2018) through the application of a holistic mental health screen that is considered within Aboriginal Australians’ perspective of social and emotional wellbeing (SEWB) rather than mental illness. (Figure 1)



*This conception of self is grounded within a collectivist perspective that views the self as inseparable from, and embedded within, family and community.

© Gee, Dudgeon, Schultz, Hart and Kelly, 2013
Artist: Tristan Schultz, RelativeCreative.

Figure 1. Social and Emotional Wellbeing from an Aboriginal and Torres Strait Islanders’ Perspective (Gee et al, 2013).

SEWB-based care models are described as a decolonising approach to health, that necessitates understanding that ‘illness’ cannot be understood without first realising the circumstances of oppression that fosters it (Coe, 2020). It must reflect a strengths-based, holistic perspective of health and acknowledge social, historical, and protective factors (Farnbarch et al., 2018).

Conversely the current approach to perinatal mental health screening with Aboriginal Mothers is embedded in a mainstream medicalised risk-focused model which is neither culturally considered nor effective.

Deepening our understanding of what is a culturally safe and responsive perinatal mental health and psychosocial assessment was a guiding imperative for the current program of research. Maintaining a strengths-based orientation rather than a pathologizing lens to understanding perinatal care needs, was equally critical in seeking more effective solutions.

1.5 The current program of research: Kalyakool Moort (Always Family).

The overall goal of this program of research was (i) to explore the experiences and needs of Aboriginal women in perinatal care; and (ii) to use this information to develop an evidence-base to guide the development of clinically and culturally effective ways for maternity care practitioners to assess and support Aboriginal women’s social and emotional wellbeing during pregnancy and early parenting. This program of work was called Kalyakool Moort which translates to ‘Always Family’. The name was gifted to the research program by Nyoongar Elders to stress the significant of ‘Family’ in the health and wellbeing of Mothers. A website was developed to assist with engagement and transparency in dissemination of findings. The artwork and logo for the program was developed by a Nyoongar artist Barbara Bynder after consultation with the Kalyakool Moort Aboriginal Advisory group. The website can be found here: https://alwaysfamily.weebly.com

1.5.1 A decolonising stance

To mitigate the effects of colonisation that are deeply embedded in the health and research sectors, maintaining a decolonising and Indigenising orientation to this research was critical and is described in more detail in Chapter 2. Briefly, there was an enduring commitment to challenging traditional (colonial, European, medical) notions but additionally, to elevating Aboriginal voices in the narrative of the perinatal experience and in the design of solutions. This seemed critical if we are to make active change in reducing maternal health. Culturally tokenistic research is at best unhelpful. Decolonising research requires researchers to fit in with Aboriginal world views and paradigms. Smith (2008 p.7) states that ‘imperialism’ dominates the mental universe of the colonised and it is "finished business".

As a relatively new researcher, exploring research paradigms and methodologies in this context was intimidating. Having witnessed researchers allowing cultural and methodological bias to sub-consciously encroach on Aboriginal values and principles, there was a strong personal commitment made to ethical and reflective practice. To mitigate these challenges and the risk of researcher bias, this research was also strongly supported from its inception by Aboriginal leadership which expanded and was maintained throughout and extended to include a comprehensive Aboriginal governance model. Establishing a broad-base of strong Aboriginal support, adopting a strong principle of power sharing and incorporating Aboriginal methodologies into the research were key. These measures were intended to ensure that the six core values of ethical conduct in research with Aboriginal and Torres Strait Islander people were honoured and integrated throughout the process (National Health and Medical Research Council (NHMRC), 2018, 2003). (Figure 2)

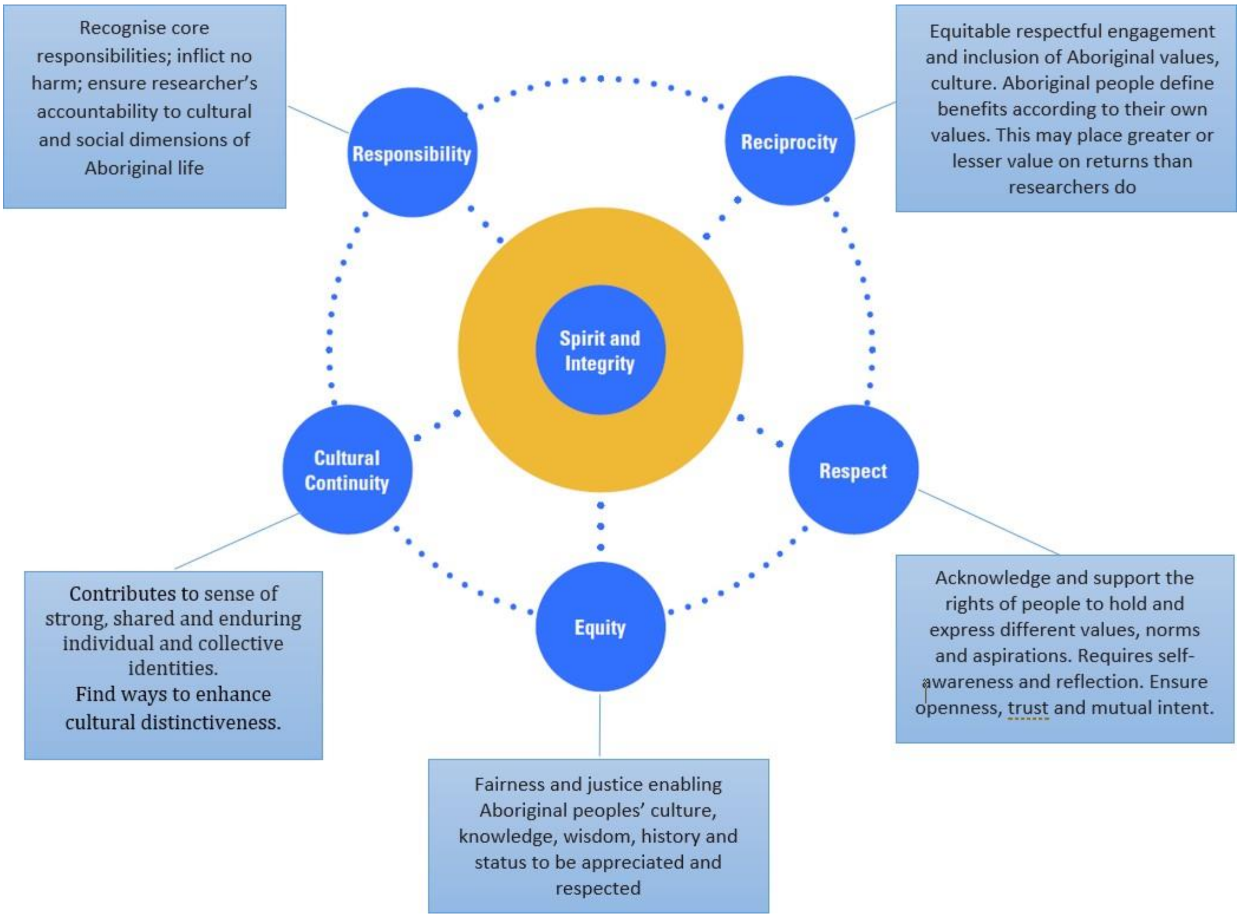


Figure 2. Six core values of ethical conduct in research with Aboriginal and Torres Strait Islander people (NHMRC, 2018).

1.5.2 Research location and cultural context

Aboriginal cultures are varied and diverse in Australia. Culturally secure research requires knowledge of local culture, knowledge, practices and priorities. Honouring Aboriginal peoples' leadership in this program of research necessitated engagement with both historical and current issues of importance to local communities. Whilst the majority of the study would be undertaken on Whadjuk Boodja (Perth region), Aboriginal people from across Western Australia and beyond have made it home. This diversity was reflected in the leadership and governance collective and in study participants to ensure that context was richly considered at all stages of the research.

Community and organisational consultation and collaborations commenced as a priority at the outset and remained a priority throughout. As a non-Indigenous midwife and researcher new to Nyoongar Boodja (south west region of Western Australia), building trust on a wider scale would take time. It is often through many small personal interactions that trust is built.

1.5.3 Navigating this thesis: A series of interconnected studies

Addressing the two urgent questions outlined above required an integrated series of studies to approach this complex and longstanding challenge from complementary directions so as to gather rich counterpointing information and to engage at depth with emergent findings. Whilst the studies in this thesis are, necessarily, presented sequentially, the studies did not follow an entirely linear process – certainly the learning process involved reiterative consideration of findings as they emerged, and often involved follow-up conversations and analytical consideration with and by the Aboriginal leadership and governance collective (LAGC) before designing or re-designing the next step. The driving force was the recognition that many before us had tried and failed to find solutions to what seem intractable health outcome statistics by tinkering around the edges and following standard research methodologies – the greatest likelihood for success was deep engagement with Aboriginal leaders to make sense of what we were seeing, and what was absent, in the data.

Deep consideration was given to methodological design and framing of the research questions. A decolonising methodology which is described in detail in Chapter 2 to lay the foundation. The first two studies reported in Chapters 3 and 4, were a deep exploration of existing evidence in the form of reviews of published research and the grey (clinical) literature. The first explored the gold standard Edinburgh Postnatal Depression Scale. The second evaluated the potential utility of a range of mental health measures. Uniquely, this study involved both a literature review and a cultural review of the instruments, the latter undertaken by the Aboriginal leadership and governance collective. These reviews established the clear need for further research and guided the studies that followed. Key work then began in working with Aboriginal Mothers and, critically, also with Fathers to (i) understand the experience of perinatal mental health screening; and (ii) understand what strong parenting is so as to inform a strengths-based approach to screening. This study is reported in Chapter 5. Expanding this investigation further involved asking similar questions of health professionals who work with Aboriginal Mothers in providing perinatal care. This study can be found in Chapter 6. Chapter 7 takes the emergent evidence-base from the preceding studies and moves to clinical translation in the form of developing culturally secure clinical practice guidelines. Although beyond the initial scope of this thesis, the iterative nature of this series of conversations also resulted in the codesigned development of a pilot perinatal mental health screening tool. Preliminary description of this novel clinical application is included in Chapter 7 and will be the subject of an ongoing program of research. Chapter 8 presents a final reflection and formulation of the theoretical and clinical contributions of this research along with consideration of future research needs.

Chapter 2 Decolonising research - Kalyakool Moort methodologies

2.1 Chapter overview

This chapter lays the foundations for the series of studies that are likely to lead to a culturally sound perinatal screening process, based on the premise that the quality of the ‘ends’ is likely to be dependent on the quality of the ‘means’. This chapter describes a decolonising methodology utilised in the project, with subsequent chapters describing the operationalisation, application and outcomes of this methodological approach.

The article presented below, currently under review for publication, can be cited as:

Kotz, J., Robinson, M., Gibson, A., Reid, C., Marriott, R., Reibel, T. (2021). Decolonising the exploration of perinatal mental health screening with Indigenous Australian parents in primary care. *Primary Health Care Research & Development,* Under review.

2.2 Decolonising the exploration of perinatal mental health screening with Indigenous Australian parents in primary care

2.2.1 Abstract

Background: Addressing mental health in primary health care is recognised as being vital, and for perinatal mental health, prevention and early detection is essential for the outcomes of both Mother and child. There is growing evidence that perinatal mental health screening practices with Indigenous Australian women are neither effective nor acceptable. Further, their perinatal mental health and wellbeing is poorly managed across most Australian healthcare settings. Young Indigenous women report experiencing the highest rates of psychological distress, compared to all other Australians. They experience disproportionately

poorer maternal and infant health outcomes with their children seven times more likely to be in out-of-home care. Compromised maternal mental health also places the developing fetus and infant at risk of lasting cognitive and developmental delay, behavioural and mental health problems, obesity and chronic disease later in life. Improved understanding of Aboriginal women's perinatal experiences is necessary for optimising successful screening and early intervention. Achieving this is dependent on adopting culturally safe research methodologies. This paper reports on the methodology which framed a study investigating Aboriginal and Torres Strait Islander perinatal mental health screening with a view to developing a culturally safe perinatal mental health assessment process.

Methodology: We describe how a decolonising research methodology was used to conduct a PhD study undertaken by the first author (Kalyakool Moort – Always Family, unpublished) using culturally relevant methods. The perspectives of Aboriginal people were integral to the study's conduct through leadership in decision making from the earliest stages of the study. This included devising the research structure; codesigning a pilot perinatal mental health assessment process; and throughout implementation and evaluation, devising solutions. Methods used included community participatory action research, codesign and yarning with data analysis applied through the cultural lenses of Aboriginal investigators to inform culturally meaningful outcomes. Mixed methods were adopted with multiple stakeholder groups and triangulation of both qualitative and quantitative data sources.

Conclusion: The Kalyakool Moort research methodology resulted in (i) clarification of the lack of an evidence-base for the use of current gold standard perinatal mental health screening (using the EPDS) with Aboriginal women (ii) establishing the challenges and obstacles experienced by Mothers and health professionals during perinatal screening (iii) describing what it is to be a strong parent, through the lens of Indigenous parents; and (iv) using this evidence-base to for clinical translation, specifically, to provide best practice clinical recommendations for perinatal clinicians and service providers and to instigate the codesign of a pilot, highly innovative, social and emotional wellbeing wrap-around perinatal screening tool (Baby Coming You Ready - BCYR). Integral to the success of the project has been the cultural safety of the Kalyakool Moort methodology used to develop the underpinning evidence-base and in progressing this evidence to clinical application. Extensive community collaboration fostered mutual trust, power-sharing and engagement with all stakeholders, deeply and at all stages of the project.

Keywords: Australian Aboriginal, decolonising research, perinatal mental health, participatory action research, codesign.

2.2.2 Background

In Australia, perinatal mental health is a national public health priority (Glover, 2011; Aktar et al., 2019; Marco et al., 2020; Zijlmans et al., 2017; Austin et al., 2006; 2007). Currently in Australia the gold standard perinatal mental health assessment screening tool is the Edinburgh Postnatal Depression Scale (EPDS) developed in Scotland in the 1980's (Cox et al., 1987). The purpose of perinatal mental health screening is to detect risk or early disease so that preventative measures or early intervention can be applied. Problems arise when we make assumptions about Western systems of assessing and managing mental health in cross-cultural settings (Vicary and Westerman, 2004). Culture, both inter-disciplinary and inter-racially, influences experience, expression and communication of symptoms and how these are managed. Whilst there have been efforts to translate and establish psychometric properties of the EPDS for diverse countries, where Indigenous peoples in particular are involved there may be additional layers of consideration in test adaptation relating to significant cultural differences and the impacts of colonisation on interpretations of mental health and of client engagement with service providers. Simply transposing or translating Aboriginal English onto Western screening tools or applying Western thinking when interpreting or proposing management strategies may therefore result in under-diagnosis, over-diagnosis and mis-diagnosis (Parker and Milroy, 2004). From a primary healthcare perspective, the current inequities in Aboriginal maternal and infant health and wellbeing outcomes could be viewed as reflecting these problems.

The negative trajectory in health and wellbeing outcomes is likely to continue for Aboriginal Mothers and infants unless culturally safe and effective early identification strategies and interventions are developed. To this end, the aim of the study was to challenge usual practice avoiding cultural limitations apparent in Western research methods, instead using decolonising methodologies which prioritise Aboriginal knowledges and ways of addressing issues of concern to Aboriginal people. For example, in designing a more effective solution, it is important to understand how Aboriginal parents and health professionals express and interpret the concept of mental health and wellbeing and also how they experience current gold standard mental health screening.

Decolonising methodology In her influential work, Smith (1999) described validating Indigenous knowledges through research which encompasses decolonisation, healing, mobilisation and transformation. Fayed et al., (2018) describe 'Two-Eyed Seeing' as a reconciliatory methodological approach to health research and practice. It advances Indigenous healing through a comprehensive 'anti-colonial' approach. Whilst and valuing mainstream perspectives, it resists the oppressive elements of colonialism that are embedded in past and contemporary systems by and emphasising Indigenous peoples' diverse health perspectives and world view. Ryder et al (2020) describe in detail an interface between Indigenous and scientific knowledge as an intersection where Indigenous researchers can generate new approaches using different lenses to non-Indigenous counterparts. Operationalising a decolonising methodology in perinatal health research has not been previously described in the literature.

While the Kalyakool Moort study was initially conceptualised by a non-Indigenous scholar (first author), at all points Aboriginal people were central and their oversight ensured that

Aboriginal knowledge was integral to study outcomes. Kovach (2009) and Tuck (2009) argue that decolonising research paradigms whilst conferring a shift of power, must purposefully consider the evolving relationship between researchers and participants. The position of non-Indigenous researchers, as power is shared, needs to consider the notion of “insider and outsider” and the associations between “self and other” and “self-as-other” (Pelzang et al., 2017 and 2018). This can and should be challenging. As a non-Indigenous scholar, without this continual repositioning of self-as-other, decolonising methodologies such as community participatory action research (CPAR) are at risk of cultural bias which diminish Indigenous ways of being and knowing. Power sharing requires a continual shift in thinking driving efforts to gather knowledge. It requires reflective thinking and an appreciation of multiple worldviews and their respective truths. On a cultural level in Australia, it necessitates a contextualised discussion and re-claiming of knowledge informed through a balance of truths and histories. This process is ongoing as colonial ideological constructs are part of the dominant (systemic and institutionalised) culture, in particular: politics, law, education, media. This requires unpacking constantly through reflection to prevent further indoctrination.

Four aspects of research design were identified that could in combination achieve this goal of privileging cultural context in our studies: (i) CPAR (ii) codesign principles (iii) yarning; and (iv) mixed methodologies.

The study framework was based around a community participatory action research (CPAR) approach. CPAR is recognised as a decolonising approach to research advocating the challenging of power relationships, with participants fully immersed as research partners throughout (Dreise and Mazurski, 2018). Pelzang and Hutchinson (2017) caution that CPAR projects with lower-level community consultation and engagement, engaging only infrequently and with ‘convenience’ community groups may fail to establish wider cultural wisdom and trust. Deep collaboration is required to ensure shared ownership of the research design, the questions asked analysis of the data and addressing of issues arising. In the current series of studies this was operationalised by inviting Aboriginal people on Nyoongar Boodjar (Country) in the south of Western Australia to engage as co-researchers, as leaders in the governance structure, and as primary participants – in this way there were multiple and varied opportunities for community members to fully participate in the research process. Results were generated through iterative reflective cycles, where participants collect and analyse data, then determine the action to take to improve the health of Aboriginal families (Baum et al., 2006).

Codesign principles were also central to the methodology developed. The process of codesign is considered to be less vulnerable to the marginalisation of Indigenous ways of knowing by non-Indigenous researchers and stakeholders who are more used to Western research methods. Codesign is a process which aims to combine the expertise of lived experience with skills or formalised knowledge which is acquired in academic/practicum settings, to identify and create theoretically, culturally and pragmatically successful outcomes (Sanders, 2008). In Aboriginal contexts, codesign plays a vital role: it reminds service providers and governments that they should do things *with*, and not *to* Aboriginal communities (Dreise and Mazurski, 2018).

In combination, CPAR and co-design principles involve the community in the full production of research, including planning, design and management ensuring a collaborative developmental process with the 'balance of rights and powers' for Aboriginal community and other stakeholders maintained (Bradwell and Marr, 2008) while developing solutions which address the complexity of identified problems.

In terms of data collection, the yarning method as described by Bessarab and Ng'andu (2010) provides a robust method for culturally safe and accurate data collection with Aboriginal people. Whilst semi-structured interviews and narrative enquiry are not new (Schmidt, 2004), yarning requires the researcher to develop a relationship that is accountable to the Aboriginal participant whilst following protocols for establishing a culturally relevant dialogue. Yarning as a research method encompasses four types of interaction: (i) a social yarn which weaves in and out of (ii) a research topic yarn which may move into (iii) a therapeutic yarn, or to a (iv) collaborative yarn. In combination, these yarning types enable issues to be deeply explored (Bessarab and Ng'andu, 2010) with the flow contextualising the tapestry of data for interpretation.

A mixed methods approach was adopted given the preliminary state of the study area - when an area of study is ill-defined, it is important not to rely on a single data source but rather to capture data in more than one way in an exploratory (rather than confirmatory) fashion. In this instance, a process of triangulation of quantitative and qualitative data; together with data from different sources, provided greater confidence in interpretations through examination of points of convergence and divergence from complementary sources (Teddlie and Tashakorri, 2012). Quantitative data were collected through anonymous online survey and was contrasted with individual and group-based conversations undertaking using yarning methodology. Similarly, multiple participant types were critical in ensuring that diverse voices were heard. These participant groups are detailed below.

A commitment was made to take a consistent decolonising approach in all aspects of the work, from the very beginning to the end of the research journey. This was intended to ensure the integrity of the entire series of studies and to engender confidence in the resultant evidence-base for clinical translation into a culturally sound perinatal mental health screening process. This will be the tangible legacy of the project for the communities involved. Reid et al (2019) suggest that involvement of key stakeholders at all stages of the research process is necessary for developing contextually relevant translation and ethical outcomes when working in complex and cross-cultural contexts (see Figure 3; and https://www.ethical-global-research.ed.ac.uk.). They highlight that a weak link in the research chain can constrain the validity of the entire project and compromise clinical application of the findings, especially in circumstances where inappropriate clinical application may result in harm to patients.

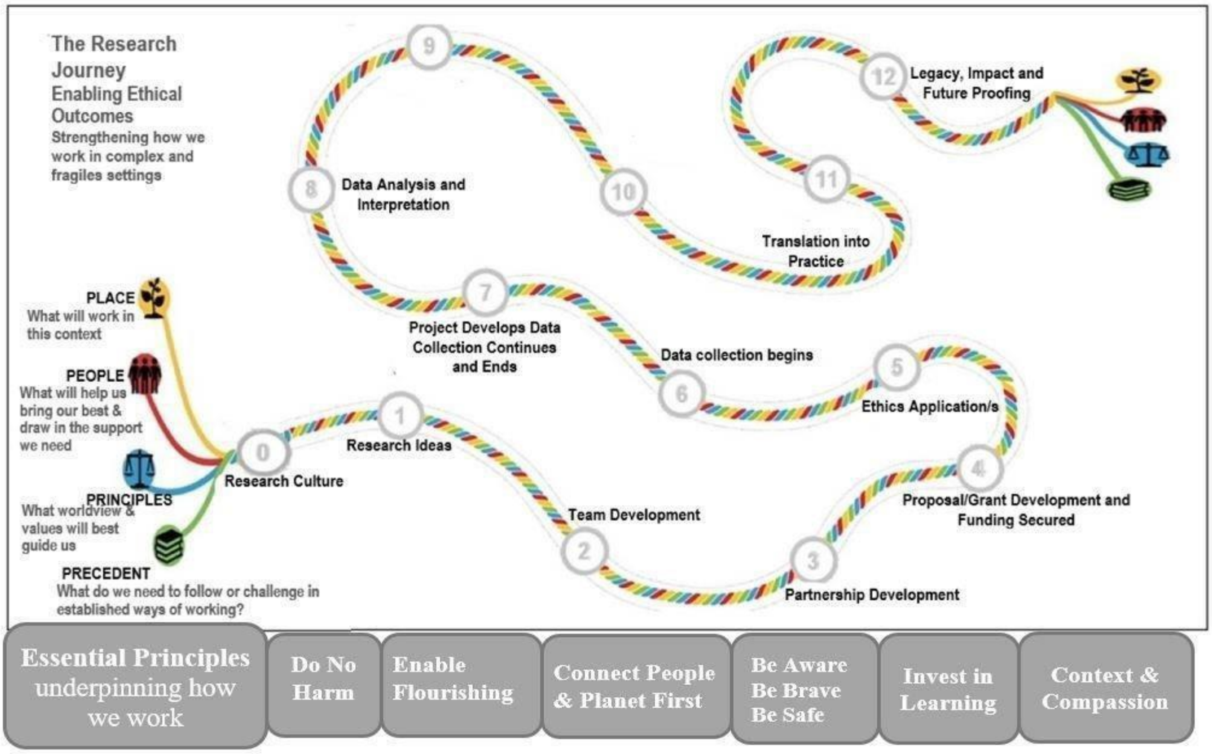


Figure 3. Stages and elements of an ethical research journey

2.2.3 The Current study

The methodological operationalisation of the decolonising approach is described below. Figure 4 outlines the considerations of the 4 P’s of ethical research identified by Reid et al (2019, 2021): Place, People, Principles and Precedents. Several examples of decolonisation at different stages of the research journey are also provided. This detailed account is important in establishing the comprehensive approach taken to ensure a culturally safe process to enable culturally safe outcomes.

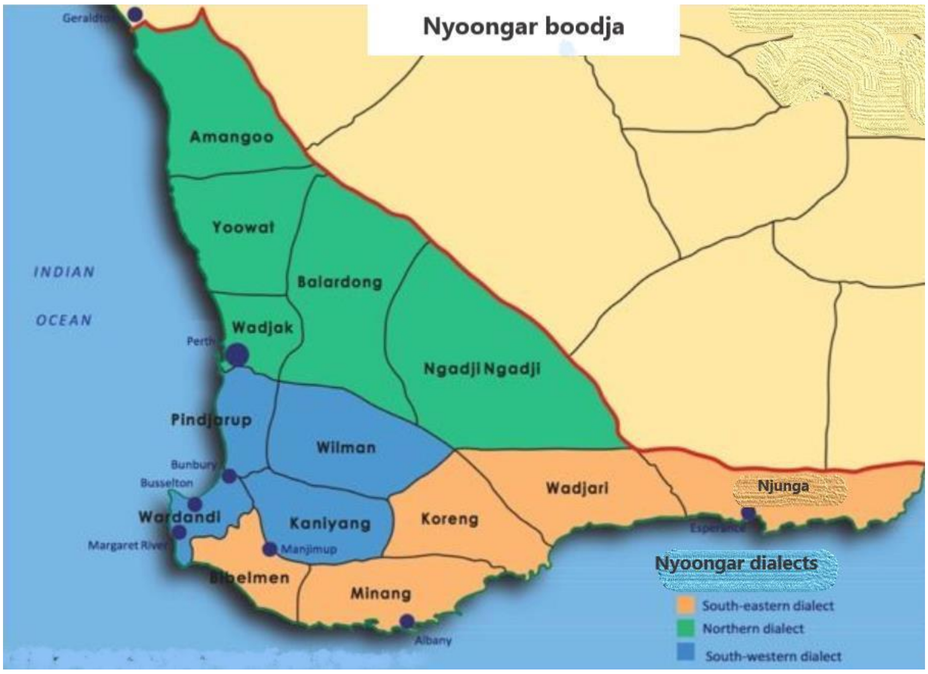
Place:

Understanding the context in which research is undertaken is critical in designing the optimal methodological approach.

The cultural safety of the project was facilitated by ensuring that the research team had a suitable academic home. The Kalyakool Moort project was based at the Ngangk Yira Research Centre for Aboriginal Health and Social Equity at Murdoch University in Western Australia. This Centre is led by Professor Rhonda Marriott, a senior Indigenous nurse and midwife who was also primary supervisor of the PhD candidate. Being anchored in an Indigenous research Centre, provided a rich environment and abundant academic and cultural support throughout the project. It also provided a safe welcoming space for Aboriginal people to attend for meetings.

The geographical location for this study is Nyoongar Boodjar (Country), which covers the South West of Western Australia and comprises metropolitan, regional, and rural communities (Figure 4). Fourteen clans make up the Nyoongar nation and they predominate here as the traditional owners of the land. It was important to understand however, that many Aboriginal and Torres Strait Islander people from across Australia have made Nyoongar Boodjar their home and so participants may associate with different language groups and have different cultural practices or beliefs, and some may feel dislocated from Country which may impact mental health and wellbeing.

Figure 4. Map of Nyoongar Boodja in Western Australia



People

Predominant Aboriginal representation in all aspects of the research was considered essential. Deciding who to involve in this collaborative effort was an important methodological step. The first author spent the first 18 months of the study getting to know community, establishing relationships, building trust and developing strong collaborations – this work built upon relationships developed during a 25-year career of working with Indigenous communities as a nurse and midwife. Snowballing (Bonevski et al., 2014) was used to engage Elders and senior Aboriginal people, Aboriginal community members including those who worked alongside Aboriginal families, and Indigenous and non-Indigenous service providers, managers and policy makers, researchers, and academics. Establishing these rich networks was essential to optimising the codesign and translational capability of the research. The research framework (Figure 5) was developed by Aboriginal community members and Elders with the first author. This process also established the research hypothesis and questions.

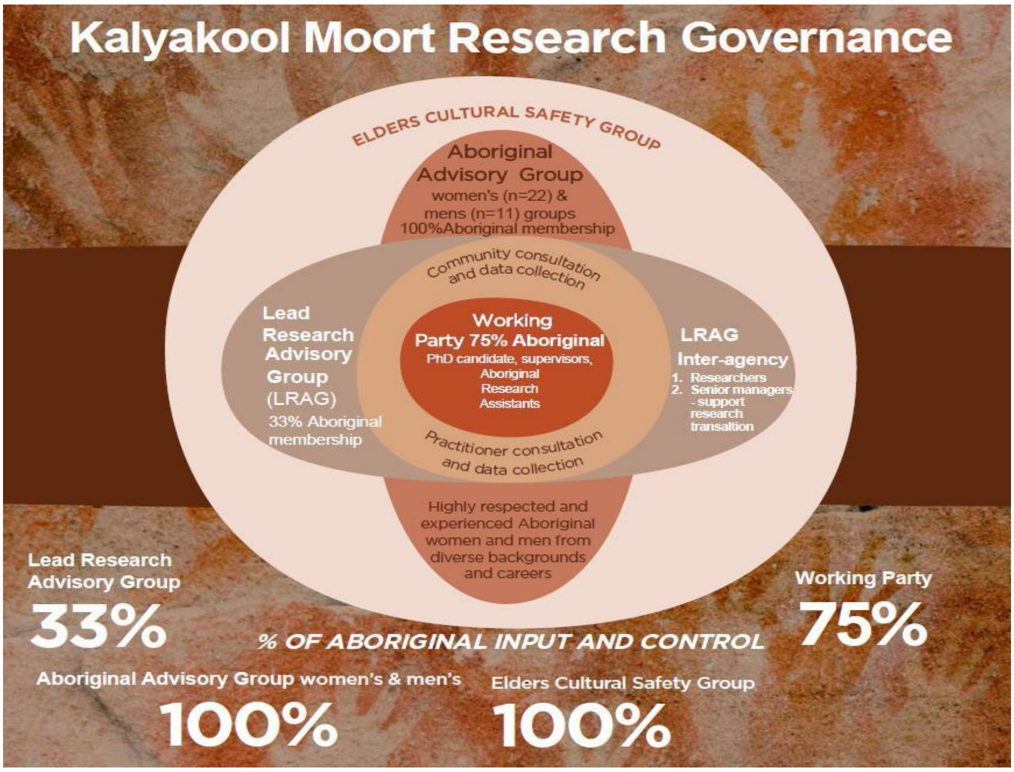


Figure 5. Kalyakool Moort Research Structure and Governance

Predominant Indigenous representation in all aspects of the research team was considered essential. The roles and responsibilities of the research team were developed by the Aboriginal Elders and Working Parties (Women's and Men's). Aboriginal people were involved as chief investigators, research team members, research assistants, and community brokers to ensure Aboriginal control of the study. Most remained committed to the research project throughout the duration of this series of studies (5-years). Their continued participation since then demonstrates endorsement of, and need for, the study.

Ultimately the research team included:

- The Lead Research Advisory Group including nineteen management and executive representatives (50% Aboriginal) from fourteen organisations who provided broad project support and research translation.
- The Aboriginal Elders Group (100% Aboriginal) including ten Nyoongar Elders who oversaw cultural safety of all aspects of the research process from the initial research structure design to the final emergent solutions.
- Aboriginal Advisory Group (100% Aboriginal) comprised thirty-five women (n=24) and men (n=11). This group met regularly as gender specific groups to address ‘women’s business’ and ‘men’s business’ and periodically met together to address shared issues. The AAG actively functioned as working parties providing leadership in the research process and supported data analysis and solution design. Most notable was their dedication to achieving the project goals. Members were identified by their managers and/or peers and /or community as being highly respected, knowledgeable and committed to working alongside and strengthening Family, Kinship ties and cultural integrity.
- Working party - Investigator team/functional working party (75% Aboriginal) - four Aboriginal research assistants (ARA)- two men, two women, the author and Principal Investigator (JK), an additional cultural advisor and two PhD supervisors the senior supervisor being Aboriginal - the fourth and fifth authors (RM and CR respectively).

These groups sometimes worked together and at other times advice or assistance was sought from the group with the most relevant expertise for a particular task. For example, the research engagement framework was developed by Aboriginal community members and Elders with the first author. The roles and responsibilities of the research team were developed by the Aboriginal Elders and Working Parties (Women's and Men's). Aboriginal people were involved as chief investigators, research team members, research assistants, and community brokers to ensure Aboriginal control of the study. Most remained committed to the research project throughout the duration of this series of studies (5-years). Their continued participation since then demonstrates endorsement of, and need for, the study. It also suggests that the group felt itself to be valued and valuable in finding solutions to significant health challenges. Together this collective provided active and pivotal leadership and governance throughout, sticking to the maxim of 'nothing about us, without us'.

Participants: Overall, 107 Aboriginal parents and health professionals from sixteen Clans or Nations and 27 non-Aboriginal health professionals (n=130) participated in either individual yarns or focus groups. An additional 155 health professionals contributed via online questionnaire. (Table 1)

Aboriginal participants living on Noongar Boodjar were from Western Australia, Queensland, South Australia and Victoria, including people who identified as: Badimaya, Balladong, Bardi, Kokotha, Mirrawong, Ngarinyin, Ngarrindjeri, Nyoongar, Nyul Yul, Tiwi, Wangai, Wajak, Yamatj, Yawuru, Yngabani and Yorta Yangban.

Table 1. Breakdown of participants in Kalyakool Moort Research

Session type	**Number**	**Participant type**	**Identifying as Aboriginal**
Individual Yarning Session	26	Mothers (n=21) Fathers (n=5)	100% (26)
Individual Semi-Structured Interviews	22	Midwife (n=8) Midwife and Child Health Nurse (n=3) Aboriginal Liaison Officer (n=6)	90% (20)
		Grandmother Support (n=3) Aboriginal Health Worker (n=2)	

Focus Groups Workshops (n=10)	82	Midwife/Child Health Nurse (n=30) Social Workers/ Counsellors (n= 18) Aboriginal Liaison Officer/Health Worker (n=17) Youth Worker / Support Worker (n=10) Manager (n=7)	75% (61)
TOTAL	**130**		
Anonymous Online Survey	155	Midwives; Child Health Nurses	10% (15)

Principles

The commitment to decolonising research methodologies is the key guiding principle of this research.

In addition, this program of research was designed to comply with all six principal ethical values (Figure 6) outlined in the National Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research (NHMRC, 2018). These values were operationalised and monitored by the Aboriginal leadership and governance collective.

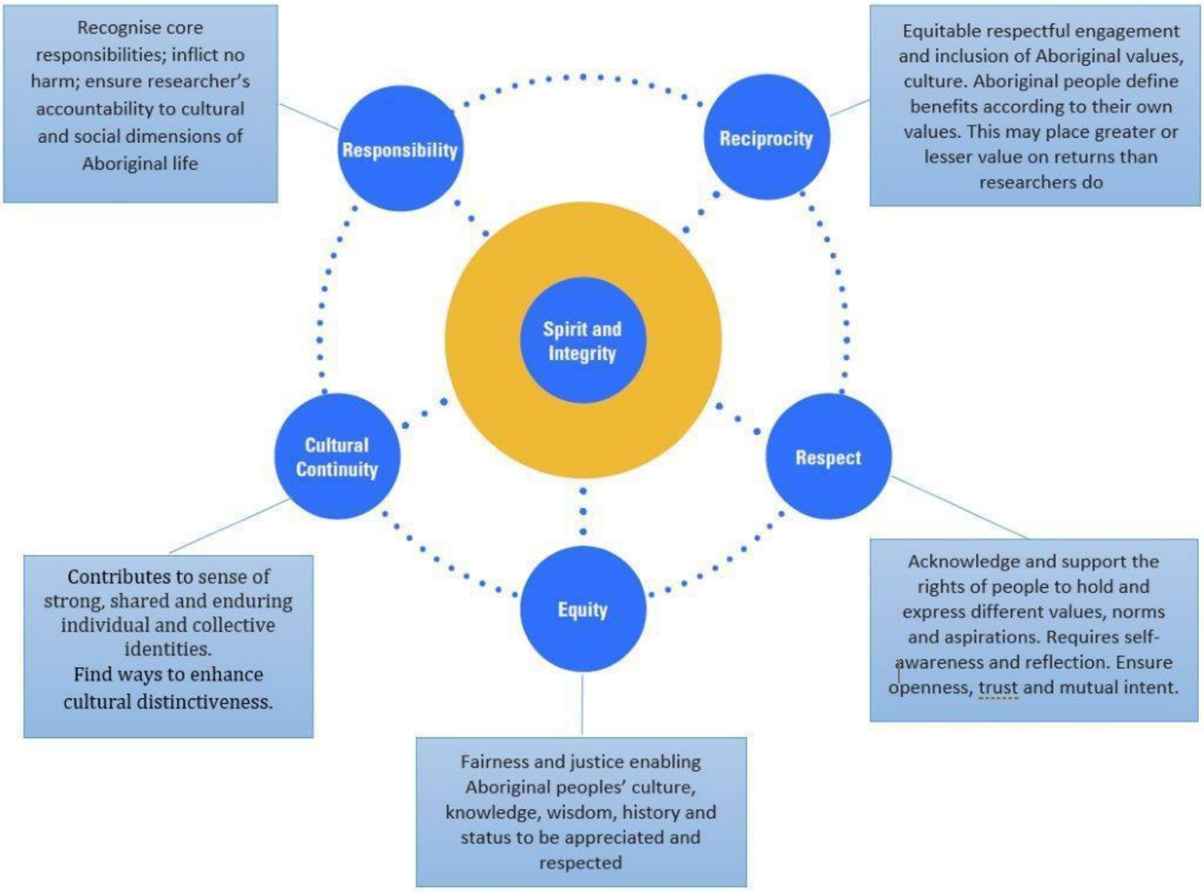


Figure 6. National Values and Ethic: Guidelines for Ethical in Aboriginal and Torres Strait Islander Health Research and examples of elements of inclusions in this research.(NHMRC, 2018)

Ethical approval was obtained from the Human Research Ethics Committee at Murdoch University (approval 2013/202), Western Australian Aboriginal Health Ethics Committee (approval 553) and the Women's and Newborn Health Service Human Research Ethics Committee (approval HREC EC00350).

Precedents

Understanding what has been done before is key to undertaking research ethically in complex environments (Reid, Calia et al, 2021). This is in recognition that research can be burdensome for vulnerable communities and all research should ensure that it does not re-invent the wheel or repeat mistakes. The entirety of this current program of research was about learning from what has gone before by reviewing the literature and by interviewing experts with lived experience, specifically, Aboriginal Mothers and Fathers, and perinatal health professionals

Operationalising of decolonisation at different stages of the research journey

Reid et al (2021) highlight that ethical research requires conscious attention to how key principles are operationalised at all levels of the research process and throughout the research journey, starting with the establishment of an ethical research culture to guide the team.

Research culture: The research culture was set by centring the project around the Aboriginal leadership and governance collective to oversee and guide all aspects of the study from beginning to end. The primary research supervisor is also a senior Aboriginal nurse and midwife as well as a Professorial researcher. Further, the 'home' of the project was an Indigenous research centre. Taken together these features facilitated a supportive, culturally strong and secure environment throughout.

Conceptualisation of the research idea*:* The Working Parties identified key issues for investigation. A yarning matrix was developed based on these key domains. This provided a guide for use in the individual yarns and yarning circles (focus groups). After receiving interrater reliability training, the four ARAs (two men and two women) collected data within the Aboriginal community and the first author facilitated the focus groups. The training included the use of yarning as a data collection strategy and dealing with disclosure. An anonymous 32-item online questionnaire for health professionals was informed by key issues identified in Working Party workshops. It was distributed through midwifery and child health networks across Western Australia and via the Kalyakool Moort website (www.alwaysfamily.weebly.com).

Data transcription: Drawing on a naturalised transcription method, digital recordings were usually transcribed by the researcher undertaking the individual yarns or yarning circles. This approach maintained a cultural lens on the transcribed data, enabling awareness of the nuances associated with low talking, silences and body language, all important aspects in

Aboriginal interactions. For example, the word ‘good’ was used frequently, but with vastly different meaning. Many Aboriginal people were uncomfortable with complaining or being critical about the care received, however, their ways of saying ‘good’ were identified in the transcripts as varying between ‘good care’ actually being regarded in a disparaging way, to ‘good care’ being identified as ‘excellent’. Overall, triangulation of results from detailed thematic analysis of individual yarns with Aboriginal parents and professionals were reinforced by results from community and professional workshops, thus increasing the robustness or trustworthiness of the data outcomes, as well as contributing to the richness and strength of findings (reported separately). The results from the health professional online survey (reported in Chapter 6) further contributed to strengthening confidence in emergent themes.

2.2.4 Data Analysis

Data analysis was carried out drawing on thematic analysis and Charmaz’s (2007) approach to grounded theory. Audios were firstly listened to, then transcribed, read, re-read then coded by each individual investigator. This ensured that initial coding was informed by first hand cultural knowledge. The research team also individually listened to, read andre-read transcripts, coding concepts and themes. Concepts were then discussed as a group and themes crystallised using inductive-deductive, comparative, interactive and iterative strategies until consensus was reached (Figure 7) with Indigenous ways of knowing, being and doing in our analysis of Indigenous responses being preferenced at all times. This upheld credibility and trustworthiness of analysis and reduced interpretive bias. Emergent key themes were further explored and relationships, consistencies and incongruities with the existing literature were examined. NVIVO was used to aid analysis by providing an additional and more manageable way of coding data and considering relationships. Themes were then categorised and reduced to those which were most significantly associated with the research questions.

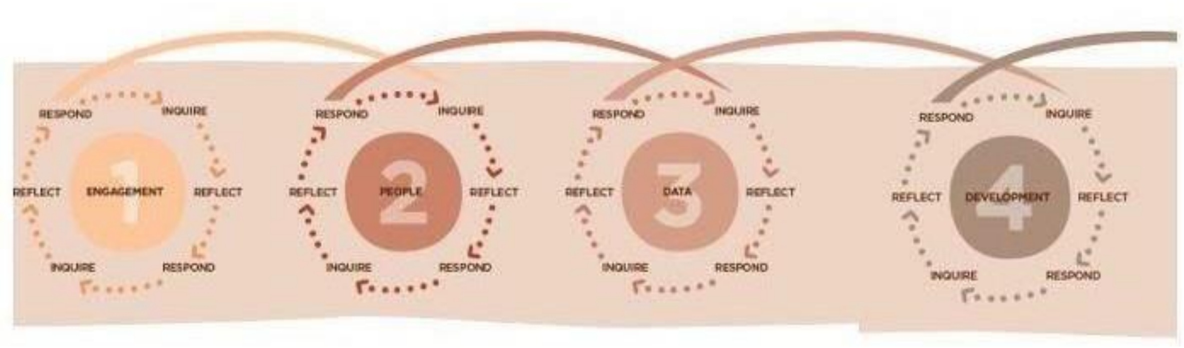


Figure 7. Iterative process of solution codesigning.

Data interpretation: Research findings were routinely reported back to the Working Parties for ongoing reflection, to inform and be informed by the unfolding themes and categories. As this iterative process continued, the Aboriginal Working Parties progressively developed recommendations and solutions from the triangulated data.

Clinical application: The ongoing work of this project is a process of taking the evidence gathered and translating it into clinical practice recommendations and tools with, and for the benefit of, Aboriginal communities. There is an exciting body of work to be undertaken in piloting an innovative strengths-based perinatal assessment and screening rubric with therapeutic potential. This innovative wrap-around program will use Aboriginal voiceovers and images on iPads to guide a clinical yarn or narrative inquiry. Piloting and evaluation will continue to draw upon our Aboriginal leadership and governance groups and to invite participation from Indigenous parents and health professionals.

2.2.5 Discussion

There is ample evidence that perinatal mental health screening among Aboriginal Mothers is not achieving desired outcomes. The Closing the Gap Prime Ministers Report (2016), highlights the perinatal period as providing an important window of opportunity for primary care providers to implement effective perinatal health and well-being strategies. The National Aboriginal and Torres Strait Islander Health Plan 2013–2023 stresses that healthcare be underpinned by culture so that:

> *"a healthy, safe and empowered life with a healthy strong connection to culture and country…receiving care based on based on the best possible evidence…free of racism and inequality…that individuals and communities actively engage in decision making and control…and that Mother and babies get the best possible care and support for a good start to life".*

The eighteen-month consultation and development period of Kalyakool Moort saw trust relationships strengthen; power was consciously shared, as Aboriginal collaborators frequently voiced "nothing about us, without us". Aboriginal people had become active researchers in this project. Recognising the benefits of power-sharing, Aboriginal community and Indigenous and non-Indigenous researchers and stakeholders had jointly committed to co-creating and facilitating the Kalyakool Moort research.

The codesigned clinical translation of the resultant evidence-base into clinical practice recommendations and a newly emerging screening tool drew on Aboriginal people's experiences and wisdom and the collective experience of Indigenous and non-Indigenous stakeholders (researchers, midwives, child health nurses, psychologists, general practitioners, mental health consultants and social workers). Aboriginal and non-Aboriginal researchers and practitioners stood side by side with community with privilege being afforded to Aboriginal perspectives.

CPAR incorporates principles congruent with codesign models of research. CPAR encourages high levels of community consultation and engagement, as was the case with Kalyakool Moort, requiring researchers and other key stakeholder to consciously acquiesce perceptions of power, influence and pre-conceived agendas. The conscious implementation of a decolonising methodology which remained critically reflexive to the outcomes of Aboriginal led conversations translated to a robust CPAR and codesign undertaking which resulted in a perinatal mental health screening solution which the Aboriginal community could own.

Deep and genuine community engagement is the solution to successful sustainable interventions that support effective perinatal primary health care. Unquestionably codesign is a preferred approach in decolonising research and to developing solutions with, and for, Aboriginal people and communities. This approach involves collaboration between researchers and end users from the outset, including jointly developing questions, deciding on research design and influencing implementation and broader dissemination strategies (Goodyear-Smith et al., 2015).

The codesign model also presented challenges. Workplace, academic and funding constraints and time limits, and restrictive requirements set by universities and human research ethics committees (HRECs), were at times at odds with the evolving and adaptive processes central to codesigned research. Institutions require precise pre-definition of methodologies, objectives, strategies, interventions, costings and outcome measurements to protect participants from harm, to support rigour and transparency and to ensure financial accountability. However, detailing all prerequisites prior to the phases of codesign research, is not always feasible (Goodyear-Smith et al., 2015). To remain true and accountable to the codesign process whilst preventing shortcuts, required commitment, patience, flexibility and resourcefulness from everyone involved.

The complex cultural interface of this research, at times also presented challenges. Being both attuned and responsive to these challenges was a priority. Research in perinatal mental health with Aboriginal families necessitates immersion in the Aboriginal world view of social and emotional wellbeing. This is both multidimensional and complex; deeply rooted in intergenerational connection to land or ‘country’, spirit, Family, Kinship connections, ancestors and community. It is also enmeshed in complex trauma but counterbalanced with an innate resilience, both at individual and community levels. Despite an ostensible appreciation of the importance of SEWB in Western healthcare system, there remains an enduring focus on mental illness and psychopathology with most professionals holding fast to the medicalised understanding of mental illness. This may in part be due to an understandable fear of ‘missing’ the worst-case scenario – suicidal intent. However, failing to appreciate SEWB from an Aboriginal person’s worldview perpetuates cultural ignorance and the fear of the consequences of being judged and misdiagnosed. With specific regard to perinatal mental health screening, without understanding the importance of SEWB within the complex whole of Aboriginal life, clinicians run the risk of missing early red-flags, thus further alienating vulnerable Mothers and families.

Further cultural complexities arose from the interdisciplinary nature of this research. Perinatal mental health care rarely involves one discipline, as each brings a unique perspective to the shared goal. So interdisciplinary collaboration and input was critical. However, most professionals are trained and socialised into their own professions, which at times resulted in biased understandings of mental health, of SEWB, and in their own roles and the roles of others. These professionally bound biases were at times in opposition to the importance that other disciplines and Aboriginal people gave them an important finding made possible through a mixed methods approach and triangulation of multiple sources and types of data. Figure 8 provides a pictorial summary of the mixed methods data triangulation used.

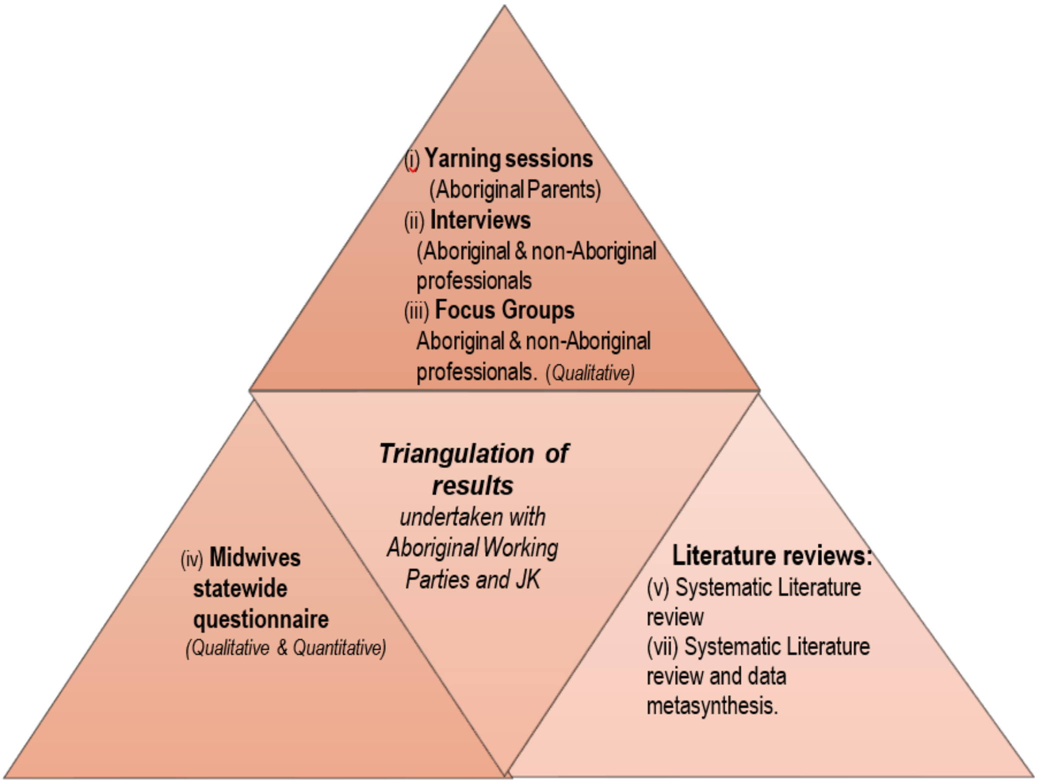


Figure 8. Pictorial representation of the mixed methods data triangulation used in Kalyakool Moort

Overall, establishing a research framework in which Aboriginal people guided process and retained privilege was definitive to achieving a successful outcome. Clinical translation emerged as evidence-informed practice guidelines and evidence based primary healthcare assessment rubric and intervention that has the potential to transform how Aboriginal women are able to participate in culturally safe and meaningful perinatal mental health screening.

2.2.6 Conclusion

The transference of existing screening tools and processes, originally adapted for the mainstream population, onto the Australian Aboriginal community is not working. It is doubtful any method will be successful unless the approach to screening and to follow-up strategies are community driven.

The decolonising approach taken in this project has been community driven from the beginning. Its success was strengthened by maintaining both a desire-based and strength-based approach to codesigning the project and contributing to the final output. Indicators of its success include the maintenance of a diverse research team and advisors; agreement on outcomes of thematic analysis across all stakeholder groups and, whilst time-consuming, the project was able to progress to identify an innovative clinical solution. While still to be tested in real-world settings, this is a highly successful research outcome from a decolonising research approach.

Chapter 3. The EPDS - reviewing the gold standard perinatal screening tool in an Aboriginal context.

When responding to a longstanding clinical issue with a significant human cost, there is an urgency to find outcome-based solutions. Hence, the first step is to look for *existing* or *adaptable* solutions in the peer-reviewed (white) or clinically-reviewed (grey) literature. And so it will be in this program of research. This approach is also congruent with adopting a decolonising research stance – making a commitment not to unnecessarily burden vulnerable communities with additional research demands without first checking whether a solution already exists. If an existing solution is found, it offers the quickest path to resolution. Two literature reviews are reported: (i) an evaluation of the evidence of the validity of the gold standard perinatal mental health screen, the EPDS, when used with Aboriginal women (Chapter 3); and (ii) in Chapter 4, an evaluation of evidence supporting the application of non-specific mental health tools in the perinatal period with Aboriginal women.

3.1 Chapter overview

The EPDS (Cox et al., 1987), originally developed to assist in identifying possible symptoms of depression in the postnatal period for women in Scotland, adequately demonstrates sensitivity and specificity to identify depressive symptoms in general populations during the antenatal period. Whilst it was never its original intent (Cox, 2017) some research has found it may be useful in identifying symptoms of anxiety (Matthey et al., 2012:2013). It is now used as the 'gold standard' in perinatal mental health screening in Australia. Whilst there have been some adaptations to the EPDS for use with Aboriginal women, little is known about mental health practices with Aboriginal Australian Mothers in the perinatal period.

To explore the current context of perinatal mental health screening among Aboriginal women in Australia, ensuring a solid base of what is known and what is current screening practice was essential. An extensive review of the white and grey literature was undertaken to assess the Australian context.

3.2 A systematic review of the literature: The EPDS and Indigenous Australian women

The literature review in this chapter has been published as:

Kotz, J., Marriott, R., & Reid, C. (2021). The EPDS and Australian Indigenous women: A systematic review of the literature. Women and Birth : *Journal of the Australian College of Midwives*, 34(2), e128-e134. https://doi.org/10.1016/j.wombi.2020.02.007

3.2.1 Abstract

Problem: The Edinburgh Postnatal Depression Scale (EPDS) is considered the ‘gold standard’ in perinatal mental health screening and the Australian Clinical Practice Guidelines recommend universal use. However, screening rates are four times lower with Indigenous Australian women compared to non-Indigenous women. Difficulties have been reported using the EPDS in this context.

Background: Evidence demonstrates the link between perinatal mental health and maternal and child outcomes. Indigenous Australian maternal and child health and wellbeing outcomes remain unacceptably poor across all measured parameters and reported psychological distress and child removal rates are increasing.

Methods: A systematic literature review was conducted to assess the effectiveness, validity, reliability, and cultural safety of the EPDS in the Indigenous Australian context and identify the availability and suitability of any adaptations.

Findings: The EPDS has not been validated for use with Indigenous Australian women.

Discussion: The findings and limitations identified in this review are consistent with concerns in other countries about the cross-cultural use of the EPDS and its sensitivity in predicting risk for postnatal depression amongst Indigenous women. Where adaptations of the

EPDS have been used there has been no psychometric and cultural validation beyond the remote communities in which they were developed.

Conclusions: There is no evidence to demonstrate that the EPDS in its current form and application is suitable for screening with Indigenous Australian women. Urgent work is required to evaluate and/or develop culturally meaningful screening tools that are predictive of risk for social and emotional wellbeing and perinatal mental distress in this context.

3.2.2 Statement of significance

For the journal Women and Birth a statement of significance of the research was required (Table 2).

Table 2. Statement of significance

Problem or issue? Perinatal mental-health screening among Indigenous Australian women is poor.
What is already known? The EPDS is considered the gold standard for perinatal mental health screening. Whilst it has been translated into a number of languages, there are concerns about its cross-cultural suitability, especially in Indigenous cultures. Reports suggest a bias in responding to the EPDS among Indigenous Australian women because of perceived consequences of mental health screening (Austin, Highet and the Expert Working Group, 2017).
What will this research add? A systematic review of the validity, reliability, and cultural safety of the EPDS and culturally driven adaptations used in an Indigenous Australian context. Evidence from the literature to guide the development of culturally safe and clinically effective perinatal screening practice.

3.2.3 Background

Perinatal mental health is a public health concern. Indigenous women in Australia have additional risk factors compared with non-Indigenous peers. A recent Western Australian study (Lima, Shepherd, Wong, O’Donnell and Marriott, 2019) found that between 1997 and 2013, over 34% of 43,383 (or 1 in three) Aboriginal babies were born to Mothers who had a hospital contact for mental illness in the five years prior, or the first-year post, birth, with the most common contacts being for substance related disorders, mood disorders and anxiety. The incidence of mental health contacts rose distinctly during this time period.

The immediate effects of sustained high levels of maternal cortisol (a feature of both antenatal depression and anxiety) include preterm birth (Duffy, Schminkey, Groer, Shelton and Dutra, 2018), and small birth size (Cherak, Giesbrecht, Metcalfe, Ronksley and Malebranche, 2018) with attendant risks for infant development (Frey and Klebanoff, 2015; 2016; Lundequist et al., 2015). Furthermore, women who experience antenatal anxiety are far more likely to experience severe postnatal depression compared to those without anxiety (Barthel et al., 2017; Austin, Tulley, Parker, 2007). When postnatal depression and anxiety are poorly managed there is a cumulative effect on other members of the Family (Myers and Johns, 2018; Beestin, Hugh-Jones and Gough, 2014). Early-life effects of postnatal depression and anxiety for the infant may include poor attachment and neglect (Parsons, Young, Rochat, Kringelbach and Stein, 2012) while subsequent effects can include cognitive, emotional, social and behavioural developmental impairments (Thompson, 2014; Posner et al., 2016; Strobel et al., 2019), and later susceptibility to adolescent psychopathology with potentially lifelong consequences (Hay et al., 2014; Davis and Sandman, 2012; Verbeek et al., 2012). There is also a high likelihood that parents self-regulate their distress through engaging in high-risk behaviours including alcohol or drug use (AOD) (Davis, Davis, Freed and Clarke, 2011). Combined, it is of utmost importance to both identify maternal perinatal distress in the form of depression or anxiety; and provide early interventions to assist women during the significant life events of pregnancy, childbirth and early parenting.

For Indigenous Australian parents, there are a number of risk factors for perinatal distress. These include concerns relating to poorer pregnancy outcomes including low gestational age with five times the rate of premature birth, and more than twice the rate of stillbirth (ABS, 2014). The risk of perinatal depression and / or anxiety further increases with the presence of significant complex, contextual factors such as historical trauma related to the Stolen Generations, as well as current trauma associated with continuing high rates of infant mortality, family violence and child removal (AIHW, 2017; Surkan and Patel, 2016). A recent study by O'Donnell, Taplin, Marriott and Stanley (2019) showed that Aboriginal infants had almost 9 times the risk of infant removal compared to non-Aboriginal children. This risk decreased but remained at twice the risk, once other infant and parent factors were considered. When Aboriginal infants who entered out-of-home care (OOHC) were compared to Aboriginal infants who had not, the highest risk factor for entering OOHC was maternal substance use which has seven times the risk, followed by maternal mental-health hospital contact. In this context, the risk of child removal is likely to be particularly salient for women during pregnancy, and especially when being asked about their mental health status – this constitutes potentially powerful situational influence or 'demand characteristic'[5] that may prevent women from feeling safe to access perinatal screening or may influence their responding during screening.

Cumulatively these effects constitute a considerable risk for perinatal mental health problems for Indigenous adults (ABS and AIHW, 2008). Indeed, a South Australian study (Weetra et al. 2016) reported that almost one in four Indigenous women reported 'high' to 'very high' levels of psychological distress using the Kessler-5 tool, in the first 12 months postpartum.

Despite these high risks for perinatal distress, and the knowledge that suicide rates amongst Indigenous Australian people are double that of non-Indigenous people (Australian Indigenous HealthInfoNet, 2019), Indigenous women are four times less likely than non-

Indigenous women to be screened using the EPDS (Gausia, et al., 2013; San Martin Porter, Macarena, Betts, Kisely, Pecoraro and Alati, 2019). Failing to address the social complexities and root causes of poor engagement with mental health screening means that outcomes are likely to continue to remain compromised. It is imperative that culturally sensitive and effective screening for Indigenous women becomes a public health priority.

The EPDS is widely used to screen for perinatal depression. It has been translated into more than sixty languages and is recommended as best practice in Australia (Austin M-P, Highet N and the Expert Working Group, 2017). However Cox (2017), one of the original authors of the EPDS, recently highlighted some of the limitations of the use of the instrument, and noted that "any screening scale must be acceptable to the Mothers themselves and to the health professionals who administer it", that we must "Be careful to check the validity of the scale *for the population of Mothers completing the EPDS*" [emphasis added] and " Establish its sensitivity, specificity, positive predictive value and optimal cut off points for the purpose of your clinical or research work" (p.789) He continues "sometimes the use of the EPDS …can be suboptimal—and occasionally dangerously misleading" (p789). This systematic review aims to contribute to evidence-informed practice by reviewing the effectiveness, validity, reliability, and cultural safety of the EPDS in the Indigenous Australian context including identifying the availability and suitability of any adaptations.

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[5] In Psychology, 'demand characteristics' are considered to be artefactual and often unconscious influences on actions. Responding to a survey according to social norms, is a form of demand characteristic.

3.2.4 Materials and Method

Methodology Rationale: The PICO (Population, Intervention, Comparison, Outcome) model (Cooke, Smith and Booth, 2012; Schardt, Adams, Owens, Keitz and Fontelo, 2007) was used as a framework for the systematic literature review search strategy (Table 3). PICO is deemed the most reliable basis for formulating a focused question to facilitate a literature search and has been adopted by the Cochrane Collaboration (O'Connor, Green and Higgins, 2008).

Table 3. The PICO Model Approach applied to the EPDS Systematic Review

PICO Model approach to finding clinically relevant evidence in the literature.		
P	Patient population problem	Perinatal mental health and wellbeing of Indigenous Australian women.
I	Intervention	Culturally relevant, safe and effective mental health screening and assessment tools for Indigenous Australian women within childbearing age group (aged approximately 13 – 50 years)
C	Comparison	PRISMA reporting for systematic reviews. Evaluation of EPDS against psychometric test parameters drawn from Groth-Marnat (2009): what constructs the test measures; standardisation; reliability; validity criteria; accuracy; replicability? Study quality: Assessed against identified theoretical frameworks and practical considerations e.g.: relevance of study question, explicit addressing of cultural considerations and ethical considerations, consideration of the impact of self- administration of the EPDS given demand characteristics and literacy challenges.
O	Outcome	Despite the uptake of use of the EPDS in Australia since late 1980s and widespread usage since the late 1990s, there is inadequate evidence of psychometric soundness of the EPDS when used in the Indigenous Australian context.
Question: What evidence exists to support the routine use of the EPDS for perinatal mental health screening with Indigenous and Torres Strait Islander Mothers?		

Source: Schardt et al., (2007).

Scope and terminology: Defining the scope of this review required theoretical consideration of contextualised perinatal screening needs, then deciding on language that was both constraining and inclusive enough to ensure the sensitivity and specificity of the search strategy.

Protocol: Methods of analysis and inclusion criteria were specified in advance and documented in a protocol which adhered to the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) (Liberati et al., 2009).

Specific eligibility criteria: Empirical studies specifically pertaining to perinatal mental health screening of Indigenous Australian women from peer-reviewed journals and grey literature from 1990 (EPDS uptake across Australia commenced early in the 1990s) through to January 2019. Studies where the EPDS had been modified in an Indigenous Australian context were included in the study.

Exclusion criteria: Cohort, population based, prevalence and longitudinal studies, program evaluations studies, needs analyses and other studies where perinatal mental health screening was a secondary focus e.g., where the study focus was on diabetes, obesity, infant health and wellbeing, models of care.

Information sources*:* Eight data bases were electronically searched: Scopus, BioMed Central, EBSCOhost- CINAHL, ProQuest, PubMed, OVID and PsychINFO. Grey literature was sourced from the International Marcé Society Conference proceedings, Indigenous Health InfoNet, Australian Institute of Health and Welfare (AIHW) and Telethon Kids Institute (TKI).

Search: The following search terms: (aborig* OR indigenous) AND (epds OR Edinburgh postnatal depression scale) OR (screen* AND mental health) AND (matern* OR antenatal OR postnatal OR perinatal) NOT cancer NOT hepatitis NOT infect* NOT cardi* NOT heart NOT educat* NOT audi* NOT infant OR paed* OR child* NOT diabet* NOT immigrant* AND lo.Exact ("Australia") AND peer reviewed journals.

3.2.5 Results

One hundred and fifty-eight results were extracted. Reviewing titles, electronic exclusion was employed to remove (where possible) further studies focusing on diabetes, cardiovascular health, obesity, infant health, program evaluations and locations external to Australia. This excluded 81 studies. Of the remaining 77 papers, duplications were removed resulting in 39 remaining studies. Bases on the same criteria, abstracts were read excluding a further 35 studies. Four studies remained. (Figure 9).

This systematic review shows that there is very limited evidence associated with the effectiveness of use of the EPDS with Indigenous Australian women. In fact, while the EPDS is considered best practice in Australia (Austin et al., 2017), no studies in our search strategy included psychometric or qualitative validation of the standard EPDS for Indigenous women.

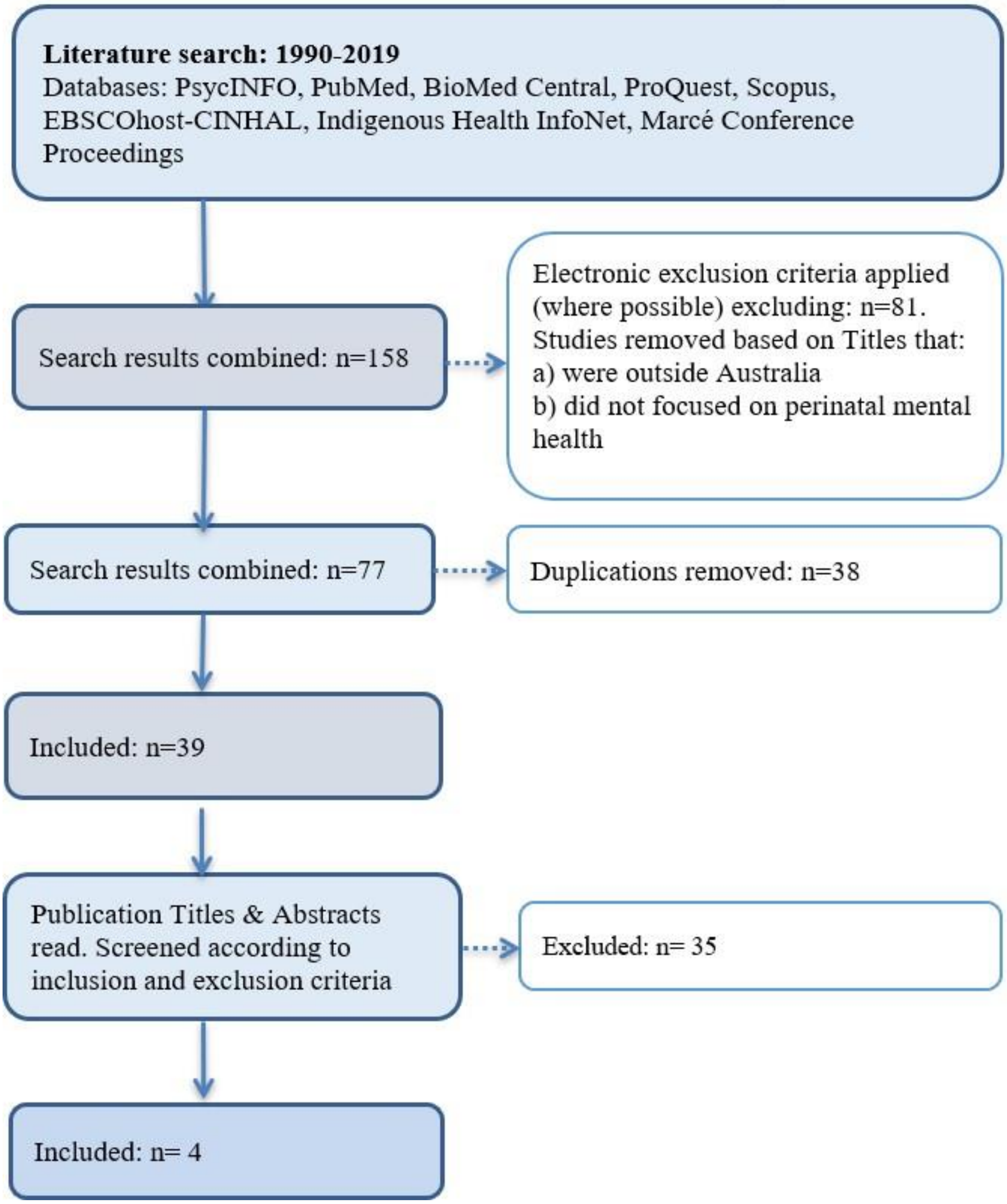

Figure 9. Inclusion Exclusion Flow Diagram adapted from PRISMA (Liberati et al, 2009)

Four papers (two studies) reported on modified versions of the EPDS for use with Indigenous Australian women (Features summarised in Table 4).

The Townsville Indigenous Islander Health Service, located in regional north-eastern Queensland, adapted the EPDS for local use by translating each question into Indigenous English (Campbell, Hayes and Buckby, 2008). A convenience sample of Aboriginal and Torres Strait Islander patients participated in this study in Townsville (n=181) and Mount Isa (n=25) comparing the adapted tool with the EPDS. Each participant received the adapted version first and then the EPDS was administered as a gold standard comparison. No difference was found between the scores. While there is no evidence supporting the use of the EPDS as a reliable comparative measure, there was a reported preference for the adapted version and suggestion from some Mothers and healthcare professionals, of difficulties in understanding some of the language in the standard EPDS (Campbell et al., 2008) and of biases in responding (Kotz, Munns, Marriott and Marley, 2016).

Two papers reported on the Kimberley Mums Mood Scale (KMMS) developed for use in the Kimberley region of Western Australia (WA). The first was a report on its development involving close community collaboration (Kotz, Pratt, Williams, 2011). The second was a validation study with a small convenience sample (n=97) (Marley et al., 2017). The KMMS included the addition of guidelines for psychosocial inquiry related to six specified domains (supports, stressors, anxiety, relationships, adverse childhood experiences and wellbeing/substance use). Question 10 of the EPDS which asks about 'harm to self' was also adapted in the KMMS to include an inquiry about 'harm to others'. Externalising expressions of anger by 'lashing out' was suggested as an additional sign of depression among Indigenous women (Kotz et al., 2016). This study compared KMMS results with a blinded mental health assessment by an Indigenous general practitioner as the gold standard. The KMMS alone had 87% sensitivity6 and 75% specificity7 with a positive predictive value of 54.1% and a negative predictive value of 94.4%. Sensitivity and specificity were defined as: high >0.90; moderate

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[6] Sensitivity - the proportion of people with the condition who have a positive result, true positive rate.

[7] Specificity- the proportion of people without the condition who have a negative result, true negative rate.

0.70–0.90 and low <0.70. With the added inclusion of psychosocial inquiry, results appeared promising within this specified remote area context. Visual prompts were used to replace Likert numerical scales. Here the use of colour, weather and faces specific to the Kimberley were locally understood and intended to convey increased meaning. Unfortunately, given the small sized convenience samples, the results did not adequately meet evaluation criteria that would support generalised use. Further, in terms of generalisability, both the KMMS and the north Queensland EPDS adaptations contain the use of regionally localised words which may be a cultural limitation in translating those adaptations for other language groups or areas.

A third study emerged from the grey literature search. An abstract from the MARCE Conference proceedings (2011) identified a further translation of the EPDS into two Indigenous languages from East Arnhem Land and Central Australia (Chapple, 2011). These translations (Yolgnu, Martha and Walpiri), used an approach described as ‘OneTalk’ technology which was developed in conjunction with Traditional Owners and elders in the Northern Territory in response to the need to communicate effectively. A ‘talking’ book includes the translated EPDS screens and information to support understanding and awareness of perinatal depression and screening. After contacting the author by phone, Chapple reported that anecdotally this adaption was well received in a small pilot of uncertain numbers. Insufficient funding prevented the project from continuing. Table 4 provides a summary of each of the modified EPDS studies.

Table 4. Summary of key feature of the modified EPDS studies

Author and Year	**Location**	**Tool**	**Research Aim and Design**	**Sample**	**Data Analysis**	**Results**
Campbell, Hayes, Buckby, 2008.	Queensland. Townsville Aboriginal and Islander Health Service (TAIHS) and the Mt. Isa Aboriginal Health Service (MTI)	Adaptations of the EPDS: 1. Townsville Aboriginal and Islander Health Service (TAIHS) 2. Mt Isa (MTI)	Aim: Evaluate reliability of the TAIHS and the MTI adaptations compared with standard EPDS version. Design: Descriptive and comparative analysis using Cronbach's alpha. Standard EPDS compared with (i) TAIHS (ii) MTI. Participants completed either of the adaptations and the standard EPDS both antenatally and postnatally (test/retest).	Aboriginal and Torres Strait Islander women from the TAIHS (N= 181) and Mt. Isa (N= 25) Inadequate sample size for reliability analysis i.e. test/retest N=45	Reliability of TAIHS and MTI compared to the standard EPDS was calculated using Cronbach's alpha. Rates of case detection used cut off score of 12 or above. Percentage of people identified as being at risk.	Both adaptations demonstrated robust internal consistency (inter-item correlation). Large dropout rates of antenatal and postnatal completion rates weakened reliability (test / retest consistency across time). Sample size completing both the EPDS and the TAIHS adaptation: a) antenatally N=24 b) postnatally N=9. Some suggestion of difficulties understanding the language used in the EPDS. Limitations: Cut-off scores were assumed as no validation was undertaken. No comparative evaluation (with the EPDS) for the MTI adaptation was reported.
Chapple 2011	Northern [8]Territory (NT). East Arnhem Land and Central Australia	Audio-visual translations of the EPDS into Yolgnu Martha and Walpiri languages.	Aim: To develop a new culturally considered approach to perinatal mental health screening. Develop 'talking' posters and screening tool (EPDS translated into language). Design: Community participatory action (CPAR) approach. An operational response to identified perinatal mental health barriers	Consultation with experts: Aboriginal women and NT Perinatal mental health reference group	Consultation with the Community and NT Perinatal Mental Health reference group.	Developed over 3 years with local women using OneTalk technology. Anecdotal evidence reported the project was well accepted as a screening and a mental health literacy tool. The program was heading towards a pilot in East Arnhem Land and Central Australia. Limitation: No formal evaluation. Discontinued funding prevented project continuation.

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[8] Kotz and Marriott are authors of the current paper.

Table 4. Summary of key feature of the modified EPDS studies (continued)

Author and Year	**Location**	**Tool**	**Research Aim and Design**	**Sample**	**Data Analysis**	**Results**
Kotz et al., 2017[1]	Western Australia (WA) Kimberley Region.	Kimberley Mums mood Scale (KMMS)	Aim: To develop a new culturally considered adaptation of the standard EPDS - (KMMS). Design: CPAR using yarning as a methodology to gather data and thematic analysis.	Workshops and focus groups with midwives CHNs and AHWs (n = 72). Initial community focus groups (n = 48). Further iterative process (n = 52). Total Kimberley women from 8 language groups: n = 100.	Thematic analysis of the qualitative data collection. The systematic, repetitive, and recursive iterative process in adapting the tool increased reliability of the development process.	Key themes and barriers to perinatal mental health and screening were identified. The KMMS may provide a culturally safe means for perinatal mental health screening. Some suggestion of difficulties understanding the language used in the EPDS and of biases in responding through fear of consequences. Limitation: Lack of validity evidence weakens this conclusion.
Marley[9] et al., 2017	Kimberley, WA.	KMMS - modified EPDS with visual Likert scale (Part I) and psychosocial inquiry (Part 2).	Aim: To determine reliability validity and acceptability of the KMMS when compared to assessment from a blinded clinical expert. Design: Cross-sectional approach (ie: looks at prevailing features in a given population at a single point in time, without manipulating variables).	Consenting Aboriginal women (n = 91) from 15 Kimberley sites providing perinatal care.	Mixed-methods approach. Internal consistency of KMMS (Part 1) measured with Cronbach's alpha. Identified risk using i) Part 1 alone and ii) overall KMMS risk (Part 1 and 2 combined) was compared to blinded reference standard GP assessment. This was determined from receiver operating characteristics (ROC) curves. Acceptability of KMMS used frequency of responses on questionnaire and interview.	KMMS may be an effective tool for identifying Kimberley Aboriginal perinatal women at risk of anxiety and depression. It appears more accepted by clinicians compared with the EPDS. KMMS seems to be a culturally safe tool. It shows internal consistency, reliability, and detected women with moderate to high risk of anxiety or depression. Some suggestion of difficulties understanding the language used in the EPDS. Limitation: Women were selected and invited to participate which may have biased results.

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[9] Kotz is second author of this paper

3.2.6 Discussion

Despite the well-established high risk of mental health challenges for Aboriginal and Torres Strait Islander Mothers, there is an absence of research investigating the psychometric properties of, or indeed qualitative experiences of, the standard EPDS when used in this context. The three adaptions identified in this systematic review search had all been developed for use in remote Australian community settings.

These three adaptations highlight some potentially important differences in the symptom profile of depression in the perinatal period (specifically, the importance of anger as a core symptom) and the importance of considering contextual factors in making sense of symptomatology. The fourth study that was undertaken in Yolngu, Martha and Walpiri languages highlighted the usefulness of images and audio to support mental health literacy within a cultural context, through fostering understanding and engagement. Whilst these are valuable insights, the four studies are very preliminary and do not provide a credible evidence-base to guide broader practice in perinatal mental health screening for Indigenous and Torres Strait Islander women.

The original intent of screening using the EPDS was as an adjunct to a psychosocial assessment through listening to the woman’s story (Cox, 2017). Increasingly questions are being raised around deficiencies in the current routine use of EPDS, in translations in different cultural contexts, in cultural adaptations and in the validation processes (Cox, 2017). This is particularly relevant among peoples from culturally diverse and low/lower- middle income countries (Thombs et al., 2015; Shrestha, Pradhan, Tran, Gualano and Fisher, 2016). Many of these communities share similar features and health statistics with Indigenous Australian communities. Cross cultural questions have been raised about the relevance of some items, differences in conceptualising of mental health (Brave Heart et al., 2011) and inconsistencies in cut-off scores (Matthey et al., 2006). These disparities raise doubts about the assumed level of confidence in using the EPDS as a routine screen standalone (Chan et al., 2021).

Many antenatal guidelines recommend the use of the EPDS as a singular risk screen (Pregnancy Care (2018b), FSH Obstetrics and Gynaecology and Women, Children and Newborn Services, 2016; Department of Health Western Australia, 2016). Deeper psychosocial inquiry may easily be overlooked in the current time and resource-poor settings.

There are strong assumptions made about screening instruments and their capacity to identify vulnerable individuals. These have far-reaching implications for clinical practice, public policy and research particularly in relation to Indigenous Australian parents. Due to these potentially significant impacts, the NHMRC GRADE guidelines emphasise that poor evidence should not be elevated to the status of best practice (Andrews et al, 2013). Instead, other factors should drive policy and clinical decision making whilst the necessary validation studies are undertaken as a matter of priority.

There is a challenge for health care providers to use a culturally competent assessment process that includes a) training on the relevance and need for culturally safe assessments b) not relying on a single measure c) using contextualising, reflective documentation based on interview and observation; and d) reporting results using cultural explanations that avoid mental health labelling (Langham et al., 2017).

Where to from here? Should we pursue an agenda of psychometric and cultural validation of the EPDS? Should new measures be commissioned? When it comes to using standardised or adaptations of standardised tools such as questionnaires and rating scales with Indigenous people, the evidence and opinions are mixed. On the one hand, some have pointed out that the validity of instruments designed for non-Indigenous people may not carry across to Indigenous people. Indeed, the thoughtless use of conventional methods may be harmful. Hunter (2002) has warned that ‘well-intentioned actions based on simplistic understandings of Indigenous perspectives continue to compound, rather than alleviate, the ongoing suffering and injustices experienced by Indigenous Australian people’ (Hunter, 2002, p578). Additionally, psychometric properties whilst important are only valuable if the consequences of the results serve the purpose for which they were intended (Messick, 1993); in this case improving outcomes for vulnerable Indigenous Mothers, children and families. Positive outcomes (such as improved rates of mental health) have not been evidenced since the introduction of routine antenatal screening using the EPDS in the mid-1990s and postnatal screening in 1997 throughout WA (Hutchinson and Joyce, 2016; AIHW, 2017). Minimally, the International Test Commission (ITC) guidelines for test adaptation, state that (i) it should not be assumed that tests used out of context are effective, rather it must be established that it is so; and further (ii) that a systematic approach to adaptations or translations should be followed to maximise the prospects of the test maintaining its effectiveness (Cheung, 2016). Pragmatically, developing new tests is challenging in relation to time, cost and resource-commitment. In the context of a mental health crisis in Indigenous Australian communities and poor maternal and child health outcomes among this population, an interim position may be to evaluate the psychometric properties of the EPDS when used in this context, or of other existing mental health scales, such as Strong Souls (Thomas, Cairney, Gunthorpe, Paradies and Sayers, 2010) or the Here and Now Aboriginal Assessment (HANAA) (Janca, Lyons, Balaratnasingam, Parfitt, Davison, Laugharne, 2015), which have been developed for Indigenous adults but have not been applied to the perinatal context.

In summary, there is no doubt that the EPDS is the most commonly used screening tool in the perinatal period. However, there is currently no evidence to support its use with Indigenous Australian women. Given the presence of complex and intergenerational risk factors, an *effective* perinatal mental health screening process is a public health priority that will save lives and families.

3.2.7 Conclusion

A premium should be placed on addressing this evidence-gap. It seems that a tripartite approach is warranted that focuses on: (i) evaluating the EPDS in context (ii) evaluating other Indigenous mental health screeners when applied to the perinatal period and (iii) beginning the longer-term task of designing a more suitable instrument in collaboration with Indigenous communities themselves. This process should be informed by a codesign with Indigenous women and midwives and reflective of the importance of a contextualised, culturally safe instrument to support women in distress at this most vulnerable of times.

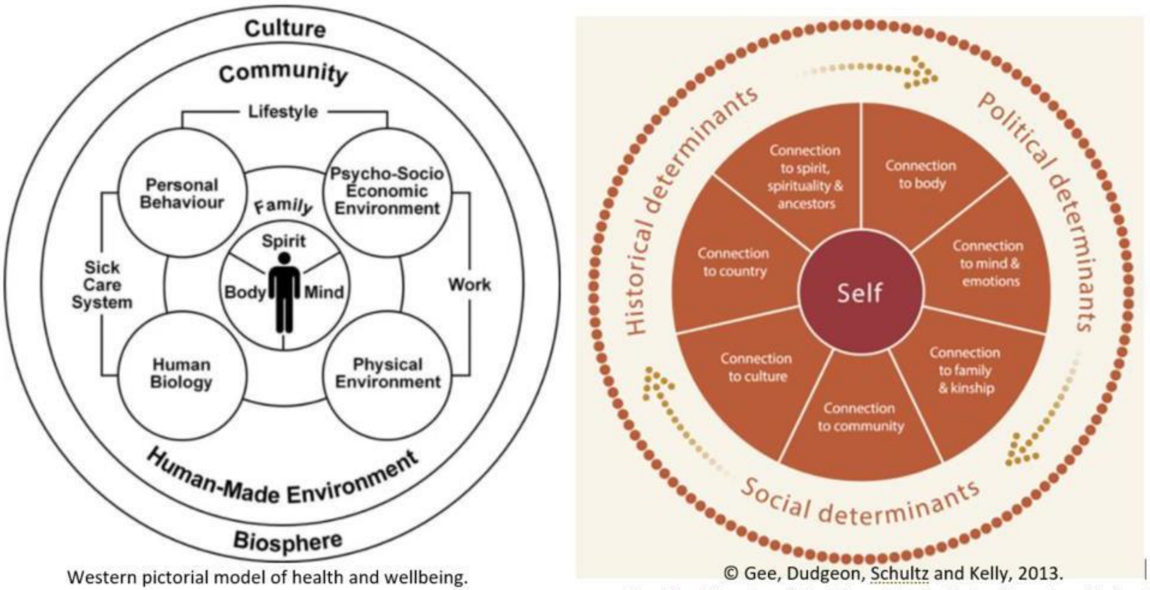
Chapter 4. Literature Review and Cultural Review of Mental Health Measures.

4.1 Chapter overview

Kotz, Marriot & Reid (2021) reported in chapter 3, indicated that there was little empirical data outlining the experience of EPDS screening or the burden, consequences and expression of perinatal depression and anxiety for Aboriginal Mothers. Progress was made towards addressing inequity in mental health screening with Aboriginal Mothers through local adaptations of the EPDS. However, each tool was population specific and focused on western notions of mental disease and risk identification. Each adaptation of the EPDS included promising elements (yarning across specified domains of inquiry, audio and visual resources and adapted language) however, there was no evidence that the use of a decolonised approach to SEWB or strengths-based inquiry was adopted.

The review in Chapter 3 concluded that "It seems that a tripartite approach is warranted that focuses on: (i) evaluating the EPDS in context, (ii) evaluating other Indigenous mental health screeners when applied to the perinatal period, and (iii) beginning the longer-term task of designing a more suitable instrument in collaboration with Indigenous communities themselves." (Kotz et al., 2021). Exploring Indigenous mental health screeners other than the EPDS also provides an opportunity to broaden the conceptualisation of mental health to include a definition that is more culturally aligned, specifically, incorporating social and emotional wellbeing (SEWB) models.

Western concepts of mental health are significantly different to those of Australian Aboriginal peoples. Recognising this, the concept of 'social and emotional wellbeing' (SEWB) emerged to encourage clinicians, and Aboriginal people themselves, to consider mental health holistically (Garvey, 2008). Gee, Dudgeon, Schultz, Hart and Kelly (2014) describe holistic health for the Aboriginal concept of ‘self’ as recognising a balance between the seven inter-connected spheres of the body, mind/emotions, Family/Kinship, community, culture, country, and spirituality. Here the description of the ‘holistic self’ is inherently different from standard biomedical Western concepts of the ‘individualistic self’ (Figure 10).



Western pictorial model of health and wellbeing.
Department of Public Health, City of Toronto.

© Gee, Dudgeon, Schultz and Kelly, 2013.
Aboriginal Peoples pictorial model of self, health and wellbeing. In
National Strategic Framework for Aboriginal and Torres Strait Islander

Diagram 1. Different models of health and wellbeing according to Western and Aboriginal Peoples concepts

Figure 10. Different models of health and wellbeing according to Western and Aboriginal peoples concepts.

Thus, for Australian Aboriginal peoples, mental health is holistic, containing both cultural and spiritual elements. Any concept of ‘mental ill-health’, including in the perinatal period, will need to take into account the entirety of an Aboriginal person’s experience across all seven inter-connected spheres. Measures that capture this may have an inherent advantage over the EPDS for clinical purposes. For research purposes they may have potential as a yardstick against which EPDS adaptations can be validated.

Hence, this systematic literature review determined the extent and efficacy of mental health and wellbeing screening tools used with Australian Aboriginal people.

In keeping with the decolonising methodological commitment, this literature review was paired with a cultural review of key mental health measures to look for points of convergence or divergence in findings resulting from traditional research processes (ie. systematic review) and Indigenous research methods which, in this instance, constituted yarning amongst Elders about the cultural safety and potential suitability of these measures for application to the perinatal period.

4.2 Perinatal mental health screening among Aboriginal Mothers. A psychometric review of Aboriginal symptoms measures and risk measures.

4.2.1 Current study

This study aimed to undertake a systematic review of culturally safe, psychometrically sound, mental health and SEWB assessments used with Australian Aboriginal women in the perinatal period.

Culturally derived measures were privileged as this prioritises respect for community expertise and recognises the importance of collaboration and 'local ownership' over the process. Additionally, culturally derived measures enhance two-way understanding and the likelihood of success where there is a complex cultural interface between the medicalised health system and Aboriginal culture (Coe, 2020; Dudgeon et al., 2020; Kotz et al., 2016).

An initial search of the literature however, failed to find any culturally derived measures of *perinatal, postnatal* or *antenatal* mental health. Therefore, the search (and study) was broadened to investigate community-derived or adapted generic (ie. not perinatal specific) assessment or screening tools that had been successfully established in an Australian Indigenous context, and which could be applicable to the perinatal period. Studies included in this review related to both mental health and SEWB among Aboriginal Australian adults, as this encompassed important similarities and differences in language, concepts and other ideas.

A key critique of health studies related to Australians Aboriginal peoples is the poor quality of the research methodology. The use of screening instruments has far-reaching implications for clinical practice, public policy and research particularly in relation to Aboriginal parents. There is an assumption that they can accurately identify vulnerable individuals. Due to these potentially significant clinical impacts, the NHMRC GRADE Guidelines emphasise that poor evidence should not be elevated to the status of best practice (Andrews et al, 2013). This study undertook not simply to synthesise the available literature but to evaluate the strength of the methodologies utilised in each study. Only then can there be confidence in the clinical application of these findings, and in the claim of evidence-based practice.

4.2.2 Materials and methods

Methodology Rationale: The PICO (Population, Intervention, Comparison, Outcome) model (Schardt, Adams, Owens, Keitz & Fontelo, 2007) was used to design and frame the research plan and question and design the systematic search strategy (Table 5) (Cooke, Smith and Booth, 2012; Schardt et al., 2007). This model provides the capacity for formulating a well-focused question to facilitate a literature search. It is deemed the most reliable basis for a search strategy and has been adopted by the Cochrane Collaboration (O’Connor, Green, & Higgins, 2008).

Table 5. The PICO Model Approach to the Systematic Review

PICO Model approach to finding clinically relevant evidence in the literature.		
P	Patient population problem	Australian Aboriginal adults.
I	Intervention	Culturally relevant, safe and effective mental health screening and assessment for Australian Aboriginal women within childbearing age group (aged approximately 13 – 50 years)
C	Comparison	PRISMA reporting for systematic reviews. Evaluation of psychometric test parameters drawn from Groth-Marnat (2009): what constructs the test measures; standardisation; reliability; validity criteria; accuracy; replicability? Decisions regarding analysis and robust nature of the study assessed against identified theoretical frameworks and practical considerations e.g.: cultural considerations, relevance and ethical considerations, self-administration, literacy.
O	Outcome	Applicability for Australian Aboriginal Mothers in the perinatal period
Question: What psychometrically sound and culturally safe mental health and wellbeing screening tools are available that may have applicability for Australian Aboriginal Mothers in the perinatal period?		

Source: Schardt, Adams, Owens, Keitz & Fontelo, 2007

Scope and terminology: Defining the scope of this review required theoretical consideration of the needs for contextualised perinatal screening, then settling on language that was both constraining and inclusive enough to ensure the sensitivity and specificity of the search. Included was empirical research on:

1. Australian Aboriginal adaptations of adult mental health screening tools.
2. SEWB assessments developed with, and used among, Australian Aboriginal populations, which reflect the importance of cultural safety, security and assessment/screening from a strength base.

The search was widened, in a stepwise and responsive process, to consider non-specific mental health and wellbeing screening and assessment tools and processes that have been used in an Australian Aboriginal context with (i) women, then (ii) families, then (iii) men. The objective was to review the psychometric properties of these tools when used in this context and to consider conceptually, the likelihood that they would be suitable for perinatal mental health screening and that they would be culturally relevant and safe as described in Scope and Terminology below.

Objectives: The review included evaluation of each tool or assessment process for viable evidence of:

- Psychometric properties of each tool when used in an Australian Aboriginal context
- Consideration of cultural bias, relevance and safety, and, in particular, congruence with current cultural models of mental health and wellbeing, specifically:

  (i) having a strength focus rather than a deficit focus

  (ii) item/domain selection seems culturally relevant
- Consideration of accessibility to a population with risk factors for low levels of formal education, specifically:

  (i) accommodates literacy demands

  (ii) adopts use of supportive images
- Capacity for interdisciplinary application in the perinatal period among Australian Aboriginal Mothers.

Methodology: This review sought to identify, appraise and synthesize results from all relevant studies of the identified tools/processes, and to arrive at conclusions regarding what might constitute a culturally relevant and effective approach to perinatal mental health screening for Aboriginal Mothers.

Protocol: Methods of analysis and inclusion criteria were specified in advance and documented in a protocol which adhered to the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) (Liberati, Altman, Tetzlaff et al, 2009).

Eligibility: These terms were included for specified reasons:

- 'Mental health': denoting emotional and social well-being and increasingly interchangeable with mental illness without specific suggestion of overt pathology or diagnosis.
- 'Social and emotional wellbeing': denoting a broader construct relating to socio-historical, environmental and personal choices that influence mental health.
- 'Wellbeing': denoting self-esteem, confidence and empowerment.
- Australian Aboriginal or Indigenous Australian adults
- Young people: those of potentially reproductive years including the World Health Organisation (WHO) definitions of 'young people' as those aged 10–24 years, 'youth' as those aged 15–24 years, and 'adolescent' as those aged 10–19 years.

Specific Eligibility Criteria: Empirical studies pertaining to assessment or screening of mental health or well-being among Aboriginal Australians adults from peer-reviewed journals and grey literature from 1996 – 2016. An additional search was undertaken from 2016-2019 to update the review.

The commencement of eligibility criteria from 1996 followed the establishment of the National Inquiry into the Separation of Aboriginal and Torres Strait Islander Children from Their Families. By 1996 the Bringing Them Home Report had been tabled and a Reconciliation Policy developed. Shifts in perceptions and documentation of the health and wellbeing of Australian Indigenous people was emerging.

The following search terms were applied to Titles and Abstracts between 1996- 30th

July 2016: mother* OR maternal OR antenatal OR postnatal OR perinatal OR paternal OR father* AND "mental health" OR wellbeing OR "social and emotional wellbeing" OR psych* AND aborig* OR indigenous AND screen* OR assess* OR tool* OR scale. Exclusion criteria anywhere in text: NOT cancer NOT hepatitis NOT infect* NOT cardi* NOT heart NOT educat* NOT audi* NOT infant OR paed* OR child* NOT diabet* NOT immigrant*. Geographical inclusion: Australia only

Information sources: Eight data bases were searched electronically: Scopus, BioMed Central, EBSCOhost- CINAHL, ProQuest, PubMed, OVID, PsychINFO. In some cases, follow-up contact with authors of selected publications or unpublished grey literature was made by phone or email to determine subsequent developments, stages of research or implementation. Grey literature was sourced from the International Marcé Society Conference proceedings, the Indigenous Health InfoNet, the Australian Institute of Health and Welfare (AIHW) - incorporating the Closing the Gap Clearinghouse, the Telethon Kids Institute (TKI) and the Australian Bureau of Statistics.

Search – refining the process: The aforementioned selection criteria frequently resulted in the extraction of either too few or too many items. Subsequently the search within each database was undertaken through several broken-down applications of search terms.

The first search was too general extracting 2,245 results from PsychINFO in Abstracts using 20 individual search terms separated by OR qualifiers. The second search was too limiting returning 13 results using terms ("social and emotional wellbeing" OR SEWB OR wellbeing OR "mental health" OR psych*) AND (screen* OR tool OR assessment OR scale) AND (aboriginal OR indigenous).

Subsequently split search combinations of the previous search terms were applied. The first used ("mental health" OR wellbeing) AND (aborig* OR indigenous) AND (screen* OR assess*) which obtained 43 results. The second Abstract search extracted 18 results using (antenatal OR postnatal OR perinatal OR mother* OR maternal OR father* OR paternal) AND (indigenous OR aborig*) AND (screen* OR assess*) NOT (educat*) NOT (infect* OR hepat*) NOT (HIV) NOT (audio* OR hearing) NOT (migrant* OR immigra*) NOT (infant* OR baby) AND lo.Exact("Australia") AND peer reviewed journal (yes). A third and final search extracted 215 results using (mother* OR maternal OR antenatal OR postnatal OR perinatal OR paternal OR father*) AND (aboriginal OR indigenous) AND ("mental health" OR wellbeing) NOT educat* NOT (infect* OR hepat*) NOT (HIV) NOT (audio OR hearing) NOT (migrant* OR immigrant*) AND lo.Exact("Australia").

Continued search applications using break-downs of terms in each data base extracted better results until publication saturation was reached ie: return of no new publications/data using search term combinations.

Study selection: Abstracts were read and screened for search terms and relevance by the author (R1), and independently verified by two other reviewers (R1 and R2). Exclusions were also reviewed by R2 and R3. Using an inclusion rather than exclusion approach, if three or more of the selection criteria search terms were present in the title or abstract and if the article appeared relevant then it was retained. Duplicate articles were removed. The remaining publications were included for the joint researcher systematic screen, then if included, the subsequent data synthesis. Authors were contacted by email or telephone for further information or clarification. A small number of articles could not be accessed due to institutional unavailability, removal from stated URLs, inability to access government reports or, as in one case, a permanent embargo of a PhD.

Appraising results: The Critical Appraisal Skills Program (CASP) (CASP, 2020), were adapted to critically assess validity, reliability, importance, usefulness, cultural and ethical considerations within the context of screening Aboriginal Australian adults. Each study was assessed using the CASP Screen to determine their worth for further appraisal. The original three CASP screening questions (CASP, 2020) were retained and a fourth question included to assess the research potential to inform perinatal screening, appraised the potential value of the outcomes to inform mental health and wellbeing assessment of Aboriginal Mothers (Table 6).

Table 6. Screening questions to determine which studies progressed for further appraisal using the relevant adapted CASP Appraisal tool.

	Question	**HINT**	**Rating**		
1	Was there a clear statement of the aims of research?	What were the goals? Why was it important? How relevant is it?	Yes	No	Can't tell
2	Is the research methodology appropriate?	Does it seek to interpret or illuminate actions or subjective experiences of participants? Is the research the right methodology for addressing the goal?	Yes	No	Can't tell
3	Is a reliable measure being employed to support the research?		Yes	No	Can't tell
4	Does the research discern or illuminate issues pertaining to Aboriginal Australians SEWB/mental health?		Yes	No	Can't tell
Worth continuing? YES NO 🗑					

In appraising potential value for use in the perinatal period, of the tools in each study, consideration was given to both cultural and mental health issues that drove the original development of the EPDS (Cox et al, 1987). Regarding cultural considerations, strength-based items were deemed important as was assessing the accessibility of supportive Family as both are deemed protective. In relation to the latter issue, it was important to be mindful of the over-representation of somatic symptoms that may be atypical (and therefore constitute clinical signs) in non-pregnant populations, but which are typical in pregnant populations and/or following childbirth. For example, changes in weight and appetite, aches, pains or tiredness.

Designed to inform quality screening practices within the Aboriginal perinatal mental context, this analysis process provided quantitative assessment against a number of qualitative criteria CASP checklists, originally designed as educational tools provide clear prompts to guide a comprehensive appraisal against specific criteria for varied research methodologies. Each original criterion was assessed with either YES, NO or CAN'T TELL responses. Given the preliminary state of the current evidence base in this study a scoring system was applied to determine levels of evidence quality. Subsequently each question contains prompts for consideration and is weighted equally with scoring from 0-5; 0 indicated impossible to say, and 5 indicated numerous instances of explicit evidence according to the following criteria:

- Explicit evidence: the element described in the criteria being assessed was clearly stated and distinctly expressed.
- Implicit evidence: it could be inferred or established that the author(s) descriptions, arguments etc. were consistent with the intent of the elements described in the criteria being assessed.

A graded assessment criterion was developed by the researchers using a rating scale adapted from CASP appraisals (Table 7).

Table 7. Rating scale for the Appraisal Criteria for adapted CASP appraisals.

Score	Scale of Appraisal
5	YES, explicitly stated with solid evidence or numerous examples
4	YES, limited evidence of detail explicitly stated but evidence implied
3	YES, minimal detail explicitly stated with minimal evidence implied
2	YES, not explicitly stated with minimal evidence implied
1	NO, not stated or implied
0	Impossible to say

Scores were totalled providing an overall rating of the relative strength of evidence available to inform perinatal mental health screening practice among the Australian Aboriginal population.

Two appraisal tools were adapted from the original CASP checklists. The first adaptation amalgamated the CASP 11 question Clinical Prediction Rule checklist with CASP Cohort Study 12 question checklist to appraising *validation studies* (Appendix A). The second amalgamated the CASP Case Control Study question checklists with the CASP Qualitative Research question checklist to appraise the combination studies (mixed methods, qualitative, cohort, etc.) Table 8 and Table 9 contain each of the adapted Appraisal Tool questions that are reported against in the results table. Clarifying hints for each assessment question are in Appendix B. The qualitative studies, whist they are reported on below, were not appraised using these methods.

Table 8. Criteria used to appraise Combined Studies that progressed through the 4-question screen (adapted from CASP Checklists, 2020)

Questions numbered according to reported results		**Rating Scale**
5	How appropriate was the research design for the population group to address the aims of the research?	Rating scale 5-0
6	Were cases recruited in an acceptable way? Was data collected in a way that appropriate addressed research aims?	Rating scale 5-0
7	Was the data collected in a way that addressed the research issue?	Rating scale 5-0
8	Have ethical issues been taken into consideration?	Rating scale 5-0
9	Are the research methods used to construct &/or measure the tool clearly described?	Rating scale 5-0
10	Was the data analysis sufficiently rigorous?	Rating scale 5-0
11	How valuable is the research?	Rating scale 5-0
12	Is there a clear statement of findings?	Rating scale 5-0

13	How valuable is the research in consideration of Australian Aboriginal adults perinatally?	Rating scale 5-0

Table 9. Criteria used to appraise Validation Screening Tools that progressed through the 4-question screen (adapted from CASP Checklists, 2020)

Questions numbered according to reported results		**Rating Scale**
5	Have ethical issues been taken into consideration	Rating scale 5-0
6	Are the statistical methods used to construct & validate / measure the tool clearly described?	Rating scale 5-0
7	Can the performance of the rule be calculated?	Rating scale 5-0
8	How precise was the estimate of tool results?	Rating scale 5-0
9	Would it be reliable & results interpretable if used with your people?	Rating scale 5-0
10	Is the tool acceptable for Aboriginal or Torres Strait Islander adults?	Rating scale 5-0
11	Would results of the tool alter your decision about management of the person, or the level/type support provided?	Rating scale 5-0

The cultural assessment criteria were based on Coffin's descriptors (2007) of cultural security where cultural security is the final stage one strives for on a continuum from cultural awareness and cultural safety. Cultural security is not an optional strategy. Nor is it solely the responsibility of individuals. Rather it involves system levels of involvement. Cultural security is proposed to effect change in all elements of the health system workforce (Coffin, 2007).

The ethical assessment criteria for research purposes are captured in the NHMRC Values and Ethics - Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research (2018).

Studies were then objectively appraised determining level of evidence drawing on the key psychological assessment evaluation criteria presented by Groth-Marnat (2009) (Table 10).

Evidence was graded as: YES (Y)-credible attempted to establish stated type of validity/reliability; NO (n)-no clear attempt to demonstrate stated type of validity/reliability.

Table 10. Psychological Assessment Evaluation Criteria used to assess Validation Studies. (Groth-Marnat (2009)

Evaluation measure	**Brief description**
Reliability measures	The degree of stability, consistency, predictability, and accuracy of the test
Stability	The extent to which the psychological processes/phenomenon measured by a test are repeatable over time.
Measurement error	The difference between a measured value and the true value, giving an indication of the possible degree of error or uncertainty.
Test-retest reliability	The degree of consistency of test outcomes/cores, when a test is administered and then repeated over time.
Parallel forms - reliability	The degree to which measurements produce similar results when using parallel forms of a test administered at several intervals, on the same individual(s).
Inter-rater or observer reliability	Measurement of the degree of agreement among independent observers who rate, code or assess the same material/test.
Internal consistency	Measurement of how test items in a test correlate against each other. This identifies the internal
	consistency of a test with one use rather than its stability over several administrations.
Cultural reliability	Is the reliability of the test originally developed for one culture equivalent in another culture?
Validity measures	The degree to which a test measures what it intends to measure and provides clinically useful information.
Face validity	Subjective judgement of the test, made by test users, that the test “looks like” it measures what it claims.
Content validity	The extent to which content of a test covers all relevant aspects of the subject/construct being measured.
Concurrent criterion validity	Compares test scores with performance on an outside measure, where both the test and the outside measure were taken at the same time (or approximately the same time.

Predictive criterion validity	Compares test scores with performance on an outside measure, where the performance measures are taken sometime after the test completion.
Construct validity	Assessment of the degree to which the test actually measures what it claims to be measuring (ie. the theoretical construct or trait). What is the degree of sensitivity (true positive identified) and specificity (true negative identified) of the test?
Convergent construct validity	The degree to which the test demonstrates high correlations with other variables that are theoretically similar.
Discriminate construct validity	The degree to which the test demonstrates low or negative correlations with other variables that are theoretically dissimilar to the test
Factor analysis	Factor analysis is a technique used to identify the degree of commonality between a large number of different variables, combine the common variables and therefore condense these into a smaller number of variables/factors.

PRISMA was adhered to as the reporting guide (Moher et al., 2015). (Results section Table 11).

Inter-rater reliability: Five reviewers contributed to data analysis and interpretation, ensuring rigour and trustworthiness. The first two, R1 (the author) and R2 undertook the primary data analysis. R1 independently read all papers appraising each paper and coding. R2 similarly read and appraised studies. Ratings were considered acceptable if the overall score variance was less than four (4) points out of a total 35 points from 7 questions. Data collection process: R1 systematically sourced and screened all data, erring on inclusion, using the protocol described. Exclusions were reviewed by R2 and R3.

Authors were contacted by email or telephone for further information or clarification. Ultimately, the results from appraising each study within each category informed the discussion and results.

4.2.4 Results

Initially 2,530 papers were selected from the electronic data base literature search. Following the Prisma Exclusion Flow Chart (Figure 11), 137 papers were selected for screening appraisal. The four screening questions eliminated a further 66 papers based on the following exclusion criteria:

- Commentaries ie: not empirical research
- Varied authors reporting data from the same research with little new data in the findings
- Failure to differentiate or focus on Aboriginal populations
- Irrelevancy
- Inaccessible publications

A total of 37 studies were appraised in this analysis. Of these, 36 were combination of mixed methods, cohort studies etc. Following the adapted CAPS screen, 18 were retained for further analysis. Thirty-five (35) were validation studies, were screened using the adapted CAPS screen and 19 of these were retained for further appraisal. The appraisal of validation studies included an additional psychometric properties assessment. A number of these studies were not primarily validation studies; however, they were included because of the incorporation of exploratory factor analysis (EFA), predictive evaluations or in one case a small, randomised control trial (RCT). This RCT (Nagel et al., 2008) included a variety of culturally considered features such as the use of images and yarning, which informed the issues of interest. Tables 11, 12, & 13 summarise the studies and aspects of the appraisal.

Inter-rater data appraisal comfortably resulted in consensus and Inter-rater assessment of Psychometric Properties Appraisal was also unequivocal.

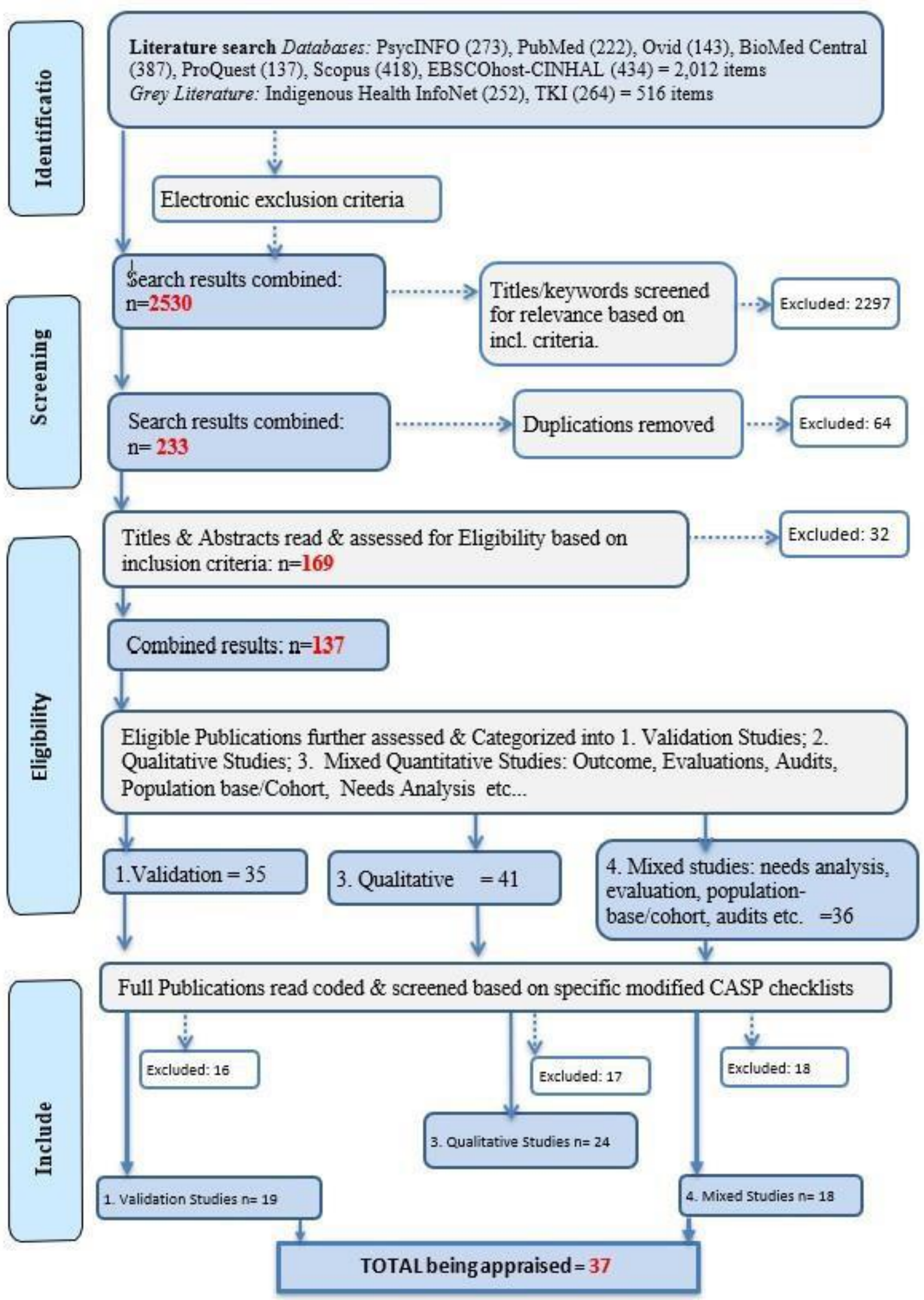


Figure 11. PRISMA Exclusion Flow Chart (Search from 1996-2019)

Some noteworthy attempts are being made to address the paucity of research relating to cultural discrepancies embedded in screening practices and in supporting the mental health and well-being of Aboriginal Australians. Twelve bespoke screening/assessment tools were identified developed specifically for use among Aboriginal populations in remote area communities. Whilst all tools include elements of assessment for SEWB, only 3 were designed specifically for SEWB or mental health among Aboriginal people.

Risk of bias: Assessing outcome reporting bias was attempted. Blinding participants and researchers can be difficult for these types of studies. Therefore, a general rating system was applied rating studies as either: High Risk (H) - case studies, pre and post-test outcome studies, comparative studies, very small number studies, poor quality studies; Medium Risk (M) - cohort studies, case-control studies, non-randomised studies, comparative studies with concurrent controls and good quality studies; and Low Risk (L) - high quality randomised control trials (RTCs). See Tables 11,12 and 13. Importantly, it should be noted that some studies, such as large population-based studies, contained large numbers with a low risk of bias and consistent findings, but may not have had significant positive clinical impact or outcomes for the targeted high-risk Aboriginal Mothers. Other studies, such as one randomised trial (RCT), had a small sample size and a moderate risk of bias. However, it has potential for larger positive impact through its focused use of culturally considered applications such image prompts, yarning and centered locus of control around the client throughout the assessment process.

Table 11. Combined Studies Appraisal form (adapted from CASP Checklist). (Cohort, Needs Analysis, Audits, Outcome, Prevalence, Population-base, Comparative, Evaluations)

Graded ASSESSMENT QUESTIONS:
5-Yes Absolutely Explicitly Stated in Explicit Detail; 4= Yes Explicitly Stated in Most Details; 3= Explicit Stated in Some Detail; 2= Not Explicitly Stated but Implied; 1=Can't Say , 0=NO, Not stated nor implied.

Author	**Title**	**Study type**	**Tool**	**Type of Research**	**Application or Source**	**Sample Population**	**Location**	**Q5**	**Q6**	**Q7**	**Q8**	**Q9**	**Q10**	**Q11**	**Q12**	**Q13**	**Score out of 45**
Berry et al (2012a)	Preliminary development & content validity of a measure of Australian Aboriginal cultural engagement	1 & 2	**ACES**	Development & preliminary validation.	Cultural Engagement Survey (ACES)	Semi-urban Aboriginal adults	NSW	4	3	4	0	4	4.5	3.5	3	2.5	29
Berry et al. (b) 2012	Growth & Empowerment (GEM) for Indigenous Australians in Substance Abuse Treatment	1	**GEM, K10, DTCQ-8 TCE**	Evaluation	Substance misuse, distress, empowerment measure	N= 103. 81% Aboriginal men	NSW.	5	4	4	4	5	5	5	5	3	40
Blignault et al. 2016	The value of partnerships: lessons from a multi-site evaluation of a national social & emotional wellbeing program	1	**GEM**	Program Evaluation. MM	SAM Our Way national program to improve SEWB	5 case study sites	NT, QLD, SA, WA	4	4	3	5	5	3	3	3	2	32
	for Indigenous youth	1			of Aboriginal youth		QLD	4	4	4	5	4	3	2	2	3	30
Eley et al	Tools & methodologies for	1		Needs	Mental Health	N=126 Aboriginal	QLD	4	4	4	5	4	3	2	2	3	30
2006	investigating the mental health needs of Indigenous patients: it's about communication	1		analysis. MM	Service review for Aboriginal Community	clients/carers (41% female). + N= 164/671 DMHS staff.	QLD	4	4	4	4	4	3	2	2	3	30
Eley et al 2007.	Perceptions of mental health service delivery among staff & Indigenous consumers: it's still about communication	1		Needs analysis	Effectiveness of Mental health Services	N=126 Aboriginal clients/carers+ N=164/671 staff.	QLD	4	4	4	4	4	3	2	2	3	30

Author	Title	Study type	Tool	Type of Research	Application or Source	Sample Population	Location	Q5	Q6	Q7	Q8	Q9	Q10	Q11	Q12	Q13	Score out of 45
Daniel, Brown, Dhurrkay, Cargo, O'Dea. 2016	Mastery, perceived stress & health-related behaviour in northeast Arnhem L&: a cross-sectional study	1	**Perlin Mastery Scale adapted**	Evaluation of stress & mastery. MM	Perceived mastery of stress & health-related behaviour.	N= 177 Yolgnu Adults. (Mean age of 35.6). Females: 97.	Remote NT	5	4	3	4	3	5	4	4	2	34
De Maio et al. 2005	Measuring the Social & Emotional Wellbeing of Aboriginal Children & the Intergenerational Effects of Forced Separation	1 & 2	**SDQ**	Population based study	Psychological adjustment SEWB WA children.	N=3,993 Adolescents (14-17 years) & their carers PLUS 1,200 non-Aboriginal comparative cohorts	WA	5	5	5	2	5	5	5	5	2	39
Ferdinand et al. 2012	Mental Health Impacts of Racial Discrimination in Victorian Aboriginal Communities. The Localities Embracing & Accepting Diversity (LEAD) Experiences of Racism Survey	1	**ERS + K6**	Population based study.	Racism & associated distress, stress. Part of LEAD study	N=755. Aboriginal adults. (Mean age 36). >50% women.	Vic.	5	5	5	2	5	5	4	5	4	40
Fleming, Gately & Kraemer. 2012	Creating HoPE: Mental Health in Western Australian Maximum-Security Prisons	1	**K10**	Prevalence study	Mental Health & substance use profile of prisoners	N=146 adult 29.45 % Aboriginal	WA. Prisons	5	5	5	5	4	5	4	3	1	37
Gausia et al. 2015	Risk of antenatal psychosocial distress in indigenous women & its management at primary health care centres in Australia	1		Audit.	Antenatal psychological distress screening	N= 797 files Aboriginal **women** from 36 health centres	NSW, QLD, SA, WA & NT	4	4	4	3	4	5	5	4	4	38
Gausia et al 2013	Antenatal emotional wellbeing screening in Aboriginal & Torres Strait Islander primary health care services in Australia	1		Audit.	Antenatal SEWB screening	N= 797 files from Aboriginal **women** from 36 health centres	NSW, QLD, SA, WA NT	5	5	5	4	4	4	5	5	4	41

Author	**Title**	**Study type**	**Tool**	**Type of Research**	**Application or Source**	**Sample Population**	**Location**	**Q5**	**Q6**	**Q7**	**Q8**	**Q9**	**Q10**	**Q11**	**Q12**	**Q13**	**Score out of 45**
Hayes et al. 2010	The interface of mental & emotional health & pregnancy in urban indigenous women: research in progress.	1	Modified **EPDS**	Exploring of EPDS wording & adaptation	Perinatal mental health	N=92/110. Aboriginal antenatal women	QLD	3	4	4	5	4	3	3	4	4	34
Heffernan et al. 2015	PTSD Among Aboriginal & Torres Strait Islander People in Custody in Australia: Prevalence & Correlates	1	**CIDI**	Cross-sectional prevalence	Trauma/offense related PTSD + PTSD with mental illnesses, AoD & suicidality.	N=396/419 Aboriginal adults. Males 331, females 65.	QLD Prisons	5	5	5	4	5	5	5	4	3	41
Janca et al. 2015	Here & Now Aboriginal Assessment: background, development & preliminary evaluation of a culturally appropriate screening tool	1	**HANAA**	Evaluation	SEWB screen Aboriginal adults mental health diagnosis	N=30. 50% male/female. (aged 18–63 years).	Perth. WA.	2	3	3	5	5	5	5	3	2	33
Jerksy et al. 2015	Improving health service access & wellbeing of young Aboriginal parents in an urban setting: mixed methods evaluation of an arts-based program	1	**GEM** & **K6+2**	Evaluation Parenting Program	Empowerment outcomes & health educational outcomes	N=92 Aboriginal parents.	NSW Sydney	5	4	4	4	5	4	4	3	4	37
Markwick et al. 2015	Social determinants & psychological distress among Aboriginal & Torres Strait Islander adults in the Australian state of Victoria: A cross-sectional population-based study	1	**K10**	Population based study.	Social determinants & psychological distress	N=339 Aboriginal adults. Total adults: 34,168 adults.	Vic. Local Gov. areas	4	4	5	3	5	5	5	5	4	40
Nadew 2012	Exposure to traumatic events, prevalence of posttraumatic stress disorder & alcohol abuse in Aboriginal communities	1	**IES & AUDIT** & **ITP**	Pop-based. Prevalence	Expl. relationship bet exposure to trauma & PTSD & alcohol abuse	N= 221 Aboriginal adults. (Mean age: 38)	Central West WA.	5	3	5	5	5	4	4	5	5	41
Nagel et al. 2008	An approach to treating depressive & psychotic illness in Indigenous communities	1	**MCP**	RTC & Evaluation of tool	Evaluation of AIMhi brief intervention. Mental health clients	N=49 Aboriginal clients PLUS 37 carers. (Mean age: 33). Approx. 50% women.	NT. Remote	5	5	5	5	5	5	4	4	3	41

Author	Title	Study type	Tool	Type of Research	Application or Source	Sample Population	Location	Q5	Q6	Q7	Q8	Q9	Q10	Q11	Q12	Q13	Score out of 45
Stevens & Paradies 2014	Changes in exposure to stressors from 2002 to 2008 for the Indigenous population & examines inter-relationships between eleven NLES items.	1 & 2	**NLES NATSISS GSS**	Comparative analysis	Pop based study. NATSISS data General pop. Comparison. NLE & Stress	Aboriginal & Torres Strait Islander	AUST	5	5	5	2	5	5	5	5	3	40
Stathis et al. 2008	Use of the Massachusetts Youth Screening (MAYSI-2) Instrument to assess mental health problems in young people within an Australian youth detention centre	1	**MAYSI-2**	Population based study	Mental health behavioural problems. Aboriginal & non-Aboriginal adolescents in detention.	164/402 Adolescents. 96/212 Indigenous. 68/190 non-Indigenous 124/298 male, 40/104 female	QLD	4	3	2	1	5	0	4	5	0	24
Tomyn, Norrish & Cummins 2011a, 2013	The Subjective Wellbeing of Indigenous Australian Adolescents: Validating the Personal Wellbeing Index-School Children (PWI-SC)	1 & 2	**PWI-SC**	Pop-based study. Norm-referenced	SEWB	N= 519 / 550 Aboriginal adolescents. 287 males. 233 females. Mean age: 14.73.	AUST	4	4	4	2	4	5	5	4	2	32
Trauer & Nagel, 2012	Outcome measurement in adult indigenous mental health consumers	1 & 2	**HoNOS** & **LSP-16**	Evaluation of mainstreams assessment use	Aboriginal mental health clients	N=271 Aboriginal adults were assessed a total of 496 times.	QLD. Far North.	5	4	4	5	4	5	5	5	4	41
Weetra et al, 2016	Stressful events, social health issues & psychological distress in Aboriginal women having a baby in SA: implications for antenatal care	1	**PRAMS & K5**	Population based study	Postnatal Aboriginal women Psychological distress	N= 344 Aboriginal **women.** Mean age: 25, remote, regional & metro.	SA	5	5	5	4	5	4	4	4	4	40

Table 12. Validation Studies Appraisal Form (adapted from CASP Checklist

(Sample Number: N= * Completion Number of Participants / Enrolled Number of Participants)								Q5	Q6	Q7	*Q8*	*Q9*	*Q10*	*Q11*	***Score -/35***
	Author	**Year**	**Title.**	**Tool**	**Application**	**Sample**	**Location**	**score**	**Score**	**Score**	**Score**	**Score**	**Score**	**score**	
1	AIHW	2009	Measuring social and emotional wellbeing of Aboriginal and Torres Strait Islander people	**K5 +2**	Pop based study.	National survey	Nationally	3	2	0	4	1	4	3	16
2	Berry al	2012	Preliminary development and content validity of a measure of Australian Aboriginal cultural engagement	**ACES**	Aboriginal adults	N= 27	New South Wales (NSW)	0	3	4	3	1	2	2	15
3	Brown et al	2016	Men, hearts, and minds: developing & piloting culturally specific psychometric tools assessing psychosocial stress and depression in central Australian men	Adapted **PHQ9, K6**	Aboriginal men	N= *186/189. Mean age 34.8.	Urban & Remote Central Australia.	4	5	5	4	3	3	4	28
4	Bright	2012	An initial review of the structure of the Westerman Aboriginal Symptom Checklist – Adults (WASC-A) using Structural Equation Modelling (SEM)	**WASC-A**	SEWB	N=*370/392	Western Australia (WA)	2	5	5	5	3	3	4	29
5	Campbell et al.	2008	Aboriginal and Torres Strait Islander women's experience when interacting with the EPDS: a brief note	**Adapted EPDS**	Perinatal depression	N=181	Queensland (QLD)	5	3	3	2	1	1	1	16
6	Esler, Johnston, Thomas & Davis.	2008	The validity of a depression screening tool modified for use with ATSI people	**PHQ-9 +** 'anger' questions	Aboriginal adult. Health disease.	N=34. 50% female. Mean age 57.7	Darwin Northern Territory (NT)	5	4	5	4	2	1	2	23
7	Haswell et al	2010	Psychometric validation of the Growth & Empowerment Measure (GEM) applied with Indigenous Australians	**GEM** Parallel measure K6 +2	SEWB Aboriginal Australians.	N=184. Mean age 39.9. 64.1% male.	Remote Rural QLD, NT, NSW.	5	5	5	4	1	3	4	27
8	Hackett et al	2019	Getting it right: Validating a culturally specific screening tool for depression (aPHQ‐9) in Aboriginal and Torres Strait Islander Australians.	**aPHQ -9**	Aboriginal adult	N=500. Mean age 43 53% female	Nationally								
9	Kowal Gunthorpe & Bailie	2007	Measuring emotional and social wellbeing in Aboriginal and Torres Strait Islander populations: an analysis of a Negative Life Events Scale	**NLES**	Aboriginal cohort	N= 135 Aboriginal carers of children	Remote. NT	4	4	4	4	3	3	3	26

10	MacNamara, Banks et al	2014	Measuring psychological distress in older Aboriginal and Torres Strait Islanders Australians: a comparison of the K-10 and K-5	**K-10 & K5**.	Psychological distress Population based study.	N=266,611N = 1,939	NSW.	5	5	5	5	2	4	4	30
11	Marley et al.	2017	Validity and acceptability of Kimberley Mum's mood scale to screen for perinatal anxiety and depression in remote aboriginal health care settings	**KMMS**	**Adapted EPDS & psychosocial screen**	N=*97/99	WA. The Kimberley	5	5	5	4	3	4	4	30
12	Ober, Dingle et al	2013	Validating a screening tool for mental health and substance use risk in an indigenous prison population	**IRIS**	AOD & mental health assessment	N=395. 84% male	Custodial centres. QLD.	5	4	5	4	2	2	2	24
13	Nagel, Robinson, Trauer & Condon	2008	An approach to treating depressive and psychotic illness in Indigenous communities	**HoNoS, Life Skills Profile, K10**	Motivational planning	N=49 Aboriginal adults	NT	3	3	4	3	3	4	5	25
14	Schlesinger et al	2007	The development and validation of the Indigenous Risk Impact Screen (IRIS): a 13-item screening instrument for alcohol and drug & mental health risk	**IRIS**	AOD & mental health risk	N=175 urban, regional & remote	QLD.	4	4	4	3	2	2	3	22
15	Stathis Doolan et al..	2014	Use of the Westerman Aboriginal Symptoms Checklist – Youth (WASC-Y) to screen for mental health problems in Indigenous youth in custody	**WASC-Y**	SEWB	N= *47/89 Aboriginal people in custody.	Custodial centres.	3	4	3	4	2	2	3	21
16	Tomyn, Fuller, Tyszkiewicz, Norrish	2013	The Psychometric Equivalence of the Personal Wellbeing Index School-Children for Indigenous and Non-Indigenous Australian Adolescents	**PWI-SC**	SEWB	N=1378 adolescents + 6401 non-Indigenous.	Victoria	3	5	4	4	2	2	3	23
17	Thomas, Cairney et al	2010	Strong Souls: development & validation of a culturally appropriate tool for assessment of SEWB in indigenous youth	**Strong Souls**	SEWB assessment	N=*345/361. Ages 13-17. (Pilot N=43).	Urban rural remote North Australia	5	5	5	4.5	1	4	5	30
18	Zubrick, S & Lawrence, D	2006	Testing the Reliability of a Measure of Aboriginal Children's Mental Health- An Analysis Based on the Western Australian Aboriginal Child Health Survey	**SDQ**	WA Aboriginal Child Health Survey	N=5289 Aboriginal children <18 years.	WA	5	5	5	5	0	1	2	23
19	Westerman	2003	Westerman Aboriginal symptom checklist-youth: Thesis	**WASC-Y**	SEWB Aboriginal adolescents	N= 183. Age13–17	Urban & remote WA.	2	5	5	5	2	2	4	25
20	Zubrick, S & Lawrence, D	2006	Testing the Reliability of a Measure of Aboriginal Children's Mental Health- An Analysis Based on the Western Australian Aboriginal Child Health Survey	**SDQ**	WA Aboriginal Child Health Survey	N=5289 Aboriginal children <18 years.	WA	5	5	5	5	0	1	2	23

Table 13. Psychometric assessment of validated studies (adapted from Groth-Marnat (2009)

Author			Tool	stability	measurement error	test-retest	parallel forms	inter-rater or observer	internal consistence	cultural	face	content	concurrent	Predictive	Convergent	Discriminate	construct	factor analysis	Will it produce accurate measurement	Is it replicable in this context?	Unequivocal	Credible	Unsupported
AIHW (2009)	N=5,757 / 258,300 Aboriginal/Non-Aboriginal	1	**K5+**	N	N	no	Y	N	Y	Y	Y	Y	N	N	N	N	N	yes	3	can't tell			y
Berry, Crowe & Deane (2012)	N= 27.	2	**ACES**	N	N	N	N	N	N	Y	Y	Y	N	N	N	N	N	N	can't tell	can't tell			y
Brown et al., (2016)	N=186	2 & 3	**MHM** 7 item depression scale. Parallel measures: PHQ9 + K6	N	N	N	Y	N	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	can't tell		y	
Bright (2012)	N=370/392	2	**WASC-A**	N	N	N	N	N	Y	Y	Y	Y	N	N	Y	Y	Y	Y	Y	can't tell		y	
Campbell, Hayes, Buckby (2007)	N=25 Mt Isa tool; N=181 TAIHS tool	2	**EPDS adaptation TAIHS**	Y	N	N	N	N	Y	Y	Y	Y	N	N	N	N	N	N	can't tell	can't tell			y
De Maio et al. (2005) Zubrick, Lawrence, De-Maio, Biddle (2006).	N=5289 Aboriginal kids.	1 & 2	**SDQ**	Y	N	N	N	Y	Y	implied	Y	Y	N	N	Y	Y	Y	Y	Y	N		y	
Esler, Johnston, Thomas & Davis (2008)	N=34 participants with CVD	2	**PHQ-9+ (anger)** Adaptation	N	N	N	N	Y	Y	implied	Y	Y	Y	Y	Y	N	N	N	yes	cant tell		y	
Haswell et al., (2010)	N=184	2	**GEM**. Parallel measure: K6	Y	Y	Y	Y	N	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	cant tell		y	
Kowal Gunthorpe & Bailie (2007)	N=419	2	**NLES**	N	Y	Y	Y	N	Y	implied	Y	Y	Y	Y	Y	Y	N??	Y	Y	cant tell		y	

Author			Tool	stability	measurement error	test-retest	parallel forms	inter-rater or observer	internal consistence	cultural	face	content	concurrent	Predictive	Convergent	Discriminate	construct	factor analysis	Will it produce accurate measurement	Is it replicable in this context?	**Unequivocal**	**Credible**	**Unsupported**
MacNamara et al., (2014)	n= 1631.	2	**K-10 & K5**	Y	Y	N	Y	N	Y		Y	Y	Y	N	Y	Y	Y	Y	Y	cant tell		y	
Stathis et al., (2012)	N= 47/89 Aboriginal/Non-Aboriginal	1 & 2	**WASC-Y**	N	N	N	Y	N	N	yes	Y	Y	Y	Y	Y	Y	N	Y	Y	cant tell		y	
Stevens & Paradies (2014)	ABS data 2002 & 2008.	1 & 2	**NLES**	N	Y	Y	N	N	N	implied	Y	Y	Y	Y	Y	Y	Y	Y	Y	cant tell		y	
Tarren-Sweeney (2013)	N= 85/171	2	**ACA**	Y	Y	Y	Y	Y	Y	N	Y	Y	N	Y	Y	Y	Y	Y	Y	N		y	
Tomyn, Fuller, Tyszkiewicz, Norrish (2014); Tomyn, Norrish & Cummins (2011a	N=1378 (2014). N= 519 (2011). N=351 non Aboriginal (2011).	2	**PWI-SC**	N	Y	N	N	N	Y	N	Y	Y	N	N	Y	Y	Y	Y	Y	N		y	
Thomas, Cairney, Gunthorpe, Paradies & Sayers (2010)	Pilot=43; N=361	1 & 2	**Strong Souls**	N	N	N	Y	Y	Y	Y	Y	Y	N	N	N	Y	Y	Y	Y	cant tell		y	
Westerman (2003)	N= 183	1 & 2	**WASC-Y**	N	N	N	N	N	Y	Y	Y	Y	N	N	Y	Y	Y	Y	Y	cant tell		y	

4.2.4.1 Bespoke Aboriginal Mental Health Assessments or Screening tools

Three tools were identified for screening SEWB of Aboriginal Australians: Strong Souls (Thomas et al., 2010; Dingwell and Cairney, 2010), the Westerman Aboriginal Symptom Checklists for adults (WASC-A) and youth (WASC-Y) (Bright, 2012, Westerman, 2003; Stathis et al., 2012) and the Here And Now Aboriginal Assessment (HANAA) (Janca et al., 2015).

Strong Souls: 25 item self-report questionnaire using plain English to measure four aspects of SEWB: resilience, anxiety, depression and suicide risk. It was developed to assess the SEWB of Aboriginal youth as part of the Aboriginal Birth Cohort (ABC) study in the Northern Territory (NT) (Sayers, Mackerras, Singh, Bucens, Flynn and Reid, 2003).

Exploratory factor analysis was undertaken exploring construct validity and Cronbach alpha used to assess reliability of the latent constructs and the tool generally. Two existing tools, the K6+, an abridged Kessler Psychological Distress Scale (Kessler et al., 2002) and WASC-Y were pilot tested alongside Strong Souls (N=24 adolescents aged <17). These tools were selected not as gold standard comparisons, rather to meet the study needs requirements which was to undertake an EFA, as both had demonstrated reliability (K6+) or validity (WASC-Y) in young Indigenous populations. Strong Souls demonstrated good face validity and strong reliability (Thomas et al., 2010) though this was for a combined sample of males and females rather than being specific to a female sample. The K6 was supplemented by two questions assessing frequency of happy and angry feelings (K6+2). Both the Strong Souls and WASC-Y demonstrated good face validity on most items.

Strong Souls established best discriminative power with its 4-point binary scale, compared to the 5-point scale on the WASC-Y and K6. The internal reliability of the K6+2 and WASC-Y were generally good but not all the reliabilities for WASC-Y subscales could be established because of the small number of items, or low endorsement of some items.

Strong Souls was divided into two subsets: SEWB and resilience. An exploratory factor analysis[1] (EFA) of the 34 items, identified four-factor constructs of anxiety, resilience, depression and suicide risk and demonstrated acceptable to sound construct validity and reliability based on eigenvalues and a scree plot. The final four-factor solution included the final 25 items that accounted for 34.5% of the variance shared across all factors. Reliability analysis performed on each of the four-factors using Cronbach alpha showed reliability coefficients 0.7. Overall, the internal consistency of Strong Souls was good (0.7%) and within each factor.

The $\chi 2$ analysis identified strong relationships (<0.0001 level of significance) between the need for follow up (thought it was unclear whether this was independently assessed) and all the mental health scales, and highly significant relationships between the suicide and resilience scales ($p<0.01$).

Interestingly the anxiety construct was associated with feelings of sadness and low mood and not depression, while anger was verified as a unique symptom of depression for Aboriginal people. Somatic symptoms such as dizziness, indigestion, and breathing difficulties were identified as being relevant for Aboriginal people, though this may be confounding in the context of pregnancy.

Using the Validation Appraisal tool (Appendix A) this study rated the highest of all appraised validation studies at 86% (30/35). It demonstrated strong, transparent cultural and ethical considerations, good psychometric properties overall. The content of the tool was considered to include items with relevance for informing aspects of perinatal screening. Specifically, there were relevant emotional and behavioural symptoms and strength-based inquiry (relating to resilience and SEWB), as well as cultural considerations (such as the presence of Family). Unique findings relating to Aboriginal people were reported also such as

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[1] A factor analysis technique where the goal is to identify the underlying relationship between the measured variables.

feelings of sadness and low mood were linked with anxiety and not depression, whereas anger was identified as a unique symptom of depression. However, its application in the perinatal period was potentially limited by the strong youth culture focus (more relevant for young Mums), the inclusion of perinatal ‘normal variant’ somatic symptoms (dizziness, indigestion, and breathing difficulties) and the absence of psychometric analysis with female-only samples.

2.WASC-A/WASC-Y: The 53 item WASC-A/WASC-Y checklists encompasses 6 self-reported constructs: depression, anxiety, alcohol and drugs, impulsivity, suicidality, and cultural resilience. Bright (2012) undertook confirmatory factor analysis[2] (CFA) for the WASC-A using structured equation modelling, including goodness of fit, construct validity[3] and reliability with 370/392 Aboriginal adults. Each of five sub-scales were analysed separately and initial findings indicate that all possess acceptable to good fit to the data. However, as each subscale was analysed separately questions remain as to whether the items accurately clustered together as one instrument.

Westerman (2002) reported on an initial validation of the WASC-Y self-report inventory with 183 Aboriginal adolescents (aged 13–17) from Western Australia (WA). This involved conducting separate EFA and reliability analysis. EFA demonstrated good factor structure, with single factors accounting for variances of 34% to 82%. Internal reliability was also sound with Cronbach’s alphas ranging from 0.75 to 0.88 in each scale. The six sub-scales (depression, anxiety, alcohol/drugs, impulsivity, suicidality, and cultural resilience) were analysed separately rather than as a whole, so again it is unclear whether the items in each construct accurately cluster together. The subscales correlated with results of clinical interviews with internal reliability coefficients of 0.67–0.88.

The gold standard in this case was a clinical interview with the author /tool developer therefore

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[2] A form of factor analysis that tests whether measures of a broad concept (construct) are consistent with a researcher's understanding of the nature of that construct (or factor)

[3] Assessment of the degree to which the test measures what it claims to be measuring.

[4] A method in research where two variables are measured so that the researcher understands and assesses the statistical relationship between them with no influence from any extraneous variable.

unintentional bias cannot be eliminated. Correlational[4] differences were found between subsets and geographical locations.

These included relationships between suicide and impulsivity, and suicide and anxiety. There was a stronger relationship also between depression and suicide and depression and anxiety for rural compared to urban youth, and cultural resiliency also had moderately stronger negative relationships with suicide, depression and anxiety in urban areas than rural areas. Overall, the Validation Appraisal tool rated both the WASC-A and WASC-Y well at 80% (29/35).

In 2012 Stathis, Doolan, Letters, Arnett, Cory and Quinlan reported results and comparisons using the WASC-Y and the Massachusetts Youth Screening Instrument (MAYSI-2) with 96/212 Aboriginal adolescents in Queensland detention centres. Findings demonstrated high levels of mental health or substance abuse problems, 100% of females and 94.6% of males scored above the clinical cut-off on at least one of the 5 mental health subscales. Females screened higher than males across all subscales. The MAYSI-2 combines depression and anxiety into a single ‘depression/anxiety’ scale, while depression and anxiety form two separate subscales in the WASC-Y. Impulsivity is screened on the WASC-Y, though not on the MAYSI-2, while the MAYSI-2 scales of Anger/Irritability, Somatic Complaints, Traumatic Experience and Thought Disturbance are not included in the WASC-Y. This made direct comparisons difficult. For those scales common to both, however high levels of mental health problems were reported on each instrument, supporting the construct validity of the WASC-Y (Stathis et al., 2012).

As with the Strong Souls, the content of the WASC-A/WASC-Y was considered to include items with relevance for informing aspects of perinatal screening. Specifically, there were relevant emotional and behavioural symptoms and strength-based inquiry (relating to resilience and SEWB), as well as cultural considerations (such as the presence of Family and cultural resilience). In addition, there are contextual items that potentially strengthen estimation of risk (eg relating to substance use and impulsivity). However, its application in the perinatal period was potentially limited by the inclusion of perinatal ‘normal variant’ somatic symptoms, as well as the absence of psychometric analysis with female-only samples.

HANAA: The Here and Now Aboriginal Assessment (HANAA) was developed in consultation with Aboriginal stakeholders and mental health professionals in WA and in the Northern Territory (NT) and designed to support health professionals working with Aboriginal people to undertake a culturally considered SEWB screen. SEWB is assessed against 10 key domains: physical health, sleep, mood, suicide risk, substance use, memory, unusual experiences, functioning, life stressors and resilience. A preliminary evaluation included exploration of cultural applicability, feasibility, reliability and validity in a convenience sample size of 30 non-randomised current psychiatric patients (Janca, Lyons, Balaratnasingam, Parfitt and Davison, 2015). As such it failed to adequately meet psychometric evaluation criteria for use as a screening tool. Reliability was assessed using Cohen’s Kappa to measure inter-rater agreement between an Aboriginal and non-Aboriginal assessor. Inter-rater agreement was strong the ‘functioning’ domain (1.000), moderate for ‘Substance use (0.735) and lowest for ‘general feeling’ (0.565) and unusual experiences (0.517). Validity was assessed by comparing results with information derived from the participant’s medical record, which was used as a ‘gold standard’. Since participant were all inpatients and there is no record of the cultural considerations in the psychiatric assessments, bias cannot be ruled out.

However, its cultural considerations through use of narrative enquiry against specified domains and use of culturally considered images were considerable strengths and increased acceptability among participants. Using the Combined Studies Appraisal tool, HANAA rated at 73% (33/45).

Comparing EPDS against bespoke SEWB tools: Strong Souls, WASC-A/Y, HANAA

As a point of reference, the EPDS is a 10 item self-report tool which predominantly focuses on symptoms of a Western construct of depression, namely the affective states of: loss of interest, self-blame, capacity for humour, sadness, teariness, unhappiness causing sleep disturbances and suicidality, the symptom of sleep difficulties. A three-item anxiety subscale is included: anxiousness/worry, panic/fear and feeling overwhelmed (Cox, Holden and Sagovsky, 1987).

In contrast, the 25-item Strong Souls and the 53-item WASC-A/WASC-Y have a more contextualised set of questions that focus on strength-based enquiry around protective, risk factors, as well as traditional and culturally recognised symptoms (eg anger) of depression, anxiety and wellbeing. Strong Souls, WASC-A/WASC-Y and HANAA all enquire about somatic symptoms, cognition and thought patterns and behavioural risks. All include enquiry specifically about 'anger', a uniquely identified expression of depression among Australian Aboriginal people (Kotz et al., 2016; Esler, Johnston, Thomas & Davis, 2008; Brown, Scales, Beever, Rickards, Rowley & O'Dea, 2012). Strong Souls and WASC-A/WASC-Y both include inquiry about racism; research shows racism is causally linked with psychological distress (Ferdinand, Paradies and Kelaher, 2012; Markwick, Ansari, Sullivan and McNeil, 2015). Strong Souls, HANAA and WASC-A/WASC-Y observe a holistic Aboriginal perspective of mental health including responsibilities and lawfulness, social and Kinship connections, relationships.

In terms of pragmatics, the language and sentence structure in the EPDS is complicated for many Aboriginal women (Campbell et al., 2007; Kotz et al., 2016) using terms such as 'things have been getting on top of me' and 'I blamed myself unnecessarily'. Conversely Strong Souls and the WASC-A/WASC-Y both use plain English. The HANAA tool incorporates narrative inquiry and comes with a training package and prompts to support narrative around each domain. This yarning style of interviewing may offer an alternative to self-report instruments that require language comprehension and literacy levels.

The WASC-A/WASC-Y uses a five-point scale. The HANNA instrument identifies either 'a problem' or 'no problem' within each domain and finally results in "no action", "re-assess" or "refer". The EPDS and Strong Souls incorporate binary scales, however at this point Strong Souls provides no validated scoring system to support cut-offs for management/follow-up.

The HANNA requires self-directed training via the manual, the WASC-A/WASC-Y requires face-to-face training and training in the use of the EPDS is recommended. Accessibility to the EPDS is freely available and scoring can be undertaken by the individual. HANNA and Strong Souls are also freely available; however, HANNA, Strong Souls and WASC-A/WASC-Y require support to administer. The WASC-A/WASC-Y requires considerable financial outlay for purchase of the tool and for the requisite training which may influence wider-spread use.

In sum, using the adapted Appraisal tools which include assessing research quality, ethical and cultural considerations and potential for relevance and capacity to inform perinatal mental health screening, both the Strong Souls and WASC-A/WASC-Y rated well (≥80%) and HANAA rated at 73%. Additionally, the evidence within Strong Souls and WASC-A/WASC-Y rated credibly when appraised using the psychometric assessment matrix. Whilst the HANAA rated well according to ethical and cultural considerations it failed to adequately meet psychometric evaluation criteria for use as a screening tool. Notably, the EPDS would rate poorly (21/35 or 60%) against the ethical, cultural, the acceptability and reliability domains for use with an Australian Aboriginal population.

In summary, the cultural conceptualisation of depression in the EPDS is extended in these other measures but they have not yet been validated in a perinatal context, and none have yet established diagnostic accuracy or predictive validity. The EPDS has established predictive validity and diagnostic accuracy in some domains but no studies have attempted to do this in an Australian Indigenous context. Notably, neither the EPDS nor any of these culturally specific scales make reference to the psychological issues associated specifically with pregnancy and the perinatal period such as the process of adjustment to Motherhood. Pregnancy and childbirth are associated with unique sets of experiences including sleep deprivation, significant psychological adjustment whilst transitioning into Motherhood for the first or subsequent times, unsteady hormones, worries about not being a ‘good Mother’ or being able to successfully breastfeed, and feelings of guilt or disappointment if the ‘joy of Motherhood’ is absent. It would seem that the absence of these considerations is a more general limitation in contextual validity of both conceptual and clinical significance in terms of the applicability of measures in clinical use during the perinatal period, and also prompted us to think about how context is a key feature of mental health and wellbeing for marginalised groups. It was this consideration that led us to expand the search to include measures that focus on broader risk or protective factors that might provide further contextualisation for this group of women who are at high risk for complex distal and proximal multimorbidity which are likely to demand a multimodal response.

4.2.4.2 Bespoke Aboriginal Assessments/Screening tools that contextualise mental health and wellbeing

A further 7 specifically designed tools were identified for use with Aboriginal Australians. Each includes cultural considerations pertaining to language and communication, and structure the screening process less on symptomology and more around protective factors and risks that are akin to a holistic understanding of SEWB. These tools all incorporate impacts of racism and trauma, including intergenerational trauma and post-traumatic stress. Those that were validation studies[5] in design (i.e. GEM, aPHQ9 etc) were evaluated against the same CASP criteria. Those that were not (i.e. ERS, MIRE, MCP) were appraised against the slightly different Combined Studies Appraisal criteria[6]. Detailed explanation assessment criteria are shown in Attachment 1 and 2.

1. Growth and Empowerment Measure (GEM): The GEM was developed by Aboriginal Australians to evaluate personal empowerment, mental wellbeing and social connectedness at both an individual and group level. It comprises three sections: the 14-item

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[5] Differing assessment criteria included: clarity and rigour or methods and analysis; whether the performance of the tool could be calculated; how precise were the estimates of the effect.

[6] Differing assessment criteria included: consideration of relationship between researcher and participants; recruitment strategies; was the data collection method the best choice to assess/address the issue

Emotional Empowerment Scale (EES14) assessing the ability to feel and express wellbeing in daily life. This includes an Inner Peace subscale; the Kessler 6 Psychological Distress Scale (K6) with two additional questions on anger and happiness (referred to in this paper as K6+2); the 12 item Empowerment Scenarios (ES12) which captures the individual's stage of empowerment and includes two subscales: healing and connection (Haswell et al., 2010).

Haswell et al., (2010) researched the GEM using a convenience sample of 170 Aboriginal participants (35.9% female, mean age 40 years) of participants in personal or organisational social health activities. They examined psychometric properties and internal structure of the EES14 and the 12S and potential subscales. Measures were further refined, then an exploration between scale relationships was undertaken using Pearson's correlations[7]. Cronbach's alpha for the K6 was 0.853. All corrected item-total correlations were >0.4 and principal component analysis supported a single component. Inclusion of the two additional items (happiness and anger) generated a slightly higher alpha (0.871; n=141), while all item- total correlations were >0.4. The EES14 showed high internal consistency (alpha =0.891, or 0.883 for the first 13 items).

Both EES14 and 12S measures gave promising results on these criteria. Internal consistency was robust, with alpha exceeding 0.7. Individual components and summary scores appeared to measure inter-related but distinct aspects of empowerment and well-being. The K6+2 demonstrated slightly enhanced internal consistency and stronger correlations with the GEM scales and subscales. The K6+2 item 'happy in yourself' loaded unequivocally with the EES14 items in the Inner peace subscale, and cross-loaded with both the K6 and anger items and the items of the other three subscales. The Inner Peace subscale of the EES14 and the Healing subscale of the 12S were closely correlated with K6+2 (r=-0.54). A subsequent EFA determined that in all cases, the K6 and the anger items loaded clearly onto one component, the EES14 and S12 subscale items loaded onto a second component. Participants who scored higher

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[7] Pearson correlation represent the relationship between two variables are placed on a scatter plot. These variables are denoted as X and Y. A scatter plot not depicting any resemblance to a linear relationship will be worthless. The closer the resemblance to a straight line of the scatter plot, the higher the strength of association.

on the newly developed scales showed lower distress on the K6, particularly when the two additional questions were included. These findings demonstrate that the addition of the anger and happiness questions, the K6+2, as a global distress screen rather than predominantly a depression screen may provide a more complete picture of the emotional experience for Aboriginal populations.

Ethical and cultural considerations rated highly for the GEM and the statistical analysis transparent and detailed. Strictly speaking, GEM is an evaluation tool and this study employed a convenience sample, with no gold standard comparison. However, findings were promising with close correlations emerging between SEWB items in GEM and the K6+2. Overall, the GEM may provide increased capacity to assess a more holistic experience of wellbeing that honours identity, values and abilities that are in harmony with others, which are all key elements of SEWB. This study rated highly on ethical/cultural and statistical analysis considerations using the Validation Studies appraisal CASP adaptation and overall was rated at 77% (27/35) in its capacity to inform perinatal mental health screening.

2. Motivational Care Planning Intervention (MCP): The MCP was developed for remote area Aboriginal clients (Nagel et al., 2008; Nagel and Thompson, 2008, 2007) as part of a broader AIMhi five-year NHMRC research project. MCP is an approach to assessment that includes brief pictorial motivational intervention for Aboriginal clients with mental illness. Strong partnerships and collaborations with local grassroots people resulted in a narrative approach (storytelling) to assessing and understanding mental health and well-being, and the use of images and plain English. Importantly it changes the focus from amelioration of symptoms to enhancing protective factors and reclaiming life in community. MCP includes motivational interviewing, problem-solving therapy, and chronic disease self-management. An adaptation of the K10, the Severity of Dependence Scale (SDS), elements of the Health of the Nation Outcome Scales (HoNOS), the Life Skills Profile (LSP-16) and a mental state examination are included in the MCP.

A small (N=46/49) randomised controlled trial (RCT) included qualitative data collection and compared the care planning treatment using the tool with a six-month delayed treatment control group from 2003–07 (Nagel et al., 2008). Strong reciprocal and ethical processes with a continual cycle of consultation, collaboration, communication and evaluation with the Aboriginal community strengthened outcome. Whilst numbers were small, results were strengthened by high level engagement and retention (74%) over an 18-month period with significant progress toward achieving set goals. Good evidence of participation, interest and engagement were generated through the process of goalsetting and collaborative care-planning. The study demonstrated that Family was pivotal to the strength, stress and change processes for clients; it became the central focus rather than the individual, and inclusion of Family in goal setting plans was essential (Nagel and Thompson, 2010).

This offers important considerations for perinatal mental health screening if sustainable change is to emerge from the process of screening. There is no evidence that screening using the EPDS supported by a referral is adequately closing the gap for Aboriginal Australians women perinatally. Strategies that screen, monitor and enhance the reliability of behavioural interventions may be a more successful approach. The use of narrative and images in parallel to standard screening/assessment tools, the high importance of Family and Kinship, the role of Family in care planning, and the importance of partnerships and collaborations in research development are all key considerations. Whilst the RTC was small and no effect sizes were reported, overall, this study rated highly at 91% (41/45) using the Combined Studies appraisal CASP adaptation.

3. The Measure of Indigenous Racism Experiences (MIRE): Aboriginal Australians and CALD Australians are both vulnerable to racism. However, the experience of Australian Aboriginal people should be considered separately due to differing needs, contexts and histories. MIRE was developed to assess self-reported racism among Aboriginal Australians. MIRE is a 31-item tool with 5 questions each containing between 3-11 exploratory items explore (i) interpersonal racism, (ii) cognitive, (iii) affective and behavioural reactions to interpersonal racism, (iv) internalized racism and (v) systemic racism scale. Paradies and Cunningham (2008) reported on the development and an exploratory factor analysis of the MIRE. This included examining content, construct and convergent validity and underlying theoretical concepts in a population health study involving 312 (68% female) Aboriginal Australians. Overall, results demonstrated good content and psychometric validity. Construct and convergent validity were also reasonably well supported, and the acceptability of MIRE items (assessed via the missing data rate) appeared to be reasonable (Paradies and Cunningham, 2008). This study was appraised at 68.57% (24/35) using the Validation Appraisal tool.

The Darwin Region Urban Indigenous Diabetes (DRUID) study used the MIRE instrument during the first six months of the study (Paradies and Cunningham, 2010) to explore causal pathways between racism and poor health among 184 adults with diabetes. It demonstrated that the experience of racism was significantly associated with depression. Importantly, responses to racism in particular lack of control, stress, negative social connections and feeling ashamed or powerless, were identified as important agents in the relationship between racism and depression. These findings were reiterated in the 2006 General Social Survey (GSS) data where 40,400 Aboriginal people reported personal experiences of racism and described feeling angry (67%), sad (28%) and ashamed or worried (17%) (ABS, 2011). This study was appraised overall at 82% using the Combined Studies Appraisal tool.

Whilst the MIRE is not strictly a mental health screening tool, it provides important insights into the impacts of racism on SEWB which may inform perinatal mental health screening.

4. Experiences of Racism Survey (ERS). Ferdinand, Paradies, Kelaher (2012) explored the experiences of racism and its relationship with SEWB among Aboriginal Australians using the ERS. The ESR, a 33-item overall this study\ tool, was used alongside the

K6 (or the K5 in one Rural Council area) and surveyed 755 Victorian Aboriginal adults (18 years or older) from rural and metropolitan council areas. Findings reported almost 100% of respondents had experienced racism in the previous 12 months, with 50% of all participants and 65% of those exposed to 12 or more incidences reporting high/very high levels of psychological distress with a dose effect evident. More than 70% experienced eight or more incidents a year. Interestingly, reported experiences of racism increased with education, and 30% reported avoiding situations in daily life because of racism. These findings were reiterated in the 2006 GSS with 33% of people reporting their response to racism was by avoiding the person or situation (ABS, 2011). Reasons for higher rates of Australian Aboriginal perinatal care avoidance are complex; however, the avoidance of situations where racism is experienced cannot be ignored. Consideration should be given to racism as a distinct risk in the perinatal period. Prevention of interpersonal and institutionalised racism, whether explicit or implicit are critical strategies for improving the mental health and well-being of Aboriginal Australians women as they experience the onset of Motherhood. Overall, this study rated highly at 88.8% (40/45) using the Combined Studies tool.

5. Indigenous Risk Impact Screen (IRIS): A study by Schlesinger, Ober, McCarthy, Watson and Seinen (2007) aimed to develop a culturally appropriate measure for AOD use that included mental health for Australian Aboriginal adults, then assess its psychometric properties determining cut-off scores to assess presence of risk. Following the developmental phase, a small pilot using principal axis factoring analysis (N=14). The resultant 13 item self-report IRIS tool was then examined for construct validity, internal reliability and convergent validity (N=175). As such, gold standard comparison and effect sizes were not undertaken. The Depression and Anxiety Scale (DASS 21), the Self Reporting Questionnaire 20 (SRQ-20), the Leeds Dependence Questionnaire (LDQ), the Alcohol Use Disorder Identification Test (AUDIT), and the Severity of Dependence Scale (SDS) were administered as referent measures. A factor analysis supported the constructs developed, with the resulting two-factor solution corresponding to an alcohol and drug subscale and a mental health subscale. The alcohol and drug and the mental health subscales both evidenced strong convergent validity with the other well-established measure. The IRIS demonstrated strong internal consistency, convergent validity and evidenced valid cut-offs for determining symptomatic individuals in terms of AOD and mental health problems in Aboriginal populations.

Whilst the study achieved its aims, overall, the IRIS focuses on risk and excludes protective factors. The unexplained high dropout rates and absence of a relevant gold standard limits the strength of these findings. Any cultural considerations or community consultations or thought to the potential for assessment fatigue were not evident in this research. Overall, this study received an average rating of 60% (21/35) using the Validation Studies tool.

The usefulness of the IRIS among 395/419 Aboriginal prisoners (83.4% male) in Queensland was reported (Ober et al., 2013). Concurrent validity was assessed against the Composite International Diagnostic Interview (CIDI). This was administered by the same specifically trained administrators who administered the IRIS.

In this setting, the IRIS appeared to be an effective screen for identifying disordered AoD use, with high sensitivity of 94% and low specificity of 33%. The tool was less effective in identifying depression (sensitivity 82%, specificity 59%) and anxiety (sensitivity 68%, specificity 60%). Whilst this was a convenience sample the larger numbers added weight to the findings. Some consideration toward cultural sensitivities were noted through the employment and training of Aboriginal administers of the tools. Overall, this study rated at 65.7% (23/35) using the Validation Appraisal tool.

6. The Indigenous Trauma Profile (ITP): A population-based study assessed the relationship between traumatic events experienced by generations of Aboriginal people and the prevalence of post-traumatic stress (PTSD) and AOD problems in three remote Aboriginal communities in WA using the ITP. Communities were selected on the basis of observable level of traumatic events, prior connection with the author and community leaders' supporting the study. 221 Aboriginal participants aged 18 to 65 years were administered the ITP in a non-blinded structured clinical interview by the author along with the CIDI, Impact of Events Scale (IES) and the AUDIT.

The rate of lifetime exposure to traumatic events was 97.3%; 55.2% of participants met DSM-1V diagnostic criteria for PTSD; of these 91% also met the diagnostic criteria for alcohol abuse. The PTSD onset age started as early as 5 years of age and steadily increased, while alcohol abuse disorder onset started at the earliest at 15 years of age and had escalated by the late teens and early twenties. The PTSD age of onset indicates that traumatic events occurred at an early age and have disrupted adult life, and there is a strong association between PTSD and alcohol abuse onset age (Nadew, 2012). Similar findings were reiterated in the state-wide WA Aboriginal Child Health (WAACH) Survey (2005. Here the Strength and Difficulties Questionnaire (SDQ) was utilised to assess risk status for clinically significant emotional or behavioural difficulties. Approximately 21% of Aboriginal adolescents (12 to 17 years) were identified as being at high-risk compared with 13% of same age non-Indigenous adolescents; with females being at a clinically significant higher risk (13.1%) compared to males (9.2%) (DeMaio et al., 2005).

ITP findings of selected traumatic events and lifetime prevalence of traumatic experiences were compared with similar variables of the Australian National Well-Being and Mental Health Survey results (2000). Higher rates of exposure to traumatic events within these communities were identified compared with the national average. Nadew states that whilst the exposure to traumatic events in these communities translated into higher rates of PTSD, this was not reflected in the clinical settings (2012).

Nadew did not report on how the ITP was developed, whether it was piloted and there was no exploration of the tools reliability or validity. Despite this, comparative patterns emerged in findings as they related to young Aboriginal women at the height of their reproductive years.

7. Perlin Mastery Scale (PMS): The PMS was developed to evaluate associations between mastery, perceived stress, and health-related behaviour for a remote Indigenous population in Australia. 177 Yolngu Aboriginal adults (15-years and over) volunteered for a community-based chronic disease risk factor screening initiative on Elcho Island in northeast Arnhem Land in the Northern Territory of Australia (Daniel et al., 2006). The PMS was adapted from existing measures with items being selected for their brevity, cultural salience and reliability and validity. A process of translation, back-translation and refinement was undertaken from English and Yolngu Matha. Cronbach's α for the translated scale used with the Yolngu was 0.76. The average inter-item correlation was 0.31 (range: 0.14–0.42). Item-total correlations ranged from 0.44–0.58. Results found that mastery was inversely correlated with perceived stress measures ($p < 0.009$): recent stress, $r = -0.47$; chronic stress, $r = -0.41$; and youth stress, $r = -0.30$. Notably in this study were low levels of mastery among men between 15–24 years. Aboriginal Australian males experience significant loss of their authority and self-esteem.

In summary, there are a number of tools that have general psychometric and cultural credentials, which can provide a broader context of risk and protective factors relevant to wellbeing and mental health in Australian Aboriginal populations. None have been specifically validated with female samples, nor applied to the perinatal period. However, those included here have demonstrable relevance to the likely engagement of Mothers with services and the experience of being supported (or otherwise) whilst during the pregnancy and birth. Specifically, risk factors include experiences of racism, lifetime exposure to trauma and conversely, experiences of mastery, growth and empowerment may promote resilience to depression or anxiety.

4.2.4.3 Adapted or Existing tools

A number of existing tools and adaptations have been used to screen Aboriginal adults. Table 6 captures each tool by author and whether tools are existing, adaptations or specifically being designed for an Aboriginal cohort (new). Adapted tools that are more frequently used among Aboriginal Australians are reported on below.

Table 14 reports the screening tools that were identified through the review and went on for further assessment.

Table 14. Tools that progressed for further assessment

EX- Existing **ADPT**- Adaptation for Aboriginal Australians **NEW**- Aboriginal Specific Instrument

Authors	**Year**	**Instrument**	
Perinatal screening for depression and anxiety			
Campbell, Hayes & Buckby	2008	EPDS adaptation for Mt Isa & Townsville Aboriginal & Islander Pop.	ADPT
Carlin, Atkinson, & Marley Marley, Kotz, Engelke, Williams, Coutinho & Trust Kotz, Munns, Marriott & Marley	2019 2017 2016	**KMMS**	ADPT
Mental health / SEWB / psychological distress			
Haswell, Kavanagh, Tsey, Reilly, Cadet-James, Laliberte. .. Doran. Blignault, Haswell & Pulver. Berry, Crowe, Deane, Billingham & Bhagerutty	2010 2016 2012	**GEM** **GEM** **GEM** Parallel tools: **DTCQ-**Drug Taking Confidence Questionnaire **TCE -** Helpfulness of treatment Components Evaluation **K10**	NEW EX EX EX
Bright.	2012	**WASC-A**	NEW
Stathis, Doolan, Arnett, Cory, Quinlan.	2012	**WASC-Y** (Westerman, 2002)	NEW
Esler, Johnston, Thomas & Davis	2008	**PHQ9**	ADPT
Thomas, Cairney, Gunthorpe, Paradies & Sayers.	2010	**Strong Souls** Parallel tools: WASC-Y & K6	NEW
AIHW (brevity, implied validity no evidence)	2009	**K6**	ADPT
Brown, Mentha, Howard, Rowley, Reilly, Paquet, & O'Dea.	2016	**PHQ9** **K6**	ADPT ADPT
Hackett, Teixeira, Farnbach…& Brown	2019	**aPHQ-9**	ADPT

McNamara, Banks, Gubhaju, Williamson, Joshy, Raphael, Eades.	2014	**K10** **K5**	EX ADPT
Nagel, Robinson, Trauer, Condon. Nagel & Thompson	2008 2010	**Stay Strong Assessment**	NEW
Janca, Lyons, Balaratnasingam, Parfitt, Davison & Laugharne.	2015	**HAANA**	NEW
Kowal, Gunthorpe, Bailie. ABS -NATSISS.	2007 2002	**NLES** **NLES**	NEW
Zubrick, Lawrence, De-Maio & Biddle. Williamson, Redman, Dadds, …& Skinner.	2006 2010	**SDQ -** Strengths & Difficulties Questionnaire **NLES** **SDQ**	ADPT
Daniel, Brown, Dhurrkay, Cargo, O'Dea.	2006	**Perlin Mastery Scale adapted**	ADPT
Substance abuse & mental health			
Schlesinger, Ober, McCarthy, Watson, Seinen. Ober, Dingle, Clavarino, Najman, Alati & Heffernan.	2007 2013	**IRIS -** Indigenous Risk Impact Screen **IRIS**	NEW
Cultural assessment & SEWB instruments			
Berry, Crowe, & Deane.	2012	**ACE -** Aboriginal Cultural Engagement Survey	NEW
Program evaluation/population-based studies using instruments relating to SEWB or mental health			
Nadew.	2012	**CIDI -** Composite International Diagnostic Interview (Mental Health) **IES -** Impact of Events Scale **AUDIT -** Alcohol Use Disorder Identification Test **ITP-** Indigenous Trauma Profile	EX EX EX NEW
De Maio, Zubrick, Silburn, Lawrence, Mitrou, Dalby …Cox.	2005	**SDQ-** Strengths and Difficulties Questionnaire adaptation	ADPT
Tomyn, Norrish & Cummins.	2011	**PWI-SC -** Personal Wellbeing Index School-Children	EX
AIHW.	2009	**K5**	EX
Ferdinand, Paradies & Kelaher.	2013	**K6** **ERS-** Experiences of Racism Survey	EX NEW
Whiteside, Klieve, Millgate, Webb, Gabriel, McPherson & Tsey.	2016	**K9**	EX
Paradies & Cunningham.	2012	**MIRE-** Measure of Indigenous Racism Experiences **LOT-R-** Life Orientation Test-Revised **CES-D** -Center of Epidemiologic Studies Depression Scale	NEW EX
Stevens and Paradies.	2014	**NLES** -Negative Life Events Scale	EX
Weetra, Glover, Buckskin, Kit, Leane, Mitchell, . . Brown.	2016	**PRAMS -** Pregnancy Risk Assessment Monitoring System **EPDS** **ANRQ**	ADPT EX EX
Truer & Nagel.	2015	**K10**	EX

		HoNOS - Health of the Nation Outcome Scales **LSP-16** - Life Skills Profile	EX EX
Stathis, Letters, Doolan, Fleming, Heath, Arnett & Cory.	2008	**MAYSI-2 -** Massachusetts Youth Screening Instrument	EX
Berry, Crowe, Deane, Billingham & Bhagerutty.	2012	**GEM** **K10 & DTCQ-8** - Drug Taking Confidence Questionnaire	 EX
Fleming, Gately & Kraemer.	2012	**K10** in HoPE study- Health of Prisoner Evaluation	EX

1. **Kessler (K) 10, K6+2, K5:** The Kessler tools (Kessler et al., 2002) have been used since 1997 in Australian National Health surveys. The K10 uses a 5-point response scale enquiring about selected physical and emotional symptoms described in the Diagnostic and Statistical Manual version V (DSM-V) designed to measure non-specific psychological distress. The K6 and K5 are truncated version of the K10. The K5 contains amended language, excludes the K6 inquiry about 'worthlessness', and is scored using categories of low/moderate (5-11) and high/very high (12/25).

No effect sizes nor gold standard comparison were reported for either the K6+2 or for the K5. However, in 2009, the Australian Institute of Health and Welfare (AIHW) published data demonstrating the convergent validity of the K-5 with various mental health indicators for Aboriginal Australians. The AIHW made comparisons against the 2004–05 National Aboriginal and Torres Strait Islander Health Survey. Results demonstrated clear patterns showing a strong association between increasing numbers of stressors (≥3 events) in the past 12 months with increasingly high to very high levels of distress. Additional clear patterns emerged between those reporting high levels of distress and reported mental illness as a stressor, reported discrimination; and reported removal from their natural Family. Anger was also clearly associated with very high psychological distress (AIHW, 2009). These results raise the question of whether mental illness among this population group a normal human response of a resilient people to extreme levels of distress is rather than a psychopathology resulting from a set of symptoms that are substantially more severe than expected in association with the distress.

Later, MacNamara et al. (2014) used results from the New South Wales (NSW) 45 and Up Study to assess the cross-cultural validity of the K-10 and K-5. They compared results between older Aboriginal people (N= 1,631) with non-Aboriginal Australians (N=231,774) and examined the factor structure, convergent validity, internal consistency and levels of missing data of K-10 and K-5. High level concordance was found in the construct of distress of Aboriginal participants by K-10 and K-5 (weighted kappa=0.87), high internal consistency (Cronbach's alpha K-10: 0.93, K-5: 0.88) compared with 0.89 for non-Aboriginal participants. Correlations between all scale items and the total scores were high with all items. Correlations ranged from 0.57-0.83 in the Aboriginal group and 0.51-0.75 in the non-Aboriginal group for the K-10, and between 0.67 and 0.77 and 0.67 and 0.78 for the K-5. The first item in the K-10, “During the past 4 weeks about how often did you feel: Tired out for no good reason?”, had the weakest correlation with the total in both participant groups. This item is not included in the K-5. Convergent validity demonstrated a strong graded relationship between distress levels and the rates of problems with daily life due to emotional problems and depression or anxiety. These results suggest that the K-10 and K-5 scales show promise for measuring psychological distress among Aboriginal and Torres Strait Islander adults. Measurement properties of the K-6 were also examined following this analysis. Whilst these data were not published the authors reported that the K6 demonstrated very similar validity and reliability to the K-5 (McNamara et al., 2014).Overall, using the Validation Studies appraisal tool this study rated well at 85.7 % (30/35).

2. Patient Health Questionnaire (PHQ) 9: The PHQ-9 comprises 9 self-report items measured on a 4-point scale reflecting the DSM-IV diagnostic criteria for major depressive episode. The PHQ-9 is intended to identify mild, moderate, moderately severe, and severe depression. While there are similarities between the PHQ-9 and the K10, the PHQ-9 has not been as widely used in Australian population surveys.

Esler, Johnston and Thomas (2007) examined the PHQ-9 with four focus groups (n=33). Participants were staff and clients from the health service: 10 males, 23 females. Similar to research by Nagel and Thompson (2010) 'Family' emerged as a pivotal strength and stress for clients. Consideration to either include or exclude 'Family' in screening process was considered crucial. The role of Family in the screening process, and the trusting relationship between the health professional and client emerged as key elements to support accuracy. Amending the wording and inclusion of an 'anger' question (culturally-specific symptom of depression) was a key inclusion.

A later small validation study with a convenience sample of clients with ischaemic health disease (N=34) was undertaken. A blinded diagnostic clinical interview with a trained general practitioner (GP) provided the 'gold standard' comparison (Esler, Johnston, Thomas and Davies, 2008). The internal consistency of the modified PHQ-9 using Cronbach's alpha for the modified PHQ was 0.8, and sensitivity and specificity were good - 80% sensitive (95% CI 66.4-93.6%) and 71.4% (95% CI 56.0-86.8%) specific. However, the small convenience sample size and uncertain 'cultural equivalence' of the gold standard limited the study strength. Using the Validation Appraisal tool this study was rated at 65.7% (23/35).

2. **aPHQ-9.** Brown et al. (2013) undertook qualitative research that resulted in the translation of the PHQ9 into plain English, then the translation/back-translation from a combined dialect of two key Western Desert languages (Brown et al., 2013). Whilst adapting the pHQ-9, seven key features were identified by the Indigenous men that were not contained within the PHQ-9: anger, weakened spirit; homesickness; irritability; excessive worry; rumination; and drug and alcohol use (Brown, 2009).

With the aim to refine the tool for future use with Aboriginal men, Brown et al. (2016) undertook a multi-stage, mixed methods study with 189 Aboriginal men across urban and remote settings in central Australia. The aim was to examine the underlying structure using exploratory factor analysis and predictive ability of the emergent psychosocial constructs.

Strong community collaboration and engagement occurred prior to the study rollout. Thematic analysis of interviews resulted in a working model of psychological distress for this population termed ‘a sense of injury’. This incorporates chronic stress, social deprivation and repeated opposition to their pursuit of determining their own health and self. Spirit or ‘Kurunpa’ was seen by men as being central to the physical, emotional and spiritual wellbeing of Aboriginal people. A bespoke 12-item tool that tapped into four contributing domains: inability to be self- determining; lack of recognition; racism and disconnectedness was used.

The K6 plus questions on worry, anger, weak spirit and homesickness, and the adapted PHQ9 were used to determine the predictive validity (using regression analysis) of the emergent psychosocial constructs to see whether psychosocial constructs/domains the proposed questionnaire were associated with depressive symptomology. Researchers used interviews to establish the domains/structure of the proposed tool. Exploratory factor analysis was utilised to determine or confirm domains.

Depressions in Aboriginal men emerged as cumulative insults to their ability to define and pursue their sense of self caused by marginalisation and oppression. Cumulative adverse life events, unrelenting sociocultural change and disconnection were seen to drive ill-health.

Results indicated that the adapted aPHQ-9 was internally consistent with a community sample of 78 Aboriginal men from central Australia (Cronbach’s $\alpha = 0.776$). Perceived injury and chronic stress factors were positively associated with high depressive scores and 40% of men rating depressive symptomology. This study advanced understanding of Aboriginal men’s psychological distress from being non-specific to a state firmly rooted in historical and present-day impacts of colonialisation (Brown et al., 2016). This study was appraised at 80% (28/35) using the Validation Appraisal tool.

Using the aPHQ-9, Hackett et al (2019) undertook a prospective observational validation study with 500 Aboriginal adults. Participants completed the aPHQ-9 and were followed up by phone or face to face for a blinded assessment using the Mini-International

Neuropsychiatric Interview (MINI) (gold standard assessment). The required effect size was 500 to achieve a precision of 0.1 for the sensitivity 95% confidence interval (CI) and a precision of 0.04 for the specificity CI.

Five-hundred Indigenous adults (with 267 women) completed both the aPHQ-9 and the MINI. Results showed that internal consistence was very good (Cronbach's α =0.88); sensitivity was 54% (95% CI, 40-68%), specificity was 91% (95% CI, 88-94%) and positive predictive value was 64%. Overall, the aPHQ-9 was demonstrated to be an acceptable screening tool for depression in this cohort.

4. NLES*:* The Negative Life Events Scale (NLES) was developed by the Australian Bureau of Statistics (ABS, 2006) as a method of measuring exposure to stress in national surveys after extensive consultation with national Aboriginal representatives. This process not been published. Neither has a psychometric analysis of the NLES been undertaken.

Kowal, Gunthorpe and Bailie (2007) evaluated the use of the NLES in a small study of Aboriginal people in 11 communities in the Northern Territory (NT). Aboriginal Australians associate the term 'stress' as a construct associated with accumulative effects of chronic stress and intergenerational trauma (Petchkovsky and San Roque, 2002). (n = 262).

Discriminative ability and endorsement rates were calculated for each item in the NLES. External reliability was undertaken by comparing the responses of married couples who lived in the same house and had been living there for longer than one year. The Kappa statistic was used to assess the agreement between their responses. Overall, results indicates that most items perform well in relation to endorsement, discriminative ability and reliability. Endorsement rates were low for divorce (15%), separation (12%) and lost job (3%), whilst death of a family member/close friend and serious illness showed good discriminative ability. showed poor endorsement rates. No gold standard assessments nor effect sizes were reported.

5. PWI-SC: The Personal Wellbeing Index-School Children (PWI-SC), developed to measure subjective experience of quality of life with school children, is an adapted version of the Personal Wellbeing Index-Adult (PWI-A) on a self-administered on a 10-point scale. It contains the same seven domains as the PWI-A (standard of living, health, relationships, achieving in life, safety, Community connections and security), and replaces the word ‘satisfaction’ with ‘happiness’ for adolescents. Based on international validation studies, it was assumed that this modified version would be suitable as a comparative study of the wellbeing of Aboriginal adolescents.

This study reported on a population-based comparison with a convenience sample of 519 Aboriginal adolescents ‘disengaged’ from education or training, and aged 12-19 years and their non- Indigenous counterparts (N=351). Tomyn et al., (2011). A Principal Axis Factor Analysis evaluated the factor structure of the PWI-SC and a standard multiple regression analysis determined how much variance in general life happiness could be accounted for by the seven PWI-SC domains. No gold standard comparisons or size effects were reported.

Gender differences amongst the Indigenous adolescents were tested using eight Independent Samples t tests. The mean SWB score for males was significantly higher than for females. Males also score significantly higher than females on six of the seven domains, with the greatest difference in ‘Health’ (8.46 points, p\.001). Females were over four times more likely than males to score 50 or less on the PWI-SC, indicating a greater risk for depression.

Overall, the PWI-SC reported good inter-item reliability and demonstrated convergent validity. The scale performed well identifying that each domain makes a unique contribution to general life happiness.

4.3. Perinatal mental health screening: A cultural review of Aboriginal symptoms and risk assessments.

As described at the outset of this chapter, the decolonising methodology at the heart of this research highlighted the importance of breaking with methodological traditions to ensure a cultural lens was maintained throughout. The traditional systematic literature review outlined above was complemented by a cultural review of key measures that may be suitable for perinatal screening.

Method: Members of the Aboriginal Advisory Group formed a Screening Tool Analysis sub-group to undertake an appraisal of relevant screening/assessment tools from Aboriginal perspectives. Eleven members, all experienced mental health or Family support professionals from the Aboriginal Advisory Group, assessed these tools for strengths and weaknesses through their cultural lens. Individually, each member considered 12 tools against specified criteria.

The sub-group used a range of criteria to establish the attributes of the selected screening tools from a cultural safety perspective. The criteria included psychometric properties; capacity to identify flags for anxiety, depression, and post-traumatic stress disorder (recognised as being supressed below the surface of intentional daily life for many Aboriginal people (Nadew, 2012; Axleby-Blake et al., 2013); language and cultural relevance and safety; somatic versus emotional and psychological signs and symptoms; screening in the perinatal and cultural context; usability including self-administration, use of visuals and associated cost; and what would be useful in an alternative screening tool and process, and why.

Results: Screening tools were selected based on previous literature reviews (Kotz et al., 2020; Kotz et al., 2021 (unpublished). An initial vetting left five screening tools for further analysis: Strong Souls (Thomas et al. 2010), PHQ9 (Spitzer et al., 1999), AimHi Stay Strong (Robinson et al., 2008), KMMS (Marely et al., 2017) and HANNA (Janca et al., 2015). Results were then discussed in groups. Finally, Stay Strong (Nagle and Griffin, 2010), HANNA (Janca et al., 2015) and the Growth and Empowerment Measure (GEM) (Haswell et al., 2010) were strongly favoured as meeting all criteria considered culturally important. These results were reported back to the Aboriginal Advisory group and concepts considered for their applicability in the perinatal context.

4.4 Discussion

This review identified studies that reflect a varied focus on Aboriginal mental health or SEWB. There has been some solid progress toward developing culturally relevant and effective assessments and screening the mental health and well-being of Aboriginal Australians.

Five unique screening/assessment tools have been developed to measure/assess wellbeing, mental-health, depression, anxiety including in some cases alcohol and other drugs (AOD) use. While some validation studies demonstrated sound psychometric properties, they lost overall strength in this appraisal system due to small numbers, the nature of the convenience samples used, or poorly or inexplicit demonstration of cultural and ethical considerations. Some tools such as the aPHQ-9, whist demonstrating good overall psychometrics, would be unsuitable in the perinatal context due to the inclusion of somatic symptoms frequently associated with the perinatal period such as tiredness and poor concentration. Additionally, there was no assessment of protective factors and no indication that the screens resulted in supportive follow-up.

The psychometric properties of validation studies are captured in Table 2.2. As there were no large, randomised control trials included in this review, none of the appraised studies could be considered Level One category or high-level evidence based on National Health and Medical Research Council (NHMRC) ranking guidelines (NHMRC, 2009). See Appendix C. Many of the validation studies could however be considered Level III-2 or 3. However, using the adapted CASP appraisal system allowed more flexible domains for grading such as ethical and cultural considerations as well as performance characteristics. Six of the 17 validation studies rated over 80% scoring more than 26 of a possible 33 (see Table 13). The highest rating validation studies included Marely et al. (2017), McNamara et al. (2014) and Thomas et al., (2010) with scores of 30/35 across domains such as ethical and cultural considerations.

The highest-ranking combined studies included Stevens and Paradies (2014), Trauer and Nagel (2012) and Weetra et al., (2016) who each ranked 40/45.

4.5 Conclusion

In the perinatal period screening Aboriginal parents is considerably more complexthan the presence or the absence of a disease. Yet this is not always reflected in the studies. Through ongoing impacts of colonisation and intergenerational trauma Aboriginal Australian's experience alienation, loss of culture, loss of a sense of personal control, and recurrent challenges to individual and collective spiritual wellbeing. These end manifestations of colonization may be considered important antecedents to violence, self-harm, alcohol and drug misuse, depression and anxiety and suicidality that impact wellbeing. Current practice has these antecedents frequently viewed in isolation. Without understanding, considering and approaching perinatal mental health screening and follow-up care from this contextualised perspective, outcomes are likely to have minimal benefit for lasting change. Wellbeing screening must be linked with healing.

Implications for research and practice: There is a need for further research to inform best practice for mental health screening for Aboriginal Mothers. None of the available instruments have sufficient supporting evidence to confidently apply them to this client group at this most vulnerable of times in their life. Exploring the experiences of Aboriginal women undergoing screening and/or accessing mental health services may assist in better understanding the needs of screening instruments and processes in this complex cultural context.

Ideally cross-cultural instrument development should be involved where mental health and SEWB scales are developed. The clinical stakes of a non-valid perinatal screen are significant in terms of effects on the Mother and infant. Researchers should become aware of priorities and deficiencies in the performance of the scales as they are developed, adapted and used before they correlate scales with health outcomes and attempt to interpret the results. This has rarely been the case.

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Chapter 5. Understanding perinatal mental health from Aboriginal parents' perspective: a conversation with Australian Aboriginal Mothers

5.1 Chapter overview

The preliminary studies in this thesis have clearly identified that current perinatal mental health screening, based on a test developed more than 50 years ago for use in a British population, lacks evidence of validity or suitability for use with Aboriginal Australian Mothers. The need for a culturally considered approach to Aboriginal screening and assessment practices is evident. Notably, in the detailed review of the literature it has also become clear that the voices of Aboriginal Mothers are absent in this literature. Lived experience is increasingly recognised as a highly valuable asset in health research and in service design (Jones et al., 2021; Horgan et al, 2021; Vignata et al., 2021; Bryant et al., 2021) This study reports on results from primary data collection resulting from individual yarns with Aboriginal Mothers with a view to developing a culturally valid evidence-base to inform future service design and delivery.

Specifically, the aim of the current study was to investigate enablers and barriers to a) effective perinatal mental-health screening; and b) strong parenting practices among Aboriginal Australian parents, from the perspective of Aboriginal communities. The latter was included in recognition of the preference for a strengths-based (rather than a deficit-based) approach to screening – understanding what it takes to be a good parent is an important counterpoint to identifying mental health struggles for new parents. Further, in recognition of the finding that poorly managed perinatal mental health is influenced by, and can have a cumulative effect on, other members of the Family (Myers and Johns, 2018; Beestin et al., 2014; Stein, 2011), this study, uniquely, included the perspective of Fathers alongside those of Mothers in this conversation about perinatal health and wellbeing.

5.2 Methods

The broader methodological context and framework for this study has been described in detail in Chapter 2. A brief summary relevant to this current study will be provided here.

Participants. A total of 37 parents participated in individual yarning session.

The 37 Aboriginal parents (27 Mothers and 10 Fathers) identified with 23 clans or Nations from across Australia. The average age at first birth for the women was 18-years, the youngest being 16 (n=4). Twenty-five women were under 40-years at the time of their yarn, 14 were under 30-years. Participating Fathers (n=10) were recruited independently and were unrelated to participating women and were Fathers (n=7) or Grandfathers (n=3).

Ethics. Ethics approvals were secured from Murdoch University Human Research Ethics Committee (Approval: 2013/202), Western Australian Aboriginal Health Ethics Committee (Approval: 553/20170519), Women and Newborn Health Service/KEMH Human Research Ethics Committee (Approval: WNHS-2014062E), East Metropolitan Health, Child and Adolescent Health Service and Fiona Stanley Hospital Service Research Ethics & Governance Office (Approval: RGS2649), St John of God Research Ethics (Approval:1162)

Data Collection. Aboriginal Research Assistants (ARAs), (three women, two men) from diverse clans/Nations, facilitated the individual gender specific parents' yarns (Bessarab and Ng'andu, 2010). Recruitment employed snowballing. Inter-rater reliability and culturally safe data collection were reinforced through ARA training workshops (facilitated by Dawn Bessarab and JK) and a co-designed prompt sheet (Table 15).

Table 15. Research Assistant prompt sheet for parent's yarn.

Beliefs & practices supporting SEWB
What/who has helped influence you as a Mum/ Dad?
What do you think helps to make good Mothers (Fathers), What to helps to make them strong? What/who currently helps you in your role as Mum/Dad? What do you think helps make or keep Family strong?

Common ‘expression’ of anxiety depression
Having a baby can be a stressful time for everyone; were there problems for you? Did you have any problems with your partner or Family? What did that look like exactly? How did that make you/your partner feel and behave?
Knowledge re perinatal depression anxiety, mental health
Most Mums get teary around day 3 after baby comes, but it usually only lasts a few days (the *babyblues).* Did this happen for you/your partner? What was this like for you/you partner? What about *postnatal depression or anxiety?* What do you know about postnatal depression or anxiety? Did this happen to you/your partner/or anyone you know? What was this like for you? What about your partner? *What about during pregnancy,* did you or anyone you know feel anxious or depressed then? What was it like? What about your partner?
Barriers & enablers to perinatal screening
Thinking back, did anyone ask you these questions (show the EPDS) What was that like for you? What did you think about it? How did you feel about this**?** Were you asked anything about other things that were happening in your life that made your life easier or harder at the time?
What might have made it easier for you to talk about this, or how you were feeling?
Supportive follow-up strategies for Mums & Dads
Did you have big worries about being a parent? Did you have someone to talk to about your worries? Who supports you? How? Did you have people to help you with your baby? …from Family/ midwife/CHN/AHW? How did they help? What other help did you have? What help would be good from Family? What support would be good from your partner? What support would be good from your midwife/CHN? Would anything else have made becoming parent easier for you?
Should Aboriginal Dads be screened? By whom?
Often when Mum gets depressed or has anxiety, Dads get depressed too, especially after baby

comes. This makes it even harder for everyone.
If there was a culturally solid screening tool, do you think Dads should be screened?
Who should screen them?

5.2 Analysis

Data were transcribed, then managed and coded using Nvivo12. Drawing on Charmaz's (2012) approach to grounded theory and thematic analysis, information was explored line by line to micro-code then macro-coded to establish central themes. JK with the second author (CR) and five (5) Aboriginal ARAs independently analysed and coded data using audio and transcribed interviews. Subsequent collective exploration elicited points of similarities and difference.

Coding from (i) Mothers and Fathers and (ii) health practitioners' data were first presented to the AWP, then the AAG, then the LRAG for further exploration and analysis.

Emerging themes were further evaluated and triangulated by the AWP and JK to synthesize barriers and enablers to effective screening and strong parenting practices and begin construction of solutions. Conceptual designs progressed through workshops facilitated with members of the AAGs and the LRAG. The Elders Cultural Security Group then considered proposed solutions and designs. This iterative circular codesign approach (Image 1) took just under 3-years. The result, a culturally responsive holistic model for perinatal screening and follow-up, is reported in chapter 7.

5.3 Results

The quotes below are characteristic of emergent themes from the yarning sessions, first (i) enablers and barriers to effective perinatal mental-health screening; and then (ii) Strong parenting practices.

5.3.1 Enablers and barriers to effective perinatal mental-health screening

5.3.1.1 Perceptions of perinatal depression and anxiety (PnD/A)

Aboriginal women commonly did not relate to notions of perinatal depression or anxiety (PnD/A). Inferences made either by participants, or to participants by a senior woman in their Family, were that these labels were a sign of '*weakness*' or '*attention seeking'*. Many women identified someone they knew who had experienced or was experiencing PnD/A symptoms, making comments like: *'you just gotta get on with it'*(F0023)*; 'women need to be strong"* (F0021); "*you've just gotta be strong physically and mentally in yourself, to have coping skills to cope, on your own"*(F0032). Women all reported challenges and crises in daily life causing high levels of distress. Circumstantial *'troubles'* were freely discussed, less so the feelings aroused. This was often frowned upon. Rarely were feelings identifiably associated with labels like 'depression' or 'anxiety'. "*Womans keep it to themselves. If you feel stressed you shouldn't show it. But there's always someone to talk to about what's going on. But I don't believe in stress. It makes it worse if you think about it. Just try to solve it somehow."* (F0015)

The reluctance to talk about feelings with their midwife or CHN was common and exacerbated by a lack of trust or perceived paucity of cultural insight, both common themes. *"..*[Midwives] *say that long as you have a healthy baby, it doesn't matter. But that is bullshit, it does matter. It is not just a physical thing it is an emotional and spiritual thing to. Because my spirit was just crushed. I was alone…I don't know about other Aboriginal women, but if I am physically and emotionally okay, I'm OK; but if my spirit is feeling like shit because I am away from country and Family and culture then I'm no good."* (F0019)

5.3.1.2 Experiences of PnD/A

Most Mothers under 40-years (22/25) reported never having experienced PnD/A, but articulate feelings and experiences associated with PnD/A according to DSM-1V criteria: "*I felt weepy and I cried every day…I didn't want to be here"* (F0010) and *"I felt just worthless, like you are not there for any purpose, only there to have that baby and that's it…I'd get up* *and do everything I had to do but I felt nothing. Nothing felt like it was worth it"* (F0020). The majority of all women (25/27) did not relate to medicalised labels to describe their distress.

A word frequency search of interviews transcripts revealed the words 'depression' and 'anxiety' were used by only three women of all women (3/27). Two had extended histories of diagnosed mental illnesses and the diagnosis appeared reassuring. For all others, word usage and occurrence, in frequency order were: *stressed/stressed out/ stress/stressful; worried/ worries; sad/upset/unhappy; struggling; Family trouble; no good; shame; panic; pain*.

All seven Fathers explicitly or implicitly described their partner's experiences of PnD/A and had little to no insight into what was happening for her at the time. Six of the seven young Fathers either did not know or chose to ignore what their partner was going through.

"at the time I didn't understand it [her depression]. *I would come home from work and I'd have stuff dumped on me every day and I didn't realise how she was feeling*. W*e were healthy and we had two beautiful kids and we've got a job, and everything was okay and nothing wrong about how we are."* (M0024)

In all but one case, the Fathers did not engage in discussion with their partner about her feelings but indicate that doing so would have made for stronger parenting and stronger partnering.

5.3.1.3 Responses to screening

EPDS screening was routine in all Western Australia health services from at least 2010. Women who birthed during this time (n=20) were asked to reflect on their experience of being screened for PnD/A. Half had no recollection of being screened suggesting they were either not screened, or the process was not sufficiently meaningful to recall.

Positive bias. All women identified the need for a screening tool that meets their cultural needs. Those who recalled the EPDS reported positively biasing their responses: *"I lied* [with EDPS] *just didn't feel comfortable, I didn't have a relationship with* [CHNs] *at all. It was different people every time."*

Underlying distrust and fear strongly influenced women to not disclose their struggles or to positively bias their SEWB screen responses.

"…I wasn't gonna say how I was feeling on that [the EPDS] *I didn't trust the health nurse. How would I know that that score* [the EPDS] *could be bad for my kids when they grow up?" (F1025)*

Two women recalled suicidal ideations. One recounting her failed suicide attempt:

"I was in an abusive relationship…I started feeling really insecure about every move I made…I had not attached myself [to the pregnancy]*…. I was still in survival mode so I wrote a letter apologising that this wasn't* [Family's] *fault, and I put myself in the bath with no water and took* [tablets] *and just thought 'f..k it I don't want to be there anymore."*(F0029)

Family and domestic violence (FDV) inquiry also appeared positively biased, with nine women reporting or inferring experiencing domestic violence (DV) during pregnancy; but not disclosing this to a clinician.

"if you tell a doctor or whatever that you man is floggin' you…then they're going to tell DCP or whatever, and then you can have your kid taken off you for that. The risks outweigh the benefits, so it's just not worth answering correctly" (F0020)

5.3.1.4 Enablers to effective screening

Trusting relationship. This was viewed by all women as imperative to promoting engagement in a therapeutic relationship. If trust was not established, it was widely viewed as disaffecting to ask personal questions. 'Trust' meant being your word, *'talking straight'* and ensuring that women can rely on what the professional says she will do, she will do. Continuity of carer was viewed as critical to this*: "it really is all about relationship you have with that person. Otherwise no-one is ever going to be honest."* [F0011]

Conversely, if trust was not present, continuity of carer was irrelevant.

"I [was assigned] *this Midwife. She was really shit. Her posture, everything about her. She was late for appointments and then she wouldn't come and pick me up... I was supposed to see her,*

but I avoided her and saw the doctor instead." (F0029)

Non-judgmental. All participants were highly sensitized to feeling 'judged' by service providers. They reported feeling judged for 'being black', too 'young', too 'old' or just being 'not good enough'. "*I knew everybody was looking at me, judgin'. We were the only black faces, I felt very uncomfortable."* Experiences of feeling judged were embodied in the service provider's use of language, tone of voice, the way questions were framed. A genuinely caring and non-judgemental approach was critical when making personal inquiries.

Yarning. This informal, relaxed, open-ended style of communication promotes trust and engagement. It was viewed as critical prior to personal inquiry: *"Blackfellas don't like…to answer* [questionnaires] *its intimidating and all of a sudden there is a barrier…yarning and having active listening skills are better* [F0029] and *"a bit of a yarn is important; some young Mothers, they bit shy, bit shame, won't speak their mind or give their opinion"* [F0011].

Aboriginal staff. Many women reported preferring another Aboriginal woman to facilitate screening or support the process. This removed the need to explain themselves, for example *"...you need to have one person, preferably a black fella, someone who is kind, and a steady person throughout your pregnancy…you much more likely to be honest then and not bottle things* up inside"[F0021].

Maternal role model. Both genders reported a preference to be screened for SEWB issues by a *'Motherly'* figure rather than by another man (for men), or a younger woman (for women):*"she don't have to be* [Aboriginal]*, but she has to be someone who is open and honest…older…who's got that Mummy feel about them."* [F0012]

"men don't like talking about their feelings…its a thing with men that they don't wanna be seen as being weak or somethin … but they need to, you know, cause they just bottle things up then explode…I reckon they would rather talk to a woman they can trust, you know a bit older woman, rather than another man, see we've all had a Mother or Grandmother we can relate to." (M006)

Encourage strengths. Whilst trust was critical in promoting engagement, so too was believing in the woman, encouraging her and focusing on her strengths. Lack of regard for a young Mother's inherent strengths was identified as strongly disaffecting; it resulted in her feeling judged. Trusting that a young Mother, with the right supports, will be able to rise up to be the best that she can be. This was particularly critical for single and young Mothers. *" …it would have been good to hear her* [CHN] *say just once "Charlotte you're doing a great job!' or 'well done Charlotte!' ...just once! It's something I've never heard my whole life, no-one has ever said that to me*". (F0011]

Kindness. Kindness, consideration, and compassion were notably absent in many women's perinatal service experiences. It was described as fundamental to developing trust. *"They just made me feel shame; I don't know how you get around that…it's easier to trust and let your guard down if they are kind"* (F0026). When kindness was shown, the care provided was highly valued, as was the professional offering it. *"She was so understanding, and very helpful… I remember they were all kind, even the receptionist. It made going there so much easier"* (F0018), and *"I wished to God that they had worked with me with my first kid. She came to my home like and was really caring and supportive"* (F0029).

Involving Family. The importance of Family and for health professionals to work with Family, emerged as a strong theme with the Fathers as well as Mothers. The majority of men reiterated the importance of Family and working with the whole Family when a Father was vulnerable. The role of the midwife and CHN was seen to be important for young Fathers, as for many it was their main connection with strong support. With the exception of a few, this perinatal encounter with midwives or child health nurses was identified by many Fathers as missed opportunities.

"A lot of nurses are trying to educate parents and it's not working; you've got to work family. It's just talk till your blue in the face. A lot of young people, it just goes straight over the top. So, you've got a work Family; but a lot of the CHNs they do not want to change." (M009)

5.3.1.5 Barriers to effective screening

Implicit racial bias and racism. Most women (n=25) reported experiencing some form racism or cultural bias. These experiences elicited strong feelings which exacerbated poor engagement and alienation from potential supports. "*I can't show my flaws to them white nurses, they're judging me, I know it by the way they look at me and treat me."*(F0021) Women were highly sensitised to the alienating language often used by health professionals. They reported overhearing themselves being referred to in comments like ***'that** Aboriginal woman'* and *'there's too many of* **them** *in there'*. This was experienced as deeply wounding.

"Coming from a minority we notice it; we really notice these divisive ways people use language. If you are a white woman nobody identifies that. But we always get pointed out for being Aboriginal, like it's a bad thing. That how they [nurses] *talk about us and to us."*(F0033)

Fear and Shame. Fear and shame was linked with perceptions of PnD/A screening. It was associated with being labelled as a bad Mother, of losing control over their self-perception as being a strong Mother*: "Yep, there is 'shame' in depression! Our Family is like yeah you just gotta toughen up and get the f..k over it, man up and get on with life"* (F0017). Score-based screening was equated with pass/fail results, further emphasising fear and shame, leaving many women feeling '*no good'* or *'winyarn'*. Added to this was stigma associated with Department of Child protection (DCP) or worse child removal: *"I don't want the risk of losing my children or anything because I'm post-natal depressed…I worry about welfare* [DCP]. *We definitely try to deal with it ourselves."* (F0027)

A common theme was the fear and shame of being labelled mentally unstable. Once attached, this did not easily go away. The fear associated with the EPDS being implemented without a cultural safety net was significant: *"I was not gonna say anything on that* [EPDS) *to fail me. How would I know what they do to my boy when he grows up if I fail."* (F0024)

Power inequity. Also commonly expressed was the lack of autonomy and control many women reported feeling within health care settings. They felt obliged to not complain or seek clarification from non-Aboriginal professionals for fear of further discrimination. Their way of managing was to accept whatever care was, or was not provided without complaint, or to avoid contact with that service or provider.

They [midwives/CHNs/doctors] *have no idea of the impact of what they say and do, of their attitude and the language they use has… They just have no idea; and I sometimes think it is a power thing, because they are the doctor or the nurse. Nothing they do is ever wrong. Because they are coming from a place of higher power and then there is just us at the bottom.”* (F0033)

Poor communication. Partially due to power differentials between Aboriginal women and their health care providers and partially due to cultural and language barriers, communication breakdowns were not uncommon. This was distancing for many, for others it directly impacted their care.

“I already had her immunised. I always made sure of that….But once I turned up for me cause I was not travelling well, and even though she still had [been immunised]*, I’d go for another surgery and they double dosed my kid, and I was like “no”, but they didn’t believe me… there is always communication problems”* (F0034)

Task oriented approach to care. The vast majority of women reported health-care professionals as being ‘task orientated’ which was at best disconcerting. They described feeling unsupported, and scrutinized by these professionals, perceiving that the ‘task’ held greater value than themselves, *“They’d pick me up and take me to my* [antenatal] *appointment…but it was just a clinical tick-box thing, there wasn’t much that that I got, I didn’t feel supported.”* For Aboriginal women genuine ‘relationships’ were central to good care. A trusting relationship was everything; appearing ‘task oriented’ was counter to this: *“everything is really clinical, and they’ve got a checklist, like the weights and all that.* [F0027]

Non-contextualised screening. Routine inquiry about symptoms of PnD/A, outside the context of their daily lives, and/or pathologizing this majority experience as a ‘disease process’, was viewed as unhelpful. The EPDS was reported as *'not relevant', 'too generalised'* and *'disconnected'*. It ignored the highly changeable and often challenging circumstances of their lives. Some women reported completing the EPDS to support their midwife, to *'help her out'*. Women viewed SEWB as more relevant to their daily lives. Rather than looking for assigned labels then providing support from this perspective, they prefered to be able to safely *'yarn'* about their lived experiences with someone who provided compassionate understanding and practical help.

"[the GP] *said I* [had] *depression...and I thought 'I know it's not depression'; he gave me tablets and I took them and they meet they jumpy so I threw them down the toilet and didn't go back…I knew something else was wrong with me; but I was in domestic violence then."* (F0018]

The lack of understanding of the nature of Family connection and unquestioning loyalty to Family were perceived as often at odds with setting healthy boundaries in the way suggested by some health professionals and was thought not to be well understood in the screening process. Drawing boundaries in the interest of self-care was challenging for many parents of both genders. Actions outside this unquestioning loyalty tended to create 'shame'. The capacity to establish boundaries whilst maintaining Family loyalty, was occasionally articulated (5/37) where a there was a strong commitment to protective parenting. However, it was never an easy thing to do.

"There is a lot more going on in our life that we can't get away from. We can't just say 'don't deal with that' ...How can you deal with that culturally? That's what we do in our families, so it just helps talking to someone who just gets that." (F0010)

"..Family obligations, you have this strong sense to provide; but … I've got kids of my own and I can't sacrifice their upbringing to do the right thing by him [cousin] *….so I help him when I can … but I have to set a standard, I can't do it every day."* (M006)

5.3.2 Strong parenting in Aboriginal communities

There were many examples of strong parenting practices within Aboriginal communities. The strength Mothers were able to draw from connection with Family and each other as Mothers as sisters/ Aunties/ Mothers was evident throughout the Mothers narrative. They all saw themselves as strong natural Mothers and demonstrated this through surviving complex and challenging circumstances in life. Important in enhancing this was having a trusted ally and champion, preferably Aboriginal who was willing and able to meet them in the safety of their home.

5.3.2.1 Mothers' perspectives:

Despite many complex stressful life events faced by Aboriginal women, there were many common highly protective themes. The 'birth Mother' was a central critical influence in the lives of participants (both genders), and a strong supportive Mother or Grandmother figure was highly protective and influential in supporting strong resilient adults and thus parents. However, the strong influence and connection to 'Family' that extended beyond the immediate Family, was a powerful influence also.

Family-Community Parenting. Family presence, acceptance, familial respect and the important role of Elders and community parenting were cornerstones for strength for the vast majority of participants. For many, strong Family connections provided physical and emotional strength and support.

" .. when I was depressed my kids went there for a week and a half, it was nothing, it was no big deal. They go there all the time, they know what their routine is, and it's quite an easy thing to manage for everyone. And sharing parenting like the discipline as well as the care." (F0010)

For others, lack of childhood maternal/parental support cemented their commitment to become stronger, more protective parents. These parents all had an additional strong maternal 'champion' frequently a Grandmother, who supported them as children/adolescents. Despite their own disrupted childhood, their parental relationships remained at least respectful, if not intact.

Connections and relationships with Family went beyond the physical and emotional, it was implicitly connected to spiritual and cultural purpose and identity.

"I was raised and surrounded by Mum's Family, and then told the right and wrong way by everybody. I learned who I was and very early protocols." (F0026)

Unquestioning loyalty to Family, the protective nature of Family connection, and Family was a strong theme. However, the unquestioning loyalty to Family was often at odds with setting healthy boundaries. Drawing boundaries in the interest of self-care was challenging for many parents of both genders. Actions outside this unquestioning loyalty tended to create 'shame'. The capacity to establish boundaries whilst maintaining Family loyalty, was occasionally articulated (5/37) where a there was a strong commitment to protective parenting. However, it was never an easy thing to do.

"There is a lot more going on in our life that we can't get away from. We can't just say 'don't deal with that' ...How can you deal with that culturally? That's what we do in our families, so it just helps talking to someone who just gets that." (F0010)

"..Family obligations, you have this strong sense to provide; but ... I've got kids of my own and I can't sacrifice their upbringing to do the right thing by him [cousin] *....so I help him when I can ... but I have to set a standard, I can't do it every day."* (M006)

Cultural identity. Cultural identity was considered strongly protective for mental health and central to strong parenting. These cultural connections to country, Kinship and Family were healing *"...but I still know where I come from, I belong and I know my Family and where I come from"*(F0033), and deeply significant "*I know that strong connection is there and in the Wheatbelt, we have a strong connection, makes us strong"*(M001). Connection to Family enabled and empowered an inner cultural strength that was hard to articulate but deeply embedded in the psyche.

"I completely associate my Family, as my culture. I learned very early protocols. Because we needed to know who was who, and what was what; so Family and culture are synonymous. And I cannot separate the two." (F0022)

A number of participants explicitly grieved their loss of cultural connection directly resulting from Stolen Generation heritage. *"We have had to grasp whatever culture we have left"*(F0033) and again *"I think about culture I think about everything I've been taught through my Family, but I have missed a lot and trying to reconnect now."*(F0023).

Maintaining respectful connection and guidance from Elders, were associated with cultural strength.

"*Nan hardly ever growled at me, but she did once. She taught me my identity. I grew up in a white home with a white Mum. One day I said to my Nan 'I'm only a quarter cast!' …and Nanna was furious at me, she slapped and she growled me and scared the shit out of me. She said "you are not a part, you are Nyoongar!"; and from then on I was like 'It is what it is! You're black that's it!. You got a black* Grandmother *so you're a black fella!' …and I was like 'OK then!', and so that grew my confidence with my identity, and I was like 'I don't give a f..k what anybody says my Nan is black! I'm black!'* (F0029)

"…for me, marrying a black woman was very important,…that was going to make me stronger as a man, as a Father and as a husband. I could picture my own parents struggling, trying to make it in this society, because they're black. They were trying to breed out the black, and they almost [succeeded] . *Its up to the next generation to bring the colour back in, bring that culture back and bring that pride back, you can struggle together."* (M003)

Identity as Mother. Both genders viewed the 'role' of Mother with deep admiration and regard. The 'Mother role' was considered a strong force holding Family together; many afforded their own strength and surivival to the presence of a strong Mother or Grandmother in their early years. *"If the Mother is strong then the Family can be strong, that's how it is"*. Many identified with a Mother or Grandmother in their lives, to whom they afforded much authority and deep respect. One young Father articulated this well:

"Boodjari is when your wife's pregnant and for me I think when you talk about Country, it's the country part, our Mother was the Country. She was the vein or the artery, where we come from, where we originate from and her, she was the matriarch, the backbone of the Family and like I said about my son's about disrespecting Mum.. Even today, a Mother should never be disrespected…. Having that connection with Country and Mum, I know that strong connection." (M001)

Aboriginal women all considered themselves culturally as proud, strong 'natural' Mothers. A deep sense of pride and strength emerged from transition into Motherhood that was difficult to articulate yet implicit in many interviews. *"We black fellas were prone to be Mothers. It naturally comes to us. We know what we need to do"*. There was no shame in birthing at a young age. Eighty percent (80%) birthed before 20-years of age (n=28); 20% transitioned from very early adolescence to Motherhood at or before 16-years (n=7). Despite challenges of caring for a newborn and children not being easy and despite additional adversity, Motherhood provided a strong sense purpose.

"I escaped [DV]…*I was sticking out really big ways with my third son, and then after I had him two weeks later, I left him for good… I had to get away…it was self-determination. My kids were my strength, they really were."* (F0018]

"having a baby saved my life, because before that I felt like I didn't have a place. And now that I brought a person into the world I needed to take responsibility for that person. And he was my motivation and it makes me make better decisions my life." (F0021)

Despite their pride and purpose in Motherhood, young Mothers reported lacking practical support, acknowledgment, or encouragement. New Mothers, particularly teenage Mothers commented that their journey was extremely hard, often feeling isolated and alone.

5.3.2.2 Father’s perspectives:

All participating men reported great pride in their role as Fathers. Whilst there can be no doubt that the Fathers embraced the notion of Fatherhood, and experienced parallel occurrences, their lived experience was very different to those reported experiences of Mothers. Most Father’s descriptions of strong parenting were gleaned from learning over time, from mistakes made.

Partner support. In all but one case, Fathers recognised that offering support to their partner during the perinatal period would make for stronger parenting and stronger partnering. *“I was off and doing my own thing, like I didn’t even care or cross my mind that that’s how* [depressed] *she’d be feeling. I didn’t think at the time I was doing anything wrong, but now I could definitely see I could’ve been supportive.*” (M007)

“she went through [depression] *with the first one really bad, and I think she goes through it every time. Probably it was my fault because I wasn’t as supportive as I should have been…I would go out for weekends and drinking and that and I probably pushed the depression a lot. And then she actually said ‘I hate this baby’, and once she had said it, I thought ‘I can’t believe it’….Looking back now I should have done a lot more for her. But like I said that’s what men do.” (M006)*

For these Fathers, conversing about worries and emotions, either their own moods or those of others, was perceived to be weakening for them as men. This was an accepted gendered norm. Talking about worries or feelings was something women did. Most of the men acknowledged the benefit of talking about their worries, yet there remained a self-imposed expectation to be *"emotionally strong and not show no weakness"*. Two of the three Grandfathers had a different perception of what constitutes being a strong man and Father when it came to reaching out for emotional support or advice.

“there’s a lot of pride in being seen as strong parent; but how are they supposed to go if they

don't express themselves about how they are feeling. You need someone to lean on who can support you; but most young blokes have got no-one." (M009)

Putting baby first. Nine out of 10 men became Fathers before their 20th birthday. All acknowledged that at the time they were engaged in the common teenage lifestyle of drinking alcohol and smoking marijuana *'the stuff normal kids do'* and *'doing stuff we shouldn't be doing'* . Two young Fathers gave up this lifestyle despite their age and whilst it was challenging being a young Father, both had strongly supportive families. Being surrounded by strong Family indeed helped ameliorate distress by 'sharing the load' of parental concerns for a number of young Fathers.

"It was around my 17th birthday…she just got back from getting a pregnancy test, and yeah it was very scary… But we decided to give the baby the best chance possible, so [my partner] *give up drinking and smoking marijuana at the time, and I done the same.. I gave up all of that to support her and it was a massive lifestyle change straight away at that age."* (M002)

Role-models. For others, their teenage lifestyle continued for many years. This created conflict within their relationship for some. For others the conflict was within their relationship and within themselves. Many young Fathers lacked strong Father role models and had no-one to turn to with struggles. One Grandfather succinctly described this complexity.

" lot of these kids they are children having children, and their parents aren't very old either; and unfortunately, a lot of Aboriginal people have lost their parents, and if they don't come from a large strong Family there is not much chance." (M009).

"They don't have the role models. They think their peers are their role models and that they can keep drinking and going out each night. And that's when the trouble begins. And if they don't take responsibility then the trouble doesn't stop, and it gets worse. (M001)

Changing roles. A traditional model of the role of the Father figure was a strong theme among all young Fathers. They saw themselves as role models for sons, and as protectors, providers and somewhat distanced from day-to-day Family life. They perceived Fatherhood as a demonstrating of their male prowess. They viewed ‘Mother’ as expert in household management and caring for infants and children.

“When I had kids, I was smoking and drinking and doing what every other kid does. It wasn’t anything unusual. But when I had my son I really did not change very much, because I thought that being the Father you protect your son you stand your ground and take no crap from no-one, be that alpha male, and teach him to be that.” (M006)

However, there was also an awareness that perhaps came with maturity that there were community responsibilities for raising children too:

“Growing up around culture..for my Grandfather.. it was everybody’s business to look after when a woman is pregnant, and the kids, they belonged to everybody, and there was the women’s business, and the men’s business. But now, just the womans who looks after the kids and that’s the role of a woman.” (M003)

Gendered parenting. A strong theme with the Fathers was explicitly gendered parenting. The majority of Fathers (6/7) would not consider changing a nappy or helping with babies or small children. They had little to do with their newborns and infants. They communicated little understanding of the concept of co-parenting, viewing their role in parenthood as the ‘outdoor parent’ playing football with their sons when they were old enough. They reported being more reserved and less emotionally expressive with sons, seeing their roles as the disciplinarian and not wanting to be seen as being too ‘soft’.

“There is definitely evidence to say that when it’s a young boy, a Mum and a couple of sisters, that boy tends to be a bit soft, if that’s there from day one. There are expectations like playing football and do things that a man would do. Dads should be spending more time with their boys.” (M001)

All Fathers had gone on to have a daughter and were surprised by the changes in their parenting styles once their daughter arrived. Having a daughter appeared to ‘soften’ their approach to parenting. They reported becoming more protective and openly affectionate.

my daughter really changed me a lot. I wanted an alcohol free violent free environment in the house. [Trouble] *is often caused by alcohol fuelled homes. I did* [drink alcohol] *when I had my sons but when I had my daughters anything that would potentially affect them I wanted to change; it was biggest change for me .. the role of the Father with the daughters was something different."* (M006)

"I've learned a lot from having daughters, girls need to be raised by a woman but they need to be loved and supported by the Dads too… even now my two girls run up to me when I get home and climb on me and give me a hug and a kiss. And it's like I haven't seen them for a whole week." (M002)

Fathers who had remained with the same partner and who had had 4 or more children (4/7) each identified becoming more engaged in co-parenting regardless of the infant's gender. *"I didn't have anything to do with the nappy changing stuff or the housework, that was her role, but I've got better at all that over time." (M007)*

Whilst the numbers of men participating in an individual yarn was not high (n=10) it is interesting to note that the majority had partners who were taking antidepressants, and that none of the men had realised when their partner first became depressed. The younger Fathers did not appear to talk about their emotions with their partners, nor with each other. Their impressions of what it constituted to be a Father and man limited their capacity to seek emotional support from others.

Many younger Fathers lacked guidance in Fatherhood or a paternal role model. They lacked clarity in their roles as Fathers and husbands, had little understanding of concepts of co-parenting and continued to engage with their peers in the same way they had prior to becoming a Father.

The Grandfathers and Fathers who had the benefit of hindsight recognised that many young Aboriginal Fathers are struggling without the strong support of familial role models and support. The dislocation and fragmentation resulting from colonisation and the Stolen

Generation raises questions about how Aboriginal men learn to be Fathers. As a result, many young Aboriginal Fathers are struggling. The perinatal period offers a window of opportunity for culturally relevant support. Fathers need to be included in the context of holistic perinatal mental health assessments.

There was a clear message that strong parenting for the men was something that you grow into by learning from mistakes, and that being a first-time parent comes with many challenges. Moreover, that perinatal health professionals have a potentially important role in supporting new parents to be informed and supported at this important time. Involving Family in perinatal care also seemed to offer great potential for working in a culturally supportive way. While a number of barriers were identified to perinatal practices, the existence of a trusting relationship throughout the perinatal period was a strong protective factor.

In summary, strong parenting seemed to involve the engagement of the broader Family and community network for support, listening to older women in the community, having Dads more engaged with kids and adopting healthy behaviours such as giving up alcohol and drug use.

Chapter 6. Health professionals' experiences facilitating perinatal mental health screen and wellbeing assessments with Australian Aboriginal women

6.1. Chapter overview

It is clear from the preceding series of studies that health professionals are a key element in the success of perinatal care. When there is a trusted relationship, the outcomes can be powerfully positive for Mother, child and Family. However, there are also many barriers to engagement for Aboriginal Mothers. This chapter presents the findings from the Aboriginal and non-Aboriginal health professional participants involved in this study. Through interviews, focus groups and a survey, the qualitative data built on the previous findings from the Mothers and Fathers.

6.2 Methods

The methodological context for this series of studies was reported in Chapter 2. Methodological issues specific to the current study will be described here.

Participants: The overall project sample (n=140) participated in either face-to-face consultations or focus groups (Table 3). A separate group responded to the statewide questionnaire (n=154). Professionals, predominantly frontline service providers, were recruited from a representative range of health services (government and non-government). A small number were in management or research roles. Sampling of participants was purposive, identified through snowballing. Overall, (n=103) service providers participated in either semi-structured interviews (n=21) or in one of 10 focus groups (n=82). Seventy-seven percent identified as Aboriginal.

Questionnaire respondents (n=154) were predominantly midwives (76%); 15% were CHNs, 9% Aboriginal health workers (AHW). Eighty-three percent (83%) were non-Indigenous (Table 5).

Project Governance. The Governance framework for *Kalyakool Moort*, codesigned with Aboriginal community included gender specific Aboriginal Advisory Groups (AAGs), the mixed gender Working Party (90% Aboriginal); the Lead Research Advisory Group (LRAG) (50% Aboriginal) and the Elders Cultural Security Group. To optimise research translation, the LRAG had high level representation all key stakeholder organisation (Table 16).

Table 16. Organisational Representation on Lead Research Advisory Group (LRAG)

Organisational Representation on Lead Research Advisory Group (LRAG)
Aboriginal Health Council of Western Australia (AHCWA)
Boodjari Yorgas (Armadale Hospital)
Center of Perinatal Excellence (COPE)
Child Community Health Services (CACH)
Department of Health Aboriginal Health Division
Health Derbarl Yerrigan Health Services
East Metropolitan Health Services
Fiona Stanley Hospital
Indigenous Parent Support Service
King Edward Memorial Hospital (KEMH)
Midland Women's Health Care Place
Moorditj Koort Community Health Center
Moort Boodjari Mia (St John of God Hospital Midland)
NGALA Family Services
Nursing and Midwifery Office, WA Department of Health
Specialist Aboriginal Mental health Service (SAMHS)
Telethon Kids Institute (TKI)
Utility Creative

WA Primary Health Alliance
WA Department of Communities
Women's and Family Health Services

Intersectoral and interprofessional diversity in the AAG membership, safeguarded multiple reflective viewpoints throughout the research. Invitations extended for membership were determined by recommendations from managers and/or community Elders based on their respected, experienced, and valued work with Aboriginal Community (Table 17). Three AAG subgroups emerged: (i) the Aboriginal working party (AWP) actively supported and worked alongside the non-Indigenous PhD student (JK), (ii) the AAG mental-health subgroup (AMHS) undertook a screening tool analysis, (iii) the data coding subgroup (DCSG). Table 17 summarises the interprofessional and interagency of the Aboriginal Advisory group.

Table 17. Aboriginal Advisory group (AAG) organizational representation

NB: WP denotes working party (AWP) subgroup; D demotes data coding subgroup (DCSG)

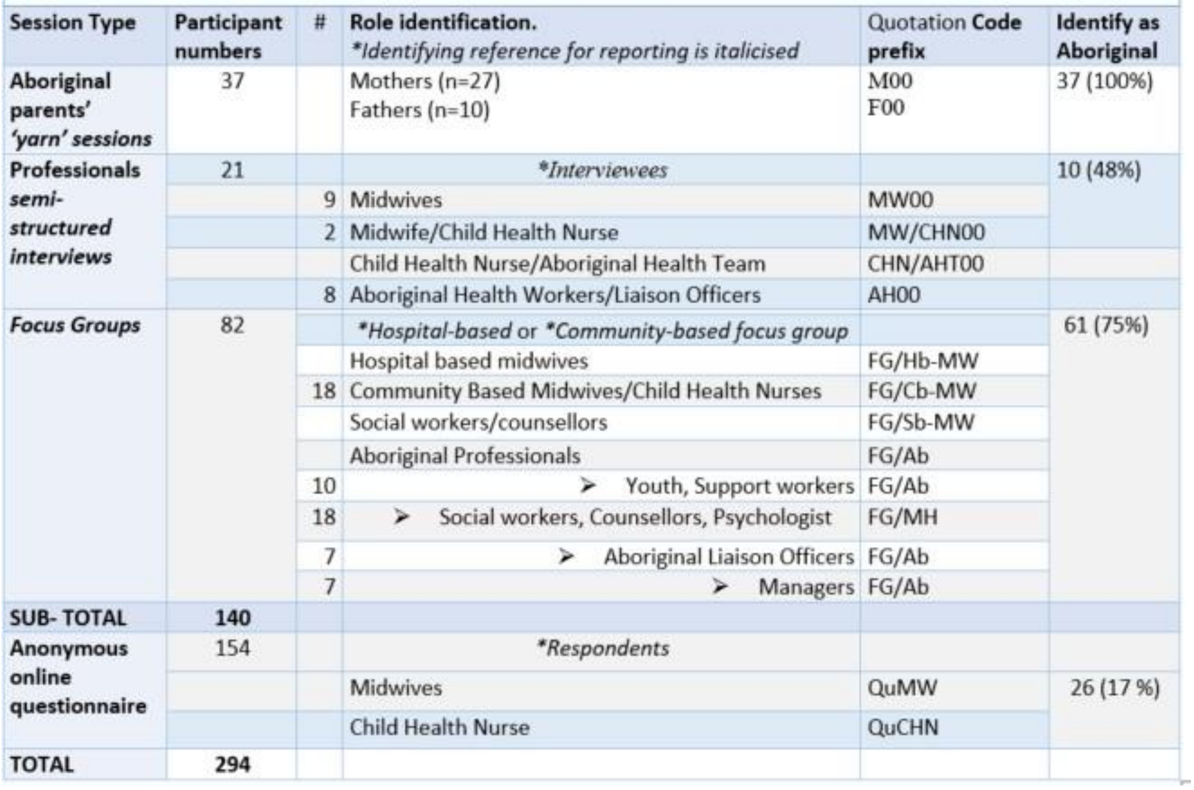
Organisation	Position	
Aboriginal Health Strategy East Metro. Health Services	Senior Project Officer	WP
Aboriginal Leadership Team: Dept. of Health.	Senior Development Officer	
AIME Mentoring Program. UWA	Manager	D
Anglicare	Support Worker	
Bentley/Armadale Medicare Local - Aboriginal Mental Health Team	Mental Health Manager	WP D
Boodjari Yorgas - Armadale Hospital	ALO	
Child and Adolescent Health Services (CAHS)	Child Health Nurse (CHN)	WP D
Dept. Child Protection & Family Services	Social Worker and Team Leader	WP
Derbarl Yerrigan Health Services	Women's Health Nurse and an AHW/Elder	WP
Family Planning WA	Aboriginal Programs Manager	
Indigenous Parent Support Program	Manager	WP
Kambarang Services	Director & Cultural Consultant	WP D

Moorditj Koort	Chief Executive Officer (CEO)	WP
Moort Boodjari Mia ... Maternity Group Practice	Manager· Women's health	WP
Murdoch University	Aboriginal Research Assistant	
North Metro. Health Services	Health Promotions Coordinator	WP
Peel Rockingham Kwinana Mental Health Service	Counsellor	WP D
Save the Children	Support Worker	
Swan Districts Hospital	ALO	
Telethon Kids Institute	Researcher	
Uniting Church in Coolbellup	Reverend & Elder	
Women's and Family Health Services	Aboriginal Programs Manager	WP
Wungen Kartup Specialist Aboriginal Mental Health	Mental Health Worker	WP

Ethics. Ethics approvals were secured from Murdoch University Human Research Ethics Committee (Approval: 2013/202) and Western Australian Aboriginal Health Ethics Committee (Approval: 553/20170519)

Data collection. Rich data were collected from health professionals using semi-structured interviews or facilitated focus groups. An anonymous online questionnaire was also distributed across Western Australian (WA) via midwifery networks (Appendix F). Table 18 describes participants demographics, coding prefixes (in quotes) and descriptors used in reporting to distinguish and provide context data referred to in this report.

Table 18. Data collection methods, demographics and reporting code identifier.



Session Type	**Participant numbers**	**#**	**Role identification.** **Identifying reference for reporting is italicised*	Quotation **Code prefix**	**Identify as Aboriginal**
Aboriginal parents' *'yarn' sessions*	37		Mothers (n=27) Fathers (n=10)	M00 F00	37 (100%)
Professionals *semi-structured interviews*	21		**Interviewees*		10 (48%)
		9	Midwives	MW00	
		2	Midwife/Child Health Nurse	MW/CHN00	
			Child Health Nurse/Aboriginal Health Team	CHN/AHT00	
		8	Aboriginal Health Workers/Liaison Officers	AH00	
Focus Groups	82		**Hospital-based or *Community-based focus group*		61 (75%)
			Hospital based midwives	FG/Hb-MW	
		18	Community Based Midwives/Child Health Nurses	FG/Cb-MW	
			Social workers/counsellors	FG/Sb-MW	
			Aboriginal Professionals	FG/Ab	
		10	➢ Youth, Support workers	FG/Ab	
		18	➢ Social workers, Counsellors, Psychologist	FG/MH	
		7	➢ Aboriginal Liaison Officers	FG/Ab	
		7	➢ Managers	FG/Ab	
SUB- TOTAL	**140**				
Anonymous online questionnaire	154		**Respondents*		
			Midwives	QuMW	26 (17 %)
			Child Health Nurse	QuCHN	
TOTAL	**294**				

Professionals were recruited 1) following brief presentations of the *Kalyakool Moort* proposal to staff in a variety of workplaces; and, 2) via subsequent snowballing. Workplace focus groups were facilitated by JK, as pre-arranged by members of the LRAG, and also conducted individual semi-structured interviews.

Interviews and smaller focus groups were audio recorded and transcribed for thematic analysis. Data from the larger focus groups used butchers' paper, workshop notes and photographs. A series of inquiry prompts were used to systematically explore themes in semi-structured interviews and focus groups. (Table 19)

Table 19. Inquiry prompts for professional semi structured interviews

Demographics
Aboriginal Torres Strait Islander
Professional background
Years of experience
Type of service
Current role

Percentage of Aboriginal clients
Thoughts about Mental Health and SEWB Screening
Current screening practices: What works well? What doesn't work so well? What screening tools do you frequently use? What works well about it/them? What doesn't work as well about it/them *What about the EPDS?* What makes it work? What doesn't work as well? *What about psychosocial and SEWB assessments?* Do you undertake these?
What domains do you explore? How? How confident do you feel doing this? What makes it work? What doesn't work about it? Any concerns? Any solutions?
Thoughts about working alongside Aboriginal women
What's it like working with Aboriginal women/ families? How do you engage & how well do you engage? What would help?
Thoughts about working including Fathers
What's is like working with Dads in the context of perinatal care? How do you and how well do you engage with them? What would help?
Thoughts about including Family/community
Do you engage with Family or others in community like Elders? How? Do you consider this important?

The professional backgrounds and experience of health professional participants varied significantly. Describing participant contributions and reporting quotes generically, could be misleading. Table 18 describes participants demographics, coding prefixes (in quotes) and descriptors used in reporting to distinguish and provide context data referred to in this report.

6.3 Analysis

Drawing on Charmaz's (2012) approach to grounded theory and thematic analysis data were managed and coded using Nvivo-12. Theory triangulation (a process where multiple professional perspectives are used in the interpretation of each set of data) was undertaken with the DCSG along with a non-Indigenous perinatal mental-health midwife/nurse and JK. Each person independently analysed and coded data, referring to both audio and transcribed interviews. Transcribed data were micro-code line by line, then macro-coded to establish dominant themes. Subsequent collective exploration of individually coded data enabled further scrutiny of similarities and differences, with priority afforded to Aboriginal perspectives.

Emerging themes and results of the anonymous professional's online questionnaire were presented to the AWP for further exploration and analysis. Data triangulation was undertaken firstly by JK and the AWP, then the AAG, LRAG and the Elders Cultural safety group using all data sources over multiple workshop sessions. (Figure 12).

Enablers of strong parenting practice and barriers to effective screening were distilled. Solutions to barriers were identified. Key elements for potential inclusion in an alternate approach to SEWB screening were extrapolated by the AWP with JK This process informed joint development of a clinical practice guidelines and a perinatal screening tool that is briefly described in Chapter 7.

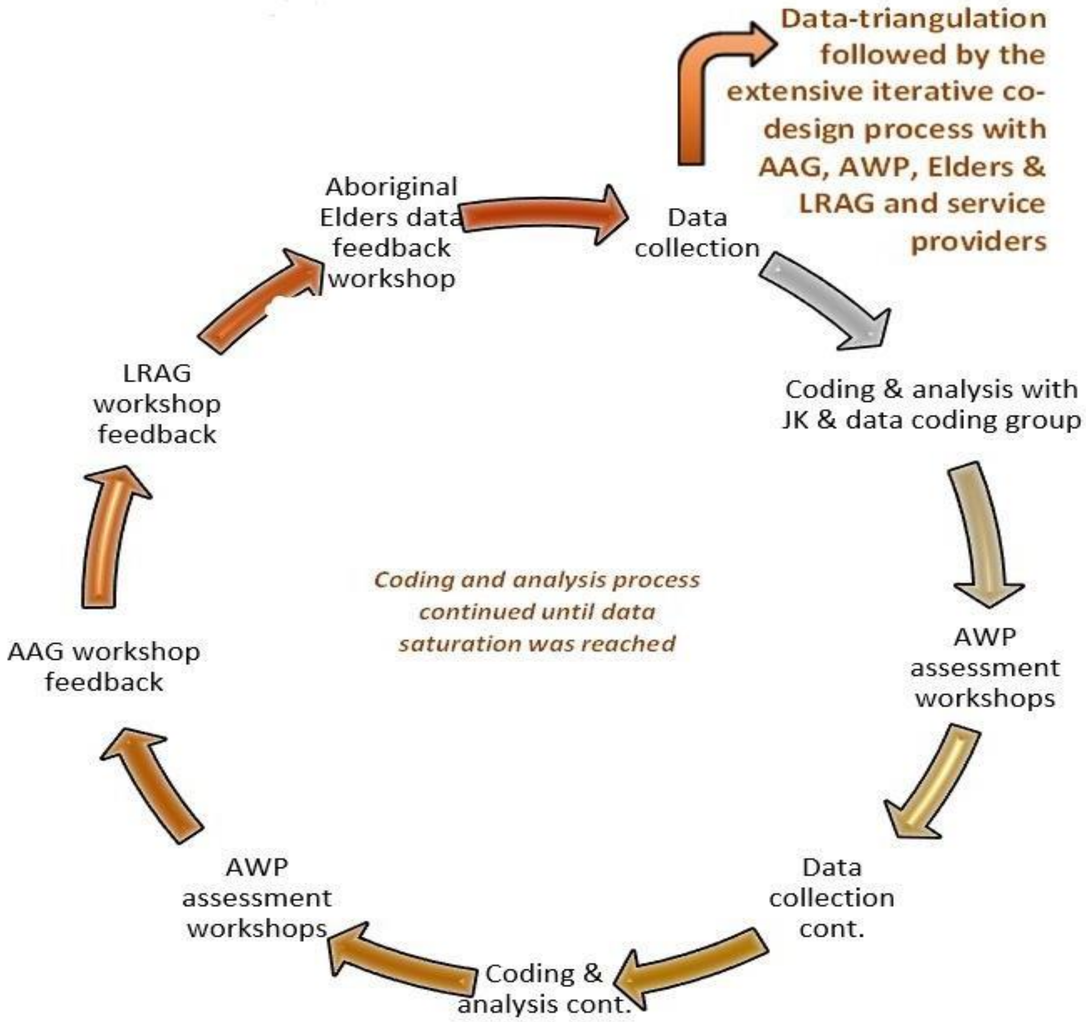
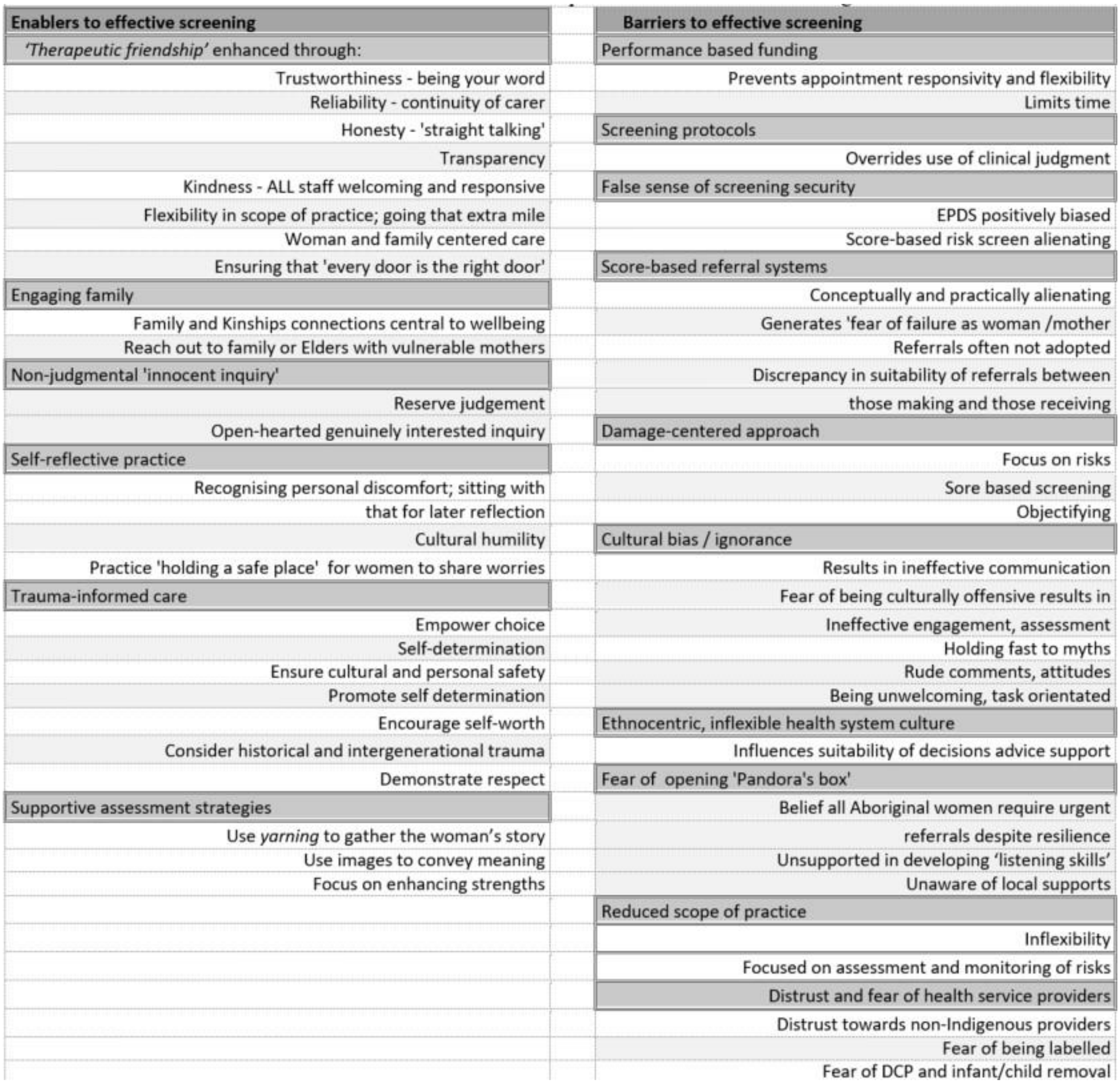


Figure 12. Thematic data analysis process.

6.4 Results

Figure 13 provides a thematic summary of barriers and enablers to perinatal mental health screening identified by the health professional interview and focus groups. The findings are also described in more detail below.



Enablers to effective screening	Barriers to effective screening
'Therapeutic friendship' enhanced through:	Performance based funding
Trustworthiness - being your word	Prevents appointment responsivity and flexibility
Reliability - continuity of carer	Limits time
Honesty - 'straight talking'	Screening protocols
Transparency	Overrides use of clinical judgment
Kindness - ALL staff welcoming and responsive	False sense of screening security
Flexibility in scope of practice; going that extra mile	EPDS positively biased
Woman and family centered care	Score-based risk screen alienating
Ensuring that 'every door is the right door'	Score-based referral systems
Engaging family	Conceptually and practically alienating
Family and Kinships connections central to wellbeing	Generates 'fear of failure as woman /mother
Reach out to family or Elders with vulnerable mothers	Referrals often not adopted
Non-judgmental 'innocent inquiry'	Discrepancy in suitability of referrals between
Reserve judgement	those making and those receiving
Open-hearted genuinely interested inquiry	Damage-centered approach
Self-reflective practice	Focus on risks
Recognising personal discomfort; sitting with	Sore based screening
that for later reflection	Objectifying
Cultural humility	Cultural bias / ignorance
Practice 'holding a safe place' for women to share worries	Results in ineffective communication
Trauma-informed care	Fear of being culturally offensive results in
Empower choice	Ineffective engagement, assessment
Self-determination	Holding fast to myths
Ensure cultural and personal safety	Rude comments, attitudes
Promote self determination	Being unwelcoming, task orientated
Encourage self-worth	Ethnocentric, inflexible health system culture
Consider historical and intergenerational trauma	Influences suitability of decisions advice support
Demonstrate respect	Fear of opening 'Pandora's box'
Supportive assessment strategies	Belief all Aboriginal women require urgent
Use *yarning* to gather the woman's story	referrals despite resilience
Use images to convey meaning	Unsupported in developing 'listening skills'
Focus on enhancing strengths	Unaware of local supports
	Reduced scope of practice
	Inflexibility
	Focused on assessment and monitoring of risks
	Distrust and fear of health service providers
	Distrust towards non-Indigenous providers
	Fear of being labelled
	Fear of DCP and infant/child removal

Figure 13. Thematic overview of barriers and enablers to effective perinatal mental health screening.

The majority (72%) of respondents saw a significant proportion of Aboriginal clients and were evenly distributed between hospital or community-based settings. (Table 20)

Table 20. Online professional survey (n=154). Demographics and summary overview

%	Demographics and summary
83%	Non-Indigenous
17%	Aboriginal
93%	Midwives, Nurses (Child Health or Community)
7%	GPs or AHWs
85%	Direct Service delivery
36%	≥ 50% Aboriginal clientele
36%	30-40% Aboriginal clientele
28%	≤10% Aboriginal clientele
3%	use PASS, Kessler 10 or KMMS
48%	modify use of EPDS
46%	rarely if ever undertake a psychosocial assessment with Aboriginal clients

6.4.1 Screening

All participants (interviewees, questionnaire respondents, focus group members) reported mental health screening as vital to supporting client safety and wellbeing. Many added that a screening tool supported their clinical judgement. All interviewees reported that the current mental health screen guidelines (EPDS and its initial use timed for the first visit) were problematic, culturally unsafe and ineffective *"we just do it on everyone and expect everyone to be OK with it, and they're like 'nah, I'm not depressed'"*. This was stated or implied by many questionnaire respondents with 88% suggesting a culturally safe alternative would improve engagement in the process. All interviewees reported that they believed routine use of the EPDS with Aboriginal women was positively biased. The majority reported effective use of the EPDS was only mediated by an established relationship of trust and timing of use.

Those who worked within Aboriginal specific maternity practices, rarely used the EPDS according to the national guidelines. Many reported using EDPS as a guide and only when women were distressed. *"I only screen if the woman is really upset or at high risk"*. Experienced practitioners who used the EPDS discretionally, often report Question 10 (suicidal ideation) as being the most useful question as *"..Because she was quiet everyone said she was non-compliant and didn't engage….and I said 'how are you feeling about the baby? Does it really stress you out?' and then she broke down crying. So we went through the medical stuff, and explained all of that, and then I gave the EPDS; and she filled it out and answered 3 to Q10* (suicidal ideation); *so we talked more and she said she had a plan and a date of when she was going to kill herself because she was going to do it when her Grandfather died. But she did come back to get care and the psych liaison would come* [to see her]" (MW0071)

Most respondents (interviewees, focus groups and questionnaire respondents) referred to complex language in the EPDS, noting the need for explanations. Fifty-one percent of questionnaire respondents reported its use as challenging or difficult.

"I [started using] *the EPDS but* [Aboriginal] *women were scoring zero, and no-one scores zero unless they are lying. So stopped using it but I felt guilty, so I spoke with the psch and she said not to worry because it wasn't culturally appropriate anyway. So now I just use my judgment and pull it out if I am worried, but never at the first visit when it's meant to be used. For me that's about developing a relationship with the client"* (MW0041)

Several interviewees reported that screening bias also pertained to routine Family and domestic violence (FDV) screening. One AHW recounted a young client who presented for her antenatal appointment. She arrived in tears with a bleeding nose, saying that she had just been assaulted by her partner's cousin at the train station. Later, when asked the routine FDV questions by her midwife, she denied any exposure or threat of violence or abuse.

*"We have a really good doctor in our team, they really open with her. She takes the time, she also is very straight with them and she says you need to do this and this, but she takes the time, and they know that she will be there regularly every time. She is reliable. They rely on her being there." (*CHN/AHT0039)

A combination of the following features was reported to build stability and trust.

Being non-judgmental and welcoming. Participants reported that Aboriginal women have complex and challenging lives. They must overcome many barriers to attend clinics. It was perceived as vital that when they do come they are welcomed with kind and compassionate, non-judgmental attention. This was crucial to build trust. Ensuring 'every door is an open door', that clinical settings and all staff are welcoming and try to be helpful whether by phone or in person.

"It all is about relationship, building up trust, being non-judgmental. Being non-judgmental is really important." (MW0041)

Strength-focussed care. Focusing on a woman's strengths, her inherent potential as a Mother was strongly iterated. Being encouraging, trusting that with the 'right supports', every Mother is able to rise up to be the best she can be.

"There are so many variables such as financial constraints, housing and overcrowding…it's easier to start to work on those issues because when they are clarified and acknowledged and referrals are in place, I can settle into the story about the baby and Mother's health, growth and development and so on" (QuCHN49)

This was viewed as particularly critical for single Mothers; the health focus on risks rather than her inherent strengths was considered further alienating from meaningful engagement. Many reported seeing first-hand the value of exploring and talking into strengths in the face of distress.

"Sometimes when my clients are stressed I bring out the EPDS; and we get to question 10 [on EPDS], they say that they are anxious and I say 'has it been like this since you've had the baby', and they say 'no I've always been like this', and then I say 'how did you manage in the past?', and sometimes they have done quite a bit of work and they have got very good strategies, and we talk some more about them, and by the end I am confident that they'll do OK." (MW/CHN0068)

Woman-centered care. This meant focusing on a woman's needs, not only the clinical checklist. The notion of being a 'therapeutic friend' was voiced by one midwife who reported having well established trusting engagement with families and the community in which she worked.

"The therapeutic friendship takes more time than the clinical therapeutic relationship, but it pays dividends in the end, because the women come back, and then their sisters come as well when they are pregnant." (MW0071)

This was referred to by another participant as being willing to occasionally work outside what was considered usual scope of practice.

"being open, honest and being frank about what you can and can't do. And if you can help them with something…like it might be filling out papers, dropping them off to Centerlink. It helps build relationship and build up a trust." (CHN/AHT0041)

Flexible time. More time, without exception, was reported as key to building effective engagement and trust. Some rapport can be built quite quickly if the woman has not experienced significant complex trauma or traumatisation within health services. However, gaining trust frequently required repeated engagement. Additional time for screening was key and was reiterated by questionnaire respondents. More than 50% of interviewees believed purposefully allocated time would improve outcomes. Additional time to follow-up the more transitory women was identified as important also. A few midwives reported that Aboriginal women preferred more frequent and shorter appointments due to the conflicting demands on their time. Questionnaire respondents identified strategies that would support successful engagement in screening; the highest rating suggestions (≥60%) included an alternative culturally safe screen, visual and audio prompts for psychosocial assessments, cultural and FDV training and professional supervision (support) from a 'trusted' mental-health professional.

6.4.2 Barriers to effective screening

Performance based funding (PBF). This emerged as theme with the majority of interviewees identified this as impairing their capacity to effectively assess and manage Aboriginal women's distress. This was reinforced by questionnaire respondents. PBF determines numbers of antenatal and child health appointments and the time allocated. Interviewees all reported that Aboriginal women required flexibility in appointment time and frequency. Professionals also need time to writeup and respond to issues arising. The current PBF model is not conducive to facilitating effective perinatal mental health screening or primary prevention strategies necessary for Aboriginal Mothers.

" Time is the huge factor, and I worry about protocols that [prevent] *facilitating screening effectively…it should be at the discretion of the practitioner, we need to* [have] *capacity for a woman to come back next week, to check her progress and to provide ongoing support. This is not possible; nurses are given to 15-minute callbacks in a week for all of their clients. It's just is untenable."* (CHN0054).

Screening protocols and procedures. The constraint of screening protocols was a strong theme. Many organisational protocols require routine EPDS screening at the initial antenatal visit, at 32-36 weeks, postpartum at 6-weeks, 3-months, 9-months and 12-months. If the score is above 10 or self-harm/suicidal ideation is indicated, a mental health referral is protocol. Many interviewees believed that the mandatory referral process was often not in a woman's best interest, and that it obstructed their clinical judgement and capacity to provide 'woman-centered care'.

"When she says 'I'm stressed and got no energy and I can't cope with my kids' and I use the EPDS and she scores high, I ***have*** *to refer her. But if she's in the right Family environment she will get the support, and I visit her after a few days and she's fine it may not be depression or anxiety just needed that time to themselves."* (CHN0056)

Additionally, social worker's in their focus group reported frequently receiving inappropriate referrals as a result of EPDS scores saying the content was ‘not useful’ and were often ‘not necessary’. This issue was reiterated by a number of interviewees.

“We’ve had 2 clinical incidents where women have said they’ve wanted to harm themselves, and we have had to escalate that to immediate intervention, and we have taken them in there for assessment; and unfortunately, that has not worked so well. They do not always assess the risk as highly as we do, and they sent them home.” (MW0071)

Some interviewees reported feeling unsupported by middle-management who demanded rigid adherence to protocol. Subsequently they felt unable to respect the woman’s wishes or circumstances.

“I know a couple [CHNs] *who haven’t followed* [EPDS] *protocol exactly, but they are still doing something that suited the client; you know gradually getting the person to the point where they are willing to get the help. What they did is go back every couple of days for a while to see how the she was, and the women appreciated that and were OK; but then they got told off by their manager because they didn’t follow the protocol.”* (CHN0039)

A small number of interviewees believed that strict adherence to protocol protected them against litigation: *“It’s not worth my registration to not follow protocol”* (CHN0053)

Referral uncertainty. Referral uptake was largely unknown. Many interviewees believed that women frequently did not attend referrals. This could be mediated where professionals were able to successfully ‘vouch’ for the person being referred to, and if home visits or transport was provided.

“I’ve often referred to mainstream social work, but it doesn’t work well. You find that the social workers are just too busy, or the women just don’t go.” (MW0073)

Whilst 70% of questionnaire respondents believed that their referrals were successfully engaged, when asked how they knew, there was less certainty.

“Well to be honest, I don’t really know, I assume they accept the referral. I don’t get feedback …so I don’t know,” (QuMW24)

Inhospitable and intimidating clinical settings. Clinics are designed to accommodate clinicians and the dominant culture. Many interviewees reported this as a barrier for Aboriginal women.

"One hospital I work in has lots of Aboriginal women birthing there, and the corridors are filled with perfect photos of perfect white babies; this says to me that clearly that 'you don't belong here'" (MW0070)

The initial reception of clients/patients is critical to supporting engagement and a sense of safety. However, many interviewees reported reception staff as being abrupt, rude or overtly racist towards Aboriginal families.

"I've spent 4 years working in rural Aboriginal health and feel safe with the women. But they have to overcome the reception staff clinics who are extremely judgmental at times; [its] *very frustrating."* (QuMW174)

6.4.3 Psychosocial assessments

There was no doubt that facilitating psychosocial assessments should be a central feature in effective Aboriginal mental-health screening. Many interviewees reported that Aboriginal women's measure of 'wellbeing' appeared much lower than non-Indigenous Mothers and demonstrated remarkable resilience against multiple daily life challenges. This highlighted the importance of comprehensive psychosocial assessments.

"Aboriginal women have the most phenomenal resilience to deal with the stressors and anxieties of daily life. So much happens and they cope…then one more thing happens and then they no longer cope. We need to make sure we know what's happening for them so we're able to be whatever support we can be to prevent this" (MW0035)

The three most common reasons for not facilitating psychosocial assessments with Aboriginal clients reported by interviewees were (i) fear of being invasive resulting in the client disengaging, (ii) lack of experience, (iii) inadequate time. *"I lack the confidence with their* *culture, and I don't want to offend".* This was reiterated by questionnaire respondents with 57% citing fear of being invasive as their greatest concern. Seventy-six percent reported that engaging Aboriginal women in psychosocial assessments was difficult, and only 25% reported undertaking routine psychosocial assessments with Aboriginal women. Twenty-two percent believed it was outside their scope of practice. Of those who facilitated psychosocial assessments, these assessments centered around supports at home, smoking, alcohol, or other drugs (AOD), history of mental illness and domestic violence (DV). Mental state examinations (MSE), or inquiry about strengths, cultural connections, anxiety, self-esteem, maternal attachment, childhood trauma or racism were notably not undertaken.

Some interviewees were experienced in working with Aboriginal families and women. From their narratives it appeared that they were committed to working alongside Aboriginal families and recognised the importance of comprehensive psychosocial assessments. '*If the problem is social the solution needs to be social*'. Their narratives demonstrated that they understood the relationship between disparities in healthcare/health status and social determinants. and believed that affecting change was limited by culturally ill-considered policies and practices where the focus remains on score-based questionnaires.

"*I think that especially with Aboriginal women because their lives are very complicated, and there so much more to the* [screening] *picture. We should be doing a psychosocial assessment, not just screening for depression or anxiety."* (MW/CHN 0057)

6.4.5 Other notable themes

Perception of roles. Midwives and CHN participants in the hospital-based focus groups, were acutely conscious of ensuring that Aboriginal women did not 'use the system' or that they were 'creating dependence'. This was at loggerheads with common thinking among the community-based midwives and CHNs interviewed, whose belief was that Aboriginal women required more support, more encouragement and more positive recognition in order to flourish as strong effective Mothers.

"I see lots of new (non-Aboriginal) *Mothers…and they are really struggling as new Mums and they have lots of supports; and I also see lots of Aboriginal new Mums who have so much going on in their lives, they are juggling kids, Family problems, they have no transport and no support and they just keep going. They don't complain but they really do need supports …they have a tipping point and one more thing happens, and they just lash out, or withdraw from services or worse."* (MW0035)

"People worry that we create dependence; it's not about that, it's about us just helping the women engage ... and we empower them to be able to engage in services that they want to. Particularly for the young and single Mums and grand multis...it's just making it easier for women." (MW 0050)

Aboriginal and non-Indigenous professional equality and collaboration. Close collaboration between non-Indigenous professionals and Aboriginal workers was considered underutilised and vital. AHWs were noted as being a source of professional cultural guidance, safety and advice. They are able to 'vouch' for the clinical staff within community and are great assets in ensuring culturally safe collaborative.

"I am comfortable [with Aboriginal clients] *but, I believe VERY STRONGLY that an AHW should be involved in all assessments. I have no problem with teaming with these wonderful staff to be able to do my job properly, and to do the best by my client/pt."* (QuMW252)

A number of interviewees reported AHWs being 'used' as 'tokenistic' support and only considered when transport was required. Non-collegial and ill-informed work with AHWs was reported to result when AHWs were called on to sort all the psychosocial issues with little to no support from clinicians, whose focus remained soley on clinical care.

"Lots of [regional and remote] *places I've worked, the AHW is seen as transport, and there is racsim among the non-Indigenous professionals towards the AWH. They are at meetings sometimes, but they never speak unless someone tells them to pick someone up. They are a*

wealth of cultural and community wisdom and [non-Indigenous staff] *should work with them more closely, value and encourage them to speak up so we can all know what's going on for the clients. Providing transport is a great opportunity to connect with women, but that's not recognised for what it can be. Its only looked at for what it seems to be, but the AHWs are the linchpin."* (MW0035)

Fear and Shame. Strongly evident in interviews, focus groups and questionnaire respondents were the disabling and alienating impacts of fear and shame experienced by Aboriginal women. Fear and shame resulted from implicit and explicit racism.

"….Aboriginal people don't complain, and no-one ends up calling nurses out on [racism]. *If a non-Aboriginal woman complains we support her to make a complaint, but for Aboriginal Mums their lives are so busy that there's no time to make a complaint."* (MW1008)

Fear of 'failing' the (EPDS) 'test' was also identified as shaming. Many interviewees identified that this equated with bad parenting, or being labelled with a mental-health disorder, or resulting in child protection and the degrading trajectory that follows. Fear also strongly associated with the dread of child removal.

".. it is a massive risk for Aboriginal women to involve other services for fear of reprisal, punishment or losing their child, whether the fear is justified or not."(QuMW21)

"they [health professionals] *call up welfare and fail to communicate with Family first, and* [Child Protection] *is just waiting for Aboriginal Mothers to 'stuff up'."* (AHW0042)

In addition to the current impacts of complex trauma (intergenerational and present), internalised fear and distrust commonly impacting Mothers' responses and are summarised below.

Table 21. Emergent fears experienced by Aboriginal mothers that impact their risk or severity of perinatal depression and/or anxiety.

Common emerging maternal 'fears' relating to being screened.
Child removal

Being ‘monitored/watched’ by Child Protective Services
Being labelled ‘mad’ ‘loopy’
Being judged or ostracised by their own Mother/Grandmother, Family or Community
Being seen as ‘weak’ or as *not* being a ‘strong’ Mother’.
The consequences of stigma for their children’s future

Professional skills gaps. Many health professionals identified gaps in confidence for themselves and with their colleagues. They identified a number of specific areas.

Psychosocial assessment skills. Most professionals wanted to support their Aboriginal clients through facilitating psychosocial assessments. Many however identified their own or their colleagues’ gaps in confidence particularly regarding FDV and dealing with disclosure. This was reiterated by 72% of questionnaire respondents.

“My experience is that [midwives, CHNs] *need more support in doing* [psychosocial assessments], *and not just training in using the EPDS. When they are asking* [Aboriginal women] *about abstract issues and it is not their core skill area, then the more they can generate innocent inquiry about concrete issues about their lives, the more likely they are to create relationship and get to the core of whether there is distress.*” [FG/MH0066]

“…we should all be doing a psychosocial assessment, not just screening for depression; allowing women to talk about their complex history, their complex Family dynamics …looking at their overall SEWB is far more important than just looking at their risk of depression.” (CHN0039)

Cultural insights. The need for deeper cultural insights was strongly identified. Many believed that their capacity to engage was limited by lack of awareness regarding Aboriginal cultural nuances. This was amplified in practitioner focus groups and questionnaire respondents. Others identified the need for change in their colleagues which was compounded by ambivalence or resistance.

“any experienced child health nurse or midwife should and could do this [psychosocial assessment]. *But there are some nurses out there that umm…because of their own history and*

their age or because they don't manage the big questions very well, and they don't get it, you know. From a cultural perspective, women want us to care about their lives. But they've been on the job a long time and they just come in to assess babies ....but it needs to change. We need to be upskilling them all to do this better." [MW/CHN 00357]

The cultural significance of Family and Kinship connections was notably absent in all but a few interviews with non-Indigenous professionals. Conversely it dominated Aboriginal professionals' interviews and focus groups. The importance of engaging with and working with Family goes beyond the understanding of non-Indigenous professionals. To generate honesty, engagement and a sense of 'healing' in perinatal care, considering Family engagement was key. Figure 14 highlights one Aboriginal professional's perspective as a word cloud. This a good illustration of the similar strong themes obtained from all the Aboriginal Mothers and Aboriginal health professionals.

Figure 14. One Aboriginal health professional's word frequency map which highlights the cultural significance of Family and Kinship Connections (MW0041)

Learning to listen. The importance of midwives and CHNs to build capacity in 'holding a safe space' for Aboriginal women to communicate their worries and distress, to simply listen, without judgement or feeling the need to ‘fix’ everything was unmistakable. This was for many at times overwhelming and left them feeling depleted or worried that they should do more. Others recognised that for Aboriginal women to be able to safely tell their story was therapeutic. The majority of women have demonstrated profound strong and resilient despite daily challenges and distress, as one midwife stated:

“[Aboriginal] *women don’t necessarily need therapy or medication straightaway they need a supportive ear, someone to talk to someone to hear them and someone to hold the space for the so that they can actually bring up their stories externalises through the speaking and make sense of it themselves. This process can be extremely empowering.”* (MW/CHN0068)

6.4.6 Perceptions of perinatal depression and anxiety (PND/A)

Focus groups with AHWs explored how PND/A is perceived by Aboriginal women, Family and Community (Table 22). Aboriginal women who feel depressed or anxious commonly present as withdrawn and disengaged or highly reactive and explosive. Self-soothing behaviours such as alcohol or drug use were other common signs of underlying distress.

Table 22. Focus groups (AHWs) perception of PND/A

What Family may see or say	What she may feel
Acting out of character	Worthless / hopeless
Over reactive/over sensitive	Isolated/lonely
Impulsive/compulsive	Harming herself or others
Substance misuse	Little understanding
Controlling	Teary
Overly tidy / perfectionism	Fearful
‘Let herself go'	Heavy weight on shoulders
Withdrawn avoidant	Tired / unable to sleep / sleeping too much
Lashing out/angry	Angry / short tempered / intolerant
Bad Mother'	Insecure
Not caring about housework/home	Unable to cope
Mad or loopy'	Deep grief

6.5 Discussion

These results must be viewed against the backdrop of colonisation, the attendant impacts of the Stolen Generation[17] and present-day social and political influences. The reductionist biomedical model of health care has an ethnocentric and racist bent (Williams et al., 2019). The dominant culture strongly influences and governs the way service providers view and respond. Aboriginal people, as a minority population, are disadvantaged in this system (Bastos et. al., 2018). The Aboriginal and Torres Strait Islander Social Justice Commissioner states that ‘daily experiences of racism and disadvantage are the norm and eat away at our health and wellbeing’ (Oscar, 2017). The insidious impacts of racism on mental and physical health is well evidenced (Cave et al., 2019; Ferdinand et al., 2012; Priest et al., 2011). Little wonder this research found continued exposure to judgment, implicit racial bias and systemic racism embedded within stories of perinatal care. These experiences elicit strong feelings of fear and shame in Aboriginal women and provoke deep distrust towards health care system and providers. The continued failure of the health system to make necessary cultural adjustments for Aboriginal women in their perinatal mental health screening and care is failing to meet their social and emotional health and wellbeing needs.

Cultural dominance. Many midwives and CHNs who worked predominantly with Aboriginal families, appeared to be able to consider the power relations and cultural differences in the health system. They recognised that suspending judgment was a necessary requisite to open trusting engagement. However, they recognised that the health system was frequently unsupportive, and that many professionals’ colleagues lacked capacity to examine their own realities, beliefs, and attitudes.

Cultural dominance is generated by belonging to a dominant culture either personally

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“The Stolen Generations refer to the Aboriginal and Torres Strait Islander children who were removed from their families by Australian Federal and State government agencies and church missions between 1910 and 1970 through a policy of assimilation. Under this policy, the forcible removal of First Australian children was made legal. Assimilation was based on a belief of white superiority and black inferiority and presumed that "full-blood" Aboriginal and Torres Strait Islander peoples would naturally die out.” ‘The Stolen Generations’ Available online at: https://www.commonground.org.au/learn/the-stolen-generations. Downloaded 6th December 2019 or professionally. Medical professional dominance is a fundamental feature of Australian

health-care (Willis, 2006). Professional dominance frequently impedes rather than improves communications (Pascoe, 2019). Professionals rapidly define ‘the problem’ and determine what is required to solve it (Bainbridge et al., 2015); this erases opportunities for Aboriginal women’s expression of their experience, wisdom and knowledge. It generates the ethnocentric view of "what's wrong" with that person (Putsch and Joyce, 1990). The considered supportive and trauma informed alternative is “why is that person feeling or behaving that way?” As soon as the professional decides that they know ‘the truth’, the working relationships begins to fracture with the woman, her Family members and indeed other professionals who may hold very different positions (DOCP, 2011). This cultural dissonance was a strong theme with practitioners. Some reflected on their own need for deeper understanding of Aboriginal knowledge and culture to improve their assessments and care. Others communicated concrete beliefs, displaying implicit or explicit racial bias.

Developing self-awareness and cultural humility are vital to modifying the effects of professional and personal cultural dominance (Foronda et al., 2016). Cultural humility bridges communication discord (Owen et al., 2016) and is key to driving the journey towards cultural safety, strengthening cultural understanding and building engagement as a ‘therapeutic friend’.

Damaged-centered care. Health screen and management guidelines instruct professionals to focus on health risks. Aboriginality, by definition, places one in a ‘risk’ category (AIHW, 2021; Griffith et al., 2020). Prevalent dialogue within the health sector, distorts the way Aboriginal people are perceived and the way they perceive themselves. It is deeply one-dimensional, self-limiting and damaging for Aboriginal families. Many professionals have come to view Aboriginal people as being somehow depleted and hopeless (Tuck, 2009). The Northern Territory Intervention[18] is a recent example of the impacts of this deficit dialogue within dominant policy (Korff, 2021).

As reported separately, Aboriginal women demonstrate great strength, capacity and resilience (Kotz et al., 2021c unpublished). Women are being undermined by perinatal care which is considered ‘damage-centered’ (Tuck, 2009). This is objectifying and at odds with participant notions of the ‘*therapeutic friend’*. Oscar (2017) states ‘we must all work harder to change the narrative of low expectations’. The 2020 Steering Committee for the Review of Government Service Provision (SCRGSP) reported that Aboriginal infant mortality may decline further with strategies focused solely on targeting risks in the perinatal period. Protective factors must be included.

This research identified that professionals generally focus on a reductionist approach to mental-health screening, driven largely by protocols and output-based funding. The model frames the thinking and funding of health but has done little to improve the health and wellbeing of Aboriginal Australians (AIHW, 2021; AHPD, 2018). Many professionals recognised the limitations in adhering to this approach with Aboriginal families.

Strength-based approach. The broader *Kalyakool Moort* research identified the high prevalence of depression and anxiety symptomology among Aboriginal women. However, the causal theories and meanings that they attributed to their patterns of distress differed dramatically from medical theory (Kotz et al., pending publication). Aboriginal women demonstrated a significantly sharper focus on the importance of being identified for their strengths as Mothers, which went frequently unacknowledged (Kotz et al., unpublished).

Their expectation or internal measure of ‘wellbeing’ appears much lower than non-Indigenous Mothers. The innate strengths and protective features present within Aboriginal Mothers is

rarely identified or harnessed by health professionals. In their own voices, both health professionals’ and Aboriginal women (Kotz et al., unpublished) have identified that these should be acknowledged and fostered. Health professionals should be supported to reorient their

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The Northern Territory Intervention was in a direct response to the ‘Little Children are Sacred Report’ into sexual abuse of Indigenous children. It was directed at addressing disproportionate levels of violence in Indigenous communities in the Northern Territory, as well as the systemic disadvantage of Indigenous people, characterised by economic deprivation, unemployment, social marginalisation, inadequate housing and poor health and justice outcomes. Benefits of the intervention remain conjectural; a lack of impartial evaluation data has impacted on the quality of the debate surrounding any real benefits. (Gray et al., 2020) thinking towards strength-based perinatal assessments that support empowering Aboriginal Mothers.

Eckermann (2010) defines strength as being drawn from cultural connections. He states that cultural connections are *‘the emotional strength, the spirit, the essence of people who strive and struggle to maintain strong identity and adapt to new and challenging environments, while they value and pass on distinctive cultural beliefs, practices and life ways.’* The protective nature of cultural connections is rarely considered in perinatal mental-health assessments, despite being known to provide a source of strength and resilience (Lowitja Institute, 2020; Dudgeon et al., 2014).

SEWB. The vast majority of professionals identified the importance of significantly expanded approaches to perinatal mental-health screening. This necessitates deep appreciation of and incorporation of the Aboriginal understanding of SEWB and the nine underpinning guiding principles (see column 2 in Table 23).

Table 23. Essential SEWB considerations for healthcare providers when undertaking psychosocial assessments.

Key SEWB considerations for health professionals providing assessments and ongoing care
Connections to
Family & Kinship
Culture
Community
Land
Spirituality
Mind and Emotions

Nine Social Emotional Wellbeing Guiding Principles
Health is holistic
Right to self determination
Need for cultural understanding
Impacts of history in trauma and loss
Recognition of human rights
Impacts of racism
Centrality of Kinship
Cultural diversity
Recognition of Aboriginal Strengths

Adapted from (Dudgeon et al., 2014)

A new culturally informed approach to perinatal mental health screening and care is critical. The process must include shared decision-making and design with Aboriginal people and genuine engagement with Aboriginal concepts of health, and to ensure translatable health benefits for Aboriginal people (AIHW, 2020a).

6.6 Conclusion

Aboriginal maternal mental-health is declining. This impacts the maternal and infant health and the SEWB of Aboriginal families. The costs to Aboriginal families, communities and the health system costs cannot be ignored. These factors, and more importantly how we treat Aboriginal Australian Mothers and families, reflect who we are as professional and demands the need for change. The generalised approach to universal perinatal mental health screening is not working for Aboriginal women, their families or indeed health professionals. Aboriginal Mothers need and should have access to culturally safe strength-based and empowering perinatal health care and support. Access to alternative culturally considered and codesigned approach to perinatal SEWB screening one that is outcome-focused that is informed by Aboriginal ways of knowing and being is critical.

Despite the efforts of many well-intentioned health professionals, current perinatal practice by and large is failing Aboriginal women, and frustrating efforts of many health professionals. ~~them.~~ Health professionals also need support and access to provide the sort of care Aboriginal women and their families need. Within a strongly medicalised culture, many lack the personal and workplace supports that are required to provide genuinely holistic trauma informed and Family centered care. With the increasingly complex challenges faced by health care providers in the workplace and Aboriginal families in an inequitable society, human centered creative collaboration is required to address this wicked problem of declining perinatal mental health among Aboriginal women.

Chapter 7. Achieving translational outcomes. Fulfilling the commitment to improving evidence-based perinatal clinical practice with Aboriginal families

7.1. Chapter overview

‘Nothing about us, without us’ is an axiom referring to the importance of closely engaging and privileging the views of key stakeholders at all stages in the development of policies and practices putatively designed for those stakeholders. This was frequently iterated throughout this research project. This ‘Lived experience’ movement is increasingly recognised as a critical and potentially invaluable aspect of research. Knowledge gained through ‘Lived experience,’ through Indigenous ways of knowing, bring diverse perspectives to health research and help reveal “blind spots” – conscious or unconscious biases – that may interfere with scientifically-rigorous research. Clinical translation is just one specifically intended primary outcome of the ‘Lived experience’ movement (Byrne and Wykes, 2020). It is embedded in the recognition that people face increasing inequalities resulting from oppression and other systemic structural processes embedded in policies, practices and procedures. These inequities are exacerbated by divided backgrounds, experiences, cultures, behaviours and world views and there must be a willingness to share and relinquish power (Byrne et al., 2018). Lived experience is critical for proactively decolonising both research and clinical practice pertaining to Aboriginal Australians. The intent of the program of research presented in this thesis was to adopt this commitment to Aboriginal influence. The purpose was to develop an evidence-base that was fit-for-purpose in clinical perinatal mental health screening and healthcare. That is, that it might address the currently failing clinical perinatal care practices by providing a contextually informed and culturally secure foundation for future practice. The value of the expertise informed by lived experience is increasingly accepted, and indeed sought, in the mental health domain (Happell et al., 2020).

7.2 Codesigning a strength-based approach to perinatal care for Aboriginal Australian parents' mental health and wellbeing.

A fundamental methodological principle of this research is that evidence-based outcomes translate directly to culturally sound clinical care. Aboriginal viewpoints were strongly represented and included nearly 80% of the 140 people who participated in interviews (parents: n=37; professionals: n=10) or focus groups (n=61). This is in addition to the rich and diverse Aboriginal membership of the leadership and governance groups who were involved in all aspects of the research journey from conceptualization, to data collection, data analysis to translation. These groups included the Lead Research Advisory Group (33% Aboriginal membership), the women's and men's Aboriginal Advisory Group ((AAG) 100% Aboriginal membership), the Elders Cultural Safety Group (100% Aboriginal membership) and the research Working Party (75% Aboriginal membership). Two subgroups of the women's and men's Aboriginal Advisory Group formed the Screening tool analysis sub-group and the data coding and analysis subgroup. (Figure 15)

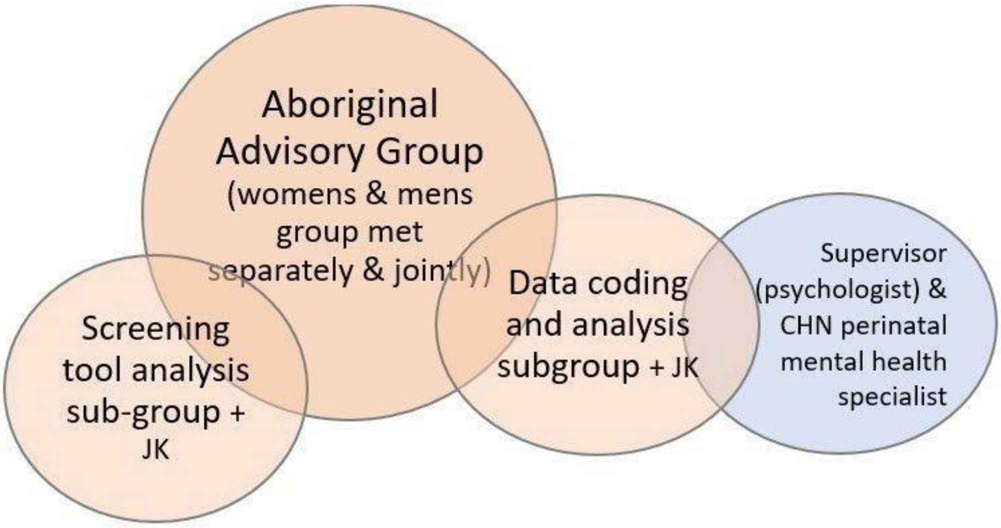


Figure 15. Screening tool analysis and data coding and analysis subgroups

Data were gathered using a range of methodologies. This required an exploratory (rather than confirmatory) approach to data gathering to ensure richness of discovery. It included in-depth (i) individual health professional interviews (n=21), (ii) ‘yarns’ with individual parents (n=37); (iii) 10 workshops (n=82), (iv) online questionnaire (n= 155) and periodic yarning circles held by the leadership and governance group. Respondents came from throughout Western Australia.

The result is a rich culturally grounded evidence-base about (i) barriers and enablers to strong perinatal screening and care; and (ii) strong parenting practices which supports consideration of a strength-based approach to perinatal mental health care. Strong themes for improving perinatal mental health screening accuracy emerged from all cohorts (see Table 23) with considerable congruence in the responses of parents and health professionals.

Table 24. Professional and parental themes (implicit and explicit) to enhance effective perinatal mental health screening for Aboriginal Mothers.

Themes identified by Professional
Develop 'therapeutic friendship'
Identify, acknowledge, encourage mitigating strengths and protective factors
Cultural safety
Practice 'holding a safe space' for women to share
Use 'yarning'
Incorporate images
Include social determinants
Include holistic assessment of wellbeing
Additional time required to assess/screen/follow-up
Professionals to practice:
• cultural flexibility
• professional flexibility
• self-reflective practice
• collaborating with Aboriginal staff
• caution against medicalised language
• caution against labelling
• working from a knowledge of complex and deep trauma

Themes identified by Parents
Develop trusting reliable relationship
Recognise centrality of Family and Kinship connections
Focus on woman, not checklist or asks
Acknowledge, encourage strengths
Less talk. Listen more
More time to 'yarn'
Incorporate smart technology
Inquire about social determinants, stressful life events
Develop assessment/screen for Fathers
Professionals to practice:
• suspending judgement
• innocent inquiry
• professional flexibility
• cultural humility
• encouraging
• being kind
• showing compassion

Triangulation of results from varied data sources established corroborating evidence, and provided multiple contexts, thus enriching understanding for the AAG and Working Party. Whilst recognising the importance of robust psychometric properties, the AAG believed that equally or more important was supporting Aboriginal parents to enhance their strengths, to identify and prioritise their worries and then to design their own solutions. This has been supported in the narratives of Aboriginal Mothers and Aboriginal health professionals This requires willingness and collaborative and requires willingness and collaborative innovation to improve our current approach to perinatal mental health screening.

7.3 Key clinical recommendations emerging from this evidence-base: Developing a new gold standard for perinatal screening practice

The following recommendations emerge from the preceding studies and strongly reflect those priorities that were reported by Mothers. These sit in contrast to their experience of current practice. They were identified as having the potential to make a significant difference to outcomes for Aboriginal women and children during their perinatal care experience. Each recommendation was also supported by the testimony of Fathers and health professionals. For brevity, to ensure a crisp narrative and to prevent repetition of detail in previous chapters, this chapter will minimize re-referencing of published sources that support these clinical recommendations – the reader is referred back to previous chapters and to the appendices for this detail.

7.3.1 Perinatal screening and care must be more than a score on a test

Professionals (implicitly or explicitly) and Mothers (explicitly) all identified the importance of having access to an alternative perinatal mental health and wellbeing assessment process for Aboriginal Mothers. The EPDS was not generally considered a good option. Comprehensive psychosocial assessments were frequently not undertaken despite this being a national guideline recommendation. Those who did undertake psychosocial assessments reported usually enquiring about physical supports at home and completing mandatorily required screening items such as those relating to alcohol, tobacco, Family, domestic violence etc. More experienced and community-based midwives and child health nurses however reported often attempting deeper inquiries with positive outcomes.

The common approach to perinatal mental health screening (routine screening at first visit) and the EPDS was frequently reported as ‘challenging’ and ‘difficult’. The majority of health professionals noted that the EPDS was frequently positively biased. More experienced professionals reported only using the EPDS when concerned about a Mother’s mental health as it broached suicidal ideation. All Aboriginal Mothers who recalled using the EPDS (n=10) reported positively biasing their results; 2 were experiencing strong suicidal ideation at the time. Despite this, ninety-three (93%) of professionals reported routinely using the EPDS with Aboriginal women with 81% modifying its use for Aboriginal Mothers.

Notably, Cox (2017), one of the original authors of the EPDS, also recently emphasised that context was critical in making the most of the EPDS. Understanding the broader social, emotional and cultural circumstances of Mothers can significantly influence how a score is interpreted. Further, that EPDS screening should be part of a broader perinatal care relationship.

7.3.2 Perinatal screening and care should be strengths-based and non-pathologising

There was strong evidence that most Aboriginal women are detached from medicalised notions of depression and anxiety. Mothers experienced medical terminology and mental illness labels as alienating, laden with meaning that they did not or did not wish to relate to. One-hundred percent of Aboriginal Mothers under 40-years (n=25/27) reported struggling with symptoms of depression or anxiety based on DSM-V criteria. Of these, only 3 who were acutely unwell, acknowledged their experience as depression; 2 derived reassurance from a diagnosis.

All Mothers described remarkable resilience against complex challenging life circumstances. A solid childhood relationship with strong Mothers or Grandmothers notably enhanced resilience *"I was lucky I had a good Grandmother who loved and taught" and "my Nan taught me my identity".* Other strengths and protective factors are outlined in some detail in Chapter 5 and included connections with culture, Family, and through self-identifying as instinctively and innately strong Mothers *"having kids and keeping all together, that's how we grow and get strong physically and spiritually".* Uusher et al., (2016) also confirms that the transformation of self through 'Motherhood' is highly protective and healing.

Protective connections for Mothers through their personal connection to self through Motherhood, through connection to Family, Culture, Country, and Kinship ties should not be underestimated. Enquiring and encouraging strengths can provide a more balanced assessment and can point to personal resources that may be profoundly helpful in working Mothers to co-plan their future.

7.3.3 Perinatal screening and care should privilege culture and context

Understanding mental health as part of a broader cultural concept of social and emotional wellbeing (SEWB) can guide the screening process to a deeper understanding of the needs of the woman, the child and the Family.

© Gee, Dudgeon, Schultz, Hart and Kelly, 2013.

Figure 16. Model of Social and Emotional Wellbeing. (Gee et al 2013)

The SEWB principles in Figure 16 are critical to informing effective perinatal psychosocial assessment and should be underpinned by these nine guiding principles for Aboriginal and Torres Strait Islander SEWB: (i) health is holistic, (ii) self-determination is central, (iii) culturally valid understandings must shape services, assessments, care and management, (iv) recognition of experiences of trauma and loss, (v) respect for rights as a human (vi) racism, stigma and social disadvantage constitute significant stressors, (vii) the centrality of Family and Kinship, (viii) there is no single culture or group, (ix) recognition of great strength, creativity, endurance and the deep relationships between human beings and their environment. Themes from all data sources matched these nine guiding principles.

7.3.4 Perinatal screening and care depend on trusting, respectful and collaborative relationships

Some Mothers noted the generosity and kindness shown towards them by their midwives. However, all Mothers reported experiences of racism, cultural bias or rudeness during perinatal care. Cultural bias, discrimination and interpersonal and systemic racism were strong themes among health professionals also. The health professional interviewees (majority currently working as community-based midwives) frequently reported witnessing implicit and explicit racial bias among their colleagues. Notable in one of the hospital-based workshops with midwives was an intolerance when discussing Aboriginal Mothers-to-be. A number of senior midwives described them as being *'disrespectful'* and *'unreliable'* appointment attendees and some of them tended to '*use the system'*. Whether all participants held these views was uncertain, as the vocal few went unchallenged by others.

Creating engagement, trust and continuity of care within a therapeutic friendship' were notably critical, then approaching assessments by first having 'yarn,' rather a 'check-list' approach. *"The white fella nurse did not explain anything, she gave me the brochures thing. She just gave me them forms. They should yarn more you know and find out that way"*. Being encouraging and using a strengths-based approach to all care were strong themes also *"they should ask about our coping skills, our coping skills and maybe our feeling…highlighting our coping skills, what makes us strong"*.

Below in Table 25. are the major thematic qualities that health professionals can and should be able to routinely practice, as strongly identified by Mothers and some health professionals. Many health professionals whilst they may be willing, lack the confidence, knowledge and support to embed these qualities into their practice. Their own cultural bias and the dominant culture of the medicalised health system are failing to support them in this. Many health professionals would respond to these features being supported and embedded into routine clinical practice. This approach requires practice and policy change.

Table 25. Qualities identified by Mothers and health professionals as supporting trusting relationship.

Professionals need to practice
Cultural flexibility
Professional flexibility
Self-reflective practice
Collaborative practice with Aboriginal colleagues
Collaborative practice with Aboriginal Family
Working from trauma informed practice
Suspend judgement
Innocent inquiry
Deep listening
Cultural humility
Being kind
Showing compassion
Professionals need to avoid
Use of medicalised language
Labelling
Making assumptions

7.3.5 Perinatal screening and care must recognize that families are critical in supporting perinatal wellbeing

All professionals, even the most experienced underestimated the importance Aboriginal people placed on Family. Making families welcome – including children, Aunties, Grandmothers and others of significance is culturally important. All professionals, even the most experienced, underestimated the importance Aboriginal people placed on Family. Involving Family in perinatal care supports two-way learning and strengthens parents' social and emotional wellbeing. Aboriginal participants stressed this as particularly relevant for young or vulnerable parents.

Current traditional models of perinatal mental health screening and assessments are targeted at women/Mothers. The evidence accumulated in this research demonstrates that for

Aboriginal women to successfully transition into Motherhood, the perinatal mental health of the whole Family needs to be considered. While current psychosocial assessments include what Family supports a woman may have; these are notional if the perinatal mental health of her partner and Family is insufficient to support her. A perinatal mental health assessment and follow-up should not be considered in isolation from other factors; nor should the approach to facilitating supports. Extended Family should be considered in relation to their capacity to directly impact the health, wellbeing and healing a Mother's perinatal journey represents and should optimally be integrated into screening, referral and feedback processes.

7.3.6 Perinatal screening and care must bring Fathers into the circle

A particularly innovative contribution from this program of research was bringing Fathers into the fold when it comes to understanding and contributing to the perinatal mental health of their partners, themselves and their families. Traditionally perinatal mental health has been considered only for Mothers. Multiple gender specific AAG sessions brainstormed solutions to address identified barriers and enhance protective factors in the process of developing a new approach to screening involving both parents, both individually, and as a couple.

Fathers play a vital role in the wellbeing of Mother and Family yet reported frequently struggling in the early years of parenting. They, like the women, became parents at a young age (9/10 under 20-years) and had few if any positive paternal role models. Like the Mothers, they identified their need for a dedicated space to explore and problem solve challenges. Parents with Family support fared well. Others not so well. Views of parenthood held by the Fathers were more consistent with traditional perspectives imposed by colonization. They viewed their roles as being the provider and disciplinarian.

The significant majority had no concept of co-parenting unless they had been Father more than 3 times with the same partner. Under these circumstances they recognised their deficit in co-parenting with previous births and had become more engaged in household management. Many reported that in hindsight that their partners had suffered depression, but at the time they were acutely unaware, rarely sharing feelings with each other.

Within the context of this research the views and perspectives of Fathers is relevant and an important contribution to improving the overall approach to perinatal mental health screening for Aboriginal families.

7.4 Bringing this vision to life

The perspectives of Aboriginal Mothers and Fathers in this research provides a powerful clarification about why current perinatal engagement and outcomes are so persistently poor. The evidence drawn from this research provides clear guidance as to how clinical practice may be improved to ensure a culturally secure experience for Aboriginal clients. However, it is also clear that recommendations need to inform change related to policy, organisational culture, resourcing and individual practice, for maximal effect. In particular, privileging culture and context requires ongoing training and a commitment to reflective practice. Tokenistic acknowledgement of Aboriginal culture is not an adequate to provoking clinical changes in practice or supporting improved perinatal care outcomes in service settings. Rather, elevating the privileging of culture and understanding the contexts and circumstances of Aboriginal peoples' lives can only be achieved if health professionals participate in ongoing training and make commitments to maintain reflective practice. One-day workshops may be transformative or may only scratch the surface. In either case, what is required is a commitment to ongoing learning and critical reflection. Publishing accounts of innovative practice and also of lived experience of service users is also helpful in enriching the evidence-base from which practitioners can draw. The perspectives of Aboriginal Mothers and Fathers in this research provides a powerful clarification about why current perinatal engagement and outcomes are so persistently poor. The evidence drawn from this research provides clear guidance as to how

clinical practice may be improved to ensure a culturally secure experience for Aboriginal clients. However, it is also clear that recommendations need to inform changes related to policy, organisational culture, resourcing and individual practice, for maximal effect. Tokenistic acknowledgement of Aboriginal culture is not an inadequate response to provoking changes in clinical practice or supporting improved perinatal care outcomes in service settings. Rather, elevating the privileging of culture and understanding the contexts and circumstances of Aboriginal peoples' lives can only be achieved if health professionals participate in ongoing training and make commitments to maintain reflective practice. Publishing accounts of innovative practice and of the lived experiences of service users is also helpful in enriching the evidence-base from which practitioners can draw. A final recommendation of Mothers, health professionals and the leadership and governance groups is that 'nothing about us, 'without us' could be more fully achieved through codesigning supportive resources for service providers and Aboriginal communities to utilise to support families during the perinatal period. This recurrent theme in our conversations led to the genesis of a codesigned perinatal screening tool for Aboriginal Mothers and Fathers. Whilst in its infancy, it will be the subject of research that extends beyond this thesis. It is introduced here as an indication of what is possible when using a richly collaborative research methodology to amplify and translate the voices of Aboriginal parents and health professionals. Results from all data sources have been explored and the iterative co-design process between Aboriginal community and Elders, Aboriginal professionals and researchers, and non- Indigenous professionals, managers and researchers has resulted in a wrap-around screen,
assessment and follow-up program for Aboriginal Mothers, Fathers.

A codesigned perinatal screening innovation. *Baby Coming You Ready* (BCYR) was codesigned in the latter part of the PhD research as a culturally secure framework for assessing perinatal wellbeing based on the Aboriginal understanding of SEWB. The idea had its genesis in interviews and focus groups and was codesigned through extensive work done by the

Aboriginal Advisory Groups, the Lead research Advisory Group, the Elders Cultural Safety Group and investigative research working party.

BCYR incorporates the clinical recommendations outlined in this chapter. It is intended to support a collaborative process between client and health professional that lasts throughout the perinatal period. The program centers around two touchscreen digitised assessment rubrics used on iPads – one for Mothers and one for Fathers – and designed to enable the Mother to control what information she is prepared to disclose. The intention is to aid enhanced engagement, mutual understanding and trust.

Using a suite of images that represent multiple facets of the perinatal experience from a culturally considered viewpoint, Aboriginal voice overs and images facilitate a yarning style approach to the Mother's perinatal story. Whilst the images focus on strengths, they also capture common worries. This allows the parent to reflect and externalise her experience should she choose, by first touching the image then yarning about it if she wishes to. This framework guides the health professional and the Mother through specified strengths-based domains of inquiry. These include but are not limited to connections to Kinships, Country and Family, growing up, current relationships and housing, access to resources and supports, how well she is coping, childhood memories and experiences, self-esteem, and racism. The use of images prompt thinking and the skip logic used in the process triggers additional or specific slides to support deeper inquiry into specified domains. These include FDV, AoD, smoking and stages of change in relation to each. It also triggers the framework to support both users to develop a safer plan and provides 'practitioner prompts' should the need arise. The skip logic ensures a personalised experience and reduces time wasted on questions that are not applicable to that person. Figure 17 shows examples of images integrated into BCYR.

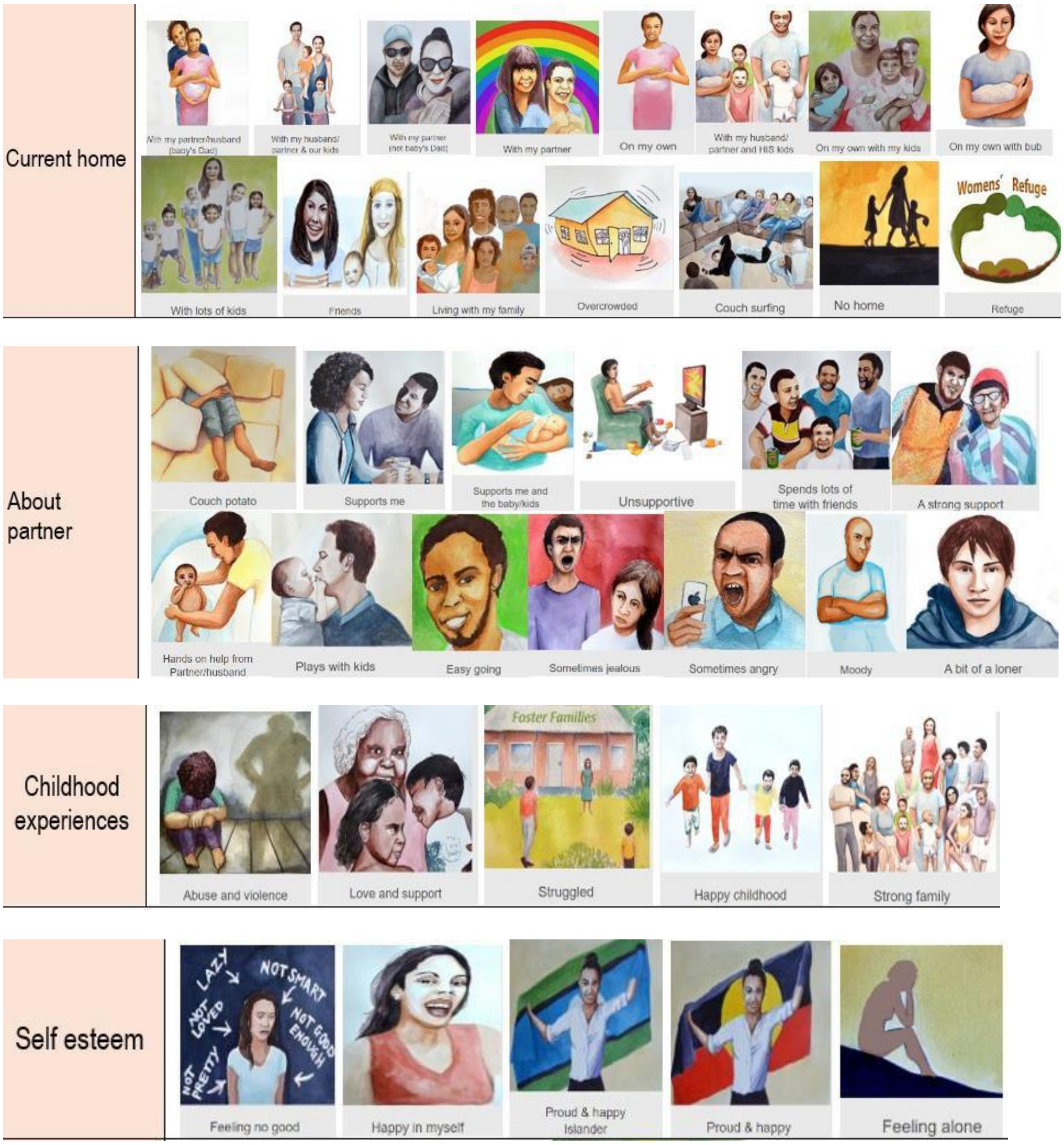


Figure 17. Examples of touch screen images in the BCYR women’s rubric

BCYR incorporates the best available mental health tools evaluated in the literature e.g. Kessler 5+2 (Mc Namara et al., 2014; AIHW, 2009) and cultural reviews e.g. Stay Strong (Nagel et al., 2008/2010), HANNA (Janca et al., 2015) and GEM (Haswell et al., 2010). Whist the evidence-based concepts and content remain the same, the images and voice overs may be adapted to suit specific cultures and communities.

It is designed to be used by the parent and health professional ‘side-by-side’ as part of a broader conversation and care planning process. A whole-of-person approach is taken to explore life context as well as strengths rather than just symptoms. A report is generated for each parent and the health professional. Recommended actions are simply described. BCYR utilises a web-based mobile platform to ensure accessibility and that the experience of screening and accessing relevant resources and educational information is simplified. An associated interactive website provides professionals and parents with culturally targeted perinatal supportive information reflecting the needs and preferences they have highlighted. www.babycomingyou ready.com.au.

While the detail and potential of this new screening tool was well beyond the planned scope of this thesis, BCYR has been the final emergent part of this PhD program of study (as seen in Figure 18 below) and will become the basis for the next program of work in this community collaboration. There is much evaluation and further development work to be done and this will be reported in the literature as it unfolds.

7.4.1 Evaluating the rubric:

Detailed evaluation of BCYR is beyond the scope of this thesis. However, beta-testing with key informants and members of the Lead Research Advisory Group and the Aboriginal Advisory Groups was undertaken and is reported in this section.

Key informant interviews: These were undertaken with 12 health professionals from mainstream services. Each professional was invited based on their high-level experience in mental health or in one case the combination of their experience in mental health and cultural expertise as an Aboriginal person. Each was asked to explore the Mothers BCYR rubric against specified criteria (Table 26).

Table 26. BCYR exploration criteria for Key informant interviews.

What are your initial impressions of BCYR
How useful do you think BCYR might be to screen for depression and/or anxiety? Why?
What are your thoughts on the proposed use of technology?
What are your thoughts about the introduction process and lead-in question?
What about the domains of inquiry?
What are your thoughts about the [guided] questions? [Useful? Quantity? Etc]
What about the Likert type questions?
And the Management Plan process, what are your thoughts about that?
What might be some of the strengths of BCYR
What might be some of the weaknesses of BCYR?
How does it compare to EPDS?
Who do you think would be the best person/profession to facilitate the rubric?

Twelve professionals were invited to participate in order to capture divergent culture, interests and perceptions. Professions represented included: social work (2), psychiatry (2), psychology (1), mental health nursing (3), midwifery (2), child health/midwife perinatal mental health clinical nurse specialist (1). One was Indigenous, two were male. The majority of key informants were not Indigenous, as cultural considerations were embedded throughout its development, and the formative evaluation would be undertaken with parents in the proof of concept and beta testing as described below.

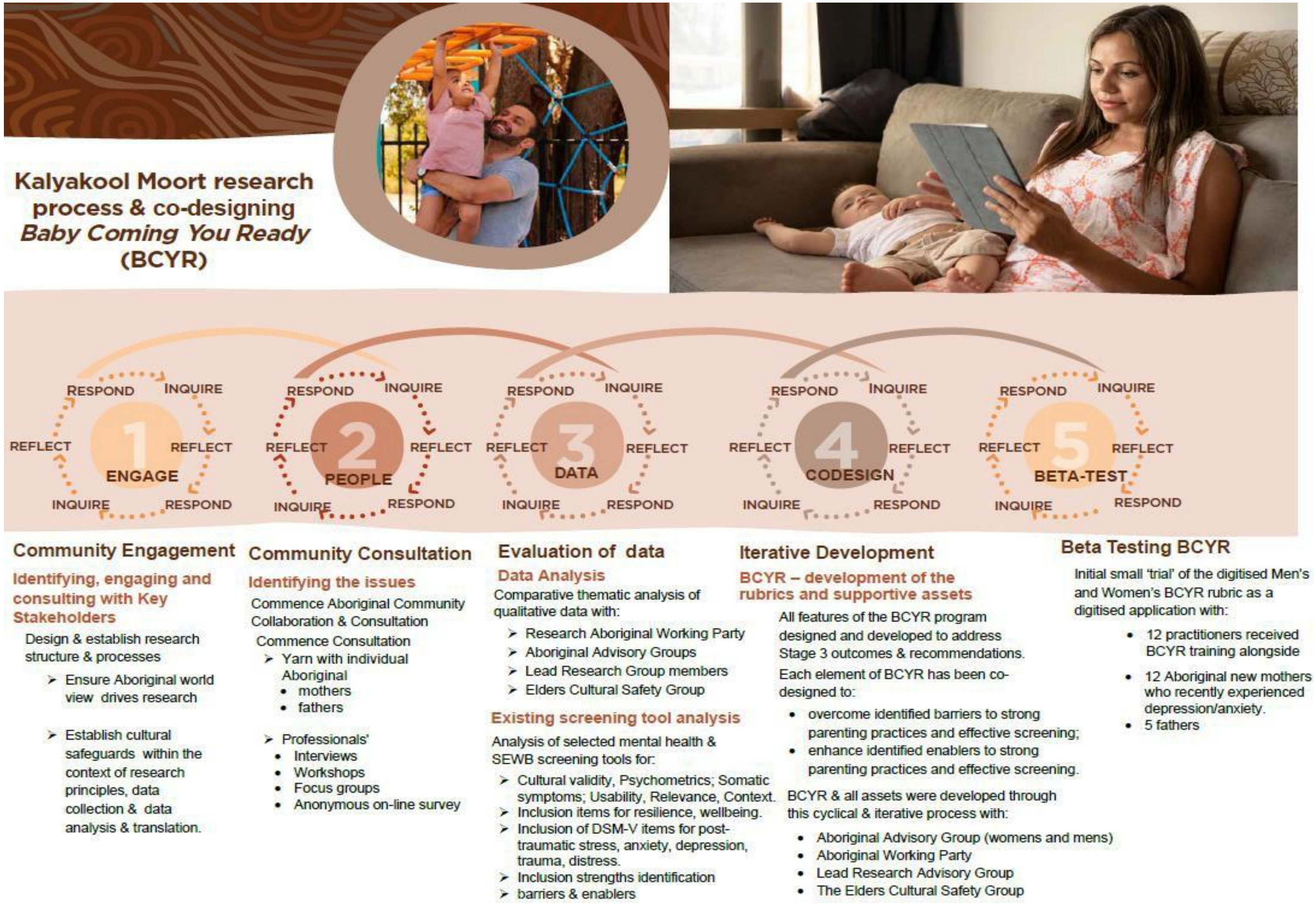
BCYR was endorsed by all mainstream service providers, as providing a culturally safe alternative approach to perinatal screening with potential to improve outcomes for Aboriginal Mothers. Salient comments are captured in Table 27.

Table 27. Key informant interview comments about BCYR

"You know I worry about the future of vulnerable families in this current push toward outcome-based performance measures [in child health). It gives me hope for the future of the wellbeing and mental health for all these vulnerable Mothers across many cultures. These Mums will be identified and get the support they need early in the piece [antenatally] and not be so vulnerable postnatally."
Midwife/child health nurse (Aboriginal Child Health Team)
"Looking at it you know it is much more than a screening tool; if you reduce its content you could limit its capacity; [as it is] it meets all current national mental health recommendations for mental health standards of care and it demonstrates the way for mental health screening."
Psychiatrist (perinatal mental health)
"*They [Aboriginal Mothers) live with stress and drama every day; these Mums don't need to be screened [with EPDS] to know they are stressed out to the max; they need to feel like someone cares about what is important to them and to feel supported; and this [rubric] will do that. When can we start using it?"*
Midwife coordinator. Aboriginal Medical Service
"We have to develop relationship with these Mothers; they aren't ever going to tell us anything unless we have that. It does all that and it helps midwives to know how to do it, and how to respond."
ALO Aboriginal Maternity Group Practice
"It complements the tool that we are rolling out in primary health care with GPs across WA. It will make so much easier for GPs to work systematically in a culturally safe way with vulnerable Aboriginal families."
Mental Health Manager (Specialist Aboriginal Mental Health Service)
"I receive so many un-necessary referrals [from the EPDS]. This make sure our time is not wasted, and midwives can do their job with more confidence and vulnerable families will be better off."
Specialist Perinatal Mental Health/Child Health Nurse

Proof of concept and beta-testing: This occurred through three stages.

1. Some members from the Lead Research Advisory Group and the Aboriginal Advisory Group (n=16) explored BCYR rubrics on iPads and role-played its use in pairs. A feedback session and workshop followed where each element of the women's rubric was reviewed and assessed as a group.
2. Midwives and child health nurses (n=12) together with 12 new Aboriginal Mothers and 5 Aboriginal Fathers facilitated the rubrics in individual pairs. Group feedback sessions followed with both the parents and health professionals.
3. Elders Cultural Safety Group reviewing the rubrics in facilitated workshops.



Kalyakool Moort research process & co-designing *Baby Coming You Ready* (BCYR)

Community Engagement

Identifying, engaging and consulting with Key Stakeholders

Design & establish research structure & processes

- ➢ Ensure Aboriginal world view drives research
- ➢ Establish cultural safeguards within the context of research principles, data collection & data analysis & translation.

Community Consultation

Identifying the issues

Commence Aboriginal Community Collaboration & Consultation

Commence Consultation

- ➢ Yarn with individual Aboriginal
  - mothers
  - fathers
- ➢ Professionals'
  - Interviews
  - Workshops
  - Focus groups
  - Anonymous on-line survey

Evaluation of data

Data Analysis

Comparative thematic analysis of qualitative data with:

- ➢ Research Aboriginal Working Party
- ➢ Aboriginal Advisory Groups
- ➢ Lead Research Group members
- ➢ Elders Cultural Safety Group

Existing screening tool analysis

Analysis of selected mental health & SEWB screening tools for:

- ➢ Cultural validity, Psychometrics; Somatic symptoms; Usability, Relevance, Context.
- ➢ Inclusion items for resilience, wellbeing.
- ➢ Inclusion of DSM-V items for post-traumatic stress, anxiety, depression, trauma, distress.
- ➢ Inclusion strengths identification
- ➢ barriers & enablers

Iterative Development

BCYR – development of the rubrics and supportive assets

All features of the BCYR program designed and developed to address Stage 3 outcomes & recommendations.

Each element of BCYR has been co-designed to:

- overcome identified barriers to strong parenting practices and effective screening;
- enhance identified enablers to strong parenting practices and effective screening.

BCYR & all assets were developed through this cyclical & iterative process with:

- Aboriginal Advisory Group (womens and mens)
- Aboriginal Working Party
- Lead Research Advisory Group
- The Elders Cultural Safety Group

Beta Testing BCYR

Initial small 'trial' of the digitised Men's and Women's BCYR rubric as a digitised application with:

- 12 practitioners received BCYR training alongside
- 12 Aboriginal new mothers who recently experienced depression/anxiety.
- 5 fathers

Figure 18. Model of the codesign approach taken in developing *Baby Coming You Ready* with Aboriginal community and Aboriginal and non- Indigenous health professionals and researchers

Beta-testing[1] the digitised BCYR rubrics with 12 Aboriginal new Mothers, 5 new Aboriginal Fathers and 12 midwives/child health nurses followed by focus groups, added strength to the cultural, face and content validity. Feedback was both affirming and helpful with many positive suggestions for improvements and amendments. Both the Mothers and Fathers reported positive experiences (Table 28).

Table 28. Mothers' and practitioners' comments about their experience using BCYR:

Mother feedback and comments
"It was the first time realised how strong I was, seeing all my strengths there like that."
"I really liked [doing] it …. I felt like I had control over it."
"It was great to see the things that are worrying me, and to sort out my worries ... they don't feel so big now."
"I like the images and the Aboriginal voices."
Practitioner feedback comments
"When I get busy, 1 sometimes forget things, and this really helps me remember all the things I need to explore."
"It gives me new ways to ask about the more difficult topics."
"The iPad and images make it easier to share and talk about things, it takes the pressure off"
"I love the images and voice overs."
"I loved how the woman grabbed the iPad from me and took over the process... she seemed to really take to it, you know, to get involved."

BCYR has demonstrated preliminary cultural, face and content validity. Each separate component/element embedded within the rubric has an evidence base i.e. the Kessler-5 (McNamara et al., 2014) plus 2; motivational interviewing against the stages of change

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[1] Beta testing is a type of 'user acceptance' evaluation of a product in real world settings. It determines a first line usability in a real-world application.

(Levounis & Marienfeld, 2017); brief intervention strategies (Saitz et al., 2014) and the use of ‘clinical yarning’ (Lin et al., 2016).

Results have confirmed the potential of BCYR though further work is required to determine its usability across the sector more widely.

7.5 Discussion

Translating the work of this PhD into clinically relevant recommendations fulfils a key aim of this thesis. From the beginning, this work has been motivated by impacting persistently poor perinatal outcomes for Mother and child through the development of an evidence-base to guide practice. The contribution of parents, health professionals and the committed work of the Aboriginal leadership and governance groups has been imperative to having confidence in developing this evidence base and in translating the findings. The promising beginnings of a culturally secure evidence-based perinatal screening tool has also been a rewarding result of this close and committed collaboration.

Chapter 8. Discussion and conclusion

8.1 Overview

This program of research was motivated by a clinical observation in my role as a midwife – how to provide effective and culturally secure perinatal screening and care for Aboriginal Mothers in the context of persistently poor perinatal outcomes for Mothers and their infants. There was no evidence-base to guide my practice or that of the many midwives and health professionals caring for Aboriginal women during this most important time as they approached Motherhood. We were simply expected to comply with the national standard of using the EPDS despite poor engagement of Aboriginal Mothers and poor outcomes (Chan et al., 2020; Freeman et al. 2018; Gausia et al., 2015; Highet and Goddard, 2014). This PhD was intended and designed to address a pernicious gap in the literature that continues to result in potentially culturally unsafe practices. In the five years it took to complete this work, and since, the perinatal outcomes for Aboriginal women and children have not improved significantly against parameters associated with antenatal distress (AIHW, 2020a). The annual Closing the Gap report stubbornly adheres to the levels of the previous 10 years (Australian Government, 2020).

8.2 Key findings

Most concerning was the finding reported in Chapter 3 that there is no published evidence supporting the use of the EPDS in perinatal screening with Aboriginal Mothers despite its routine use for this purpose and national guidelines that indicate it as the gold standard tool in Australia. Indeed, the yarns, interviews and focus groups undertaken with Aboriginal Mothers and health professionals suggest that it is experienced negatively by both groups, perhaps providing an explanation for poor engagement which in turn contributes to persistently poor perinatal outcomes. There is no validated alternative that has widespread cultural adaptability in the perinatal context, and only a few mental health measures designed for an Aboriginal context that might potentially be evaluated for their relevance for perinatal application. In this respect, the key findings from this research offer evidence for better approaches to perinatal mental health screening for Aboriginal women.

Aboriginal Mothers, Fathers and health professionals were invited to talk about the barriers and enablers to successful perinatal screening; and also, to talk about how they perceive strong parenting (Chapters 5 & 6). There was strong engagement with this project and a desire to contribute to improved knowledge about these issues. A wealth of information was provided that informed the development of clinical recommendations for changes in practice. As outlined in Chapter 7 Aboriginal parents and health professionals felt that the time limitations imposed on screening assessments prevented the development of strong and trusting relationships with the health profession. Given the historical context which continues to influence how these interactions continue to take place, a lack of trust is unsurprisingly common and often underpins Aboriginal women's non-attendance or positive bias in responding to screening practice. It was also clear that an ongoing, relationship was considered necessary to make engagement seem worthwhile and safe. Further, families and Fathers did not feel welcome in perinatal care services yet have much to offer and much to benefit from being engaged.

It is clear from the studies undertaken that the need for a strength-based holistic approach to perinatal mental health and wellbeing screening is critical to counter current approaches to pathology based perinatal mental health screening. What is clear in the evidence is that Aboriginal people do not consider or relate to their mental health according to medicalised notions. Pathology-based assessments diminish and disaffect Aboriginal Mothers, who deserve acknowledgement and encouragement for the extraordinary strength and resilience they display against enormous personal, environmental, and systemic challenges. In response, this research has demonstrated the strong notion that social and emotional wellbeing is a more helpful framework for perinatal screening.

Practitioners reported feeling under-prepared and under-resourced to provide effective and culturally secure perinatal screening and care for Aboriginal clients. Even those who felt confident to do so were not necessarily experienced this way by their clients. Many clinicians seemed afraid, reserved or ignorant about the importance of inquiry which incorporates knowledge of cultural nuances and protective factors for Aboriginal women. They lacked confidence to ask ‘hard’ questions about suicidal ideation, history of abuse or FDV in a culturally safe way. Health professionals with the requisite experience described taking time, being culturally attuned and compassionate. Overall, health professionals in this research were requesting additional supports to provide better care.

It was clear that current clinical perinatal practices are not fit-for-purpose when working with Aboriginal women. It is hoped that the evidence-base gathered in these studies will assist practitioners, service providers and policy makers to re-consider current best practice guidelines. The clinical recommendations made in chapter 7 are intended to provide a starting point for these conversations.

In addition to the theoretical and clinical contributions outlined above, this program of research addressed important methodological issues. Two systematic literature reviews highlighted significant gaps in the evidence-base for Aboriginal perinatal screening. This was not simply an absence of studies but also significant methodological limitations in those studies that have been undertaken. Rather than simply synthesising study findings, it was critical to subject each study to a methodological quality evaluation. In doing so, it supported the GRADE recommendation that poor quality evidence should not be elevated to the status of best practice when the consequences of doing so may negatively impact the clinical care decisions for vulnerable populations.

The most powerful methodological finding was that a decolonising approach was able to be successfully operationalised at all levels of the research journey. This required a strong commitment from all parties and ongoing conversations about what was working and what was not. It resulted in rich and trustworthy data, and strong clinical translation with the design of a new screening tool, able to be piloted and evaluated for suitability. The relationships built as the program of research unfolded allowed an adaptive project that could flexibly address emergent findings. Well executed decolonising methodologies, such as those employed throughout the Kalyakool Moort research, fulfil a need identified by and for Aboriginal community.

Creating an evidence-base is painstaking work. Conceptual, methodological and pragmatic challenges are equally taxing and often perplexing. However, the light at the end of a tunnel is improved clinical practice guidelines and stronger perinatal outcomes for Mothers, children and families. This collaborative project has also unexpectedly led to a possible new approach to perinatal mental health screening and management, *Baby Coming You Ready,* which will continue to be codesigned to address the clear gaps identified by both parents and professionals.

8.3 Challenges of the research program

As with all research, there were a number of challenges along the way.

Time: It takes time to undertake safe effective practice in the context of working with Aboriginal families and communities. Being strongly committed to working in decolonising framework means that things take time and do not easily sit within the framework of academic institutions or funding bodies. The process has required patience, persistence, and passion to ensure that adequate time was allowed, and cultural considerations and protocols were adhered to.

Engaging men: This perinatal screening research has naturally focused on Mothers. However, within the context of Aboriginal communities the inclusion of Fathers (birth Fathers or otherwise) was vital. Engaging Aboriginal men as members of the Advisory group was somewhat challenging as many initially considered that the perinatal period was ‘women’s business’. That said, the men who did engage from the outset remained active and committed throughout the research process.

Male Aboriginal research assistants were engaged to ‘yarn’ with Fathers in the data collection. This proved somewhat problematic when it came to discussing emotions and feelings. Indeed, many men indicated that they would rather ‘open up’ to an older woman so as to not feel shame among their peers.

Being non-Indigenous: Being non-Indigenous and researching in an Aboriginal community where I was previously unknown, presented some challenges. There was suspicion from many Aboriginal professionals, people and Elders which was understandable. Overcoming this took time, patience and the support (and “vouching”) of those Aboriginal people who had already engaged with the process and myself.

Interprofessional collaboration: Being a practicing clinician working in community settings where holistic care is critical, the delineation and boundaries of different professional paradigms of thinking and scope of practice can be problematic. These differences also became apparent, on occasions, in the interdisciplinary advisory group discussions when discussing barriers and enablers to perinatal mental health and screening. There were different conceptualisations e.g: concepts of screening versus making diagnoses and considering SEWB and mental *health* versus mental illness/disease. Navigating this was at times challenging for all participants. Despite these challenges, this interdisciplinary approach was vital in the codesign process.

Triangulating different sources of data: Triangulating data sources is a strength of exploratory research of this kind. The data sources in this research included literature reviews, health professional interviews, focus groups and a statewide questionnaire and individual yarns with parents. Drawing on theory, clinical experience and the Aboriginal leadership and governance groups was both supportive and valuable to an otherwise complex process. This also ensured the strongest and most defensible outcome.

Desire based approach to decolonising research: This methodology was energising and engaging for the Aboriginal Advisory Group members. They embraced having equal (if not more) power in the process and responded to this freedom to codesign solutions with commitment and passion. Each element of the codesigned solution was visionary and simple in concept. However, translating this into a tangible reality with its various components such as extensive use of touch screen images on iPads, skip logic, voice overs and transferable data reporting was a complex process. This required time and accessing numerous sources of funding.

Large leadership and governance teams: This research program engaged Aboriginal community members and Elders, and key stakeholders from multiple health, government and non-government organisations for whom research was not necessarily their core business. This required significant flexibility with formal and catchup meetings to ensure ongoing engagement. This sometimes required meeting out of hours as well as additional time, as electronic communication (emails) was not always possible or ideal.

8.4 Limitations of the research program

This series of studies have contributed theoretical, clinical and methodological innovations to perinatal practice with Aboriginal families. However, there are several limitations that need to be addressed.

State-based research: The Aboriginal people committed to supporting this research were from many clans or Nations and were considerate of the broad cultural diversity they were aiming to consider in designing solutions to screening barriers. However, the great majority had strong Nyoongar connections or were from across WA. Care was taken to accommodate wide adaptability in the solution designs; however, this cannot be assumed, and wider research is required to determine cultural adaptably.

Engaging men: Using ‘yarning’ as a culturally safe and effective research method for data collection with Aboriginal peoples is well evidenced. Inter-rater reliability training with Dawn Bessarab, the designer of ‘yarning’ as a robust method for data collection, proved effective for Aboriginal women collecting data from other women. However, the effectiveness of the process was at times compromised by younger male Aboriginal research assistants yarning with Fathers. There was at times obvious discomfort and therefore less disclosure when talking about personal experiences. This was overcome by engaging an older woman who was able to create a sense of safety with Fathers who emersed themselves in the yarning process. However overall numbers of Fathers participating in yarns was low (n=10).

COVID-19 pandemic: This potential for outbreak and subsequent community ‘lockdowns’ put a halt on continued engagement with some Aboriginal Advisory Group members and the Elders Cultural Safety Group. This was problematic as the personal isolation for them in community was significant. For the research process the impact was less problematic as fortunately relationships were well established by this stage, so potential disengagement in the research was insignificant.

The necessary lockdowns proved to some extent advantageous. It has led to strengthened commitment to the importance of IT based solutions to increase accessibility for Aboriginal women.

8.5 Recommendations for future research

This research has led to a clear set of priorities for future research, especially around clinical translation research. Future research would see a health technology assessment of the evidence-based solutions as it translates from proof of concept (beta-testing) to a clinical practice.

Development and evaluation of training modules for professional development and/or operationalised guides and resources, would also be helpful. Evaluation of same will be key to ensuring that we are effectively working toward change in practice that will potentially improve perinatal outcomes. A long-term research commitment to match perinatal outcomes to this intervention is essential and will require mapping where these recommendations have been most fully (or poorly) adopted.

The literature review identified some mental health tools designed for Aboriginal services that have potential to be more fully psychometrically and culturally evaluated. The study reported in Chapter 4 highlights which tools may benefit from further work.

The interviews with Fathers, while few in number, provided some key insights into male experience in perinatal period, and also into the experiences of the Family unit. Further exploration of the male experience and also the male perspective on the broader Family experience seems to offer great potential in shifting the conversation about perinatal mental health as being simply ‘women’s business’ to a more systemic understanding of the impact of individual wellbeing on Family dynamics and vice versa.

Baby Coming You Ready is only at the beginning of its development. The quality, effectiveness and efficacy of the BCYR tool and training needs to be piloted in clinical practice across different organisations and geographical locations in Western Australia. If it proves effective and culturally safe, national and potentially international trial sites could be explored. Iterative cycles of co-development, review and revision will be critical in exploring the potential of this novel approach to screening.

Exploration of the BCYR rubric for non-Indigenous women and men – although the intent of this research was to develop perinatal tools that address the specific gap in services for Aboriginal women, it seems possible that the clinical recommendations and indeed the clinical tool that resulted may also constitute a significant advance in perinatal screening practice for non-Indigenous women. Similarly, the men's BCYR may prove a useful innovation for non-Indigenous men who are also left out of the perinatal services in standard care, and who also have a significant role to play in influencing the mental health levels in the Family as a whole.

This program of research has instigated a cascade of activity and will continue to do so. Research priorities will be emergent from application but should always remain strongly committed to adopting the principles of decolonising research outlined in this thesis. The methodology is perhaps the most impactful aspect of this program of work – making an early commitment to take the hard road has paid rich dividends. De-coupling Indigenous research questions from a deep engagement with this methodological framework would simply return us to repeat the mistakes of the past.

In conclusion.

This research program, through its set of in depths studies, has identified and reported on important systemic barriers within the health care system which are impacting the effective engagement of Aboriginal women in their maternal care. Further, it has identified the barriers maternity care health nurses face and perpetuate through professional expectations and practices, inadequate supports and through the bias of their own profession and personal cultural lens. Importantly it has also identified and reiterated the extraordinary resilience of Aboriginal women and the cultural, familial, and personal influences that sustain them against complex trauma and a health system that fails to recognise its role in compounding this. With each of these barriers, solutions have also been identified and reported on. Through the decolonising the approach to this participatory action research people have been empowered to take control of their own circumstances and collaboratively codesign their own solutions. The result is an innovative approach to perinatal mental health screening and practice which may advance both clinical practice and health care outcomes for Aboriginal women families.

Overall, all aims, and objectives of this research program have been addressed. Appendix H captures existing risk factors for perinatal depression and anxiety from the literature and summarises the points that have emerged from this thesis. The recommendations for clinical practice provide concrete translational results for the future of Aboriginal maternity care and potentially have wider application.

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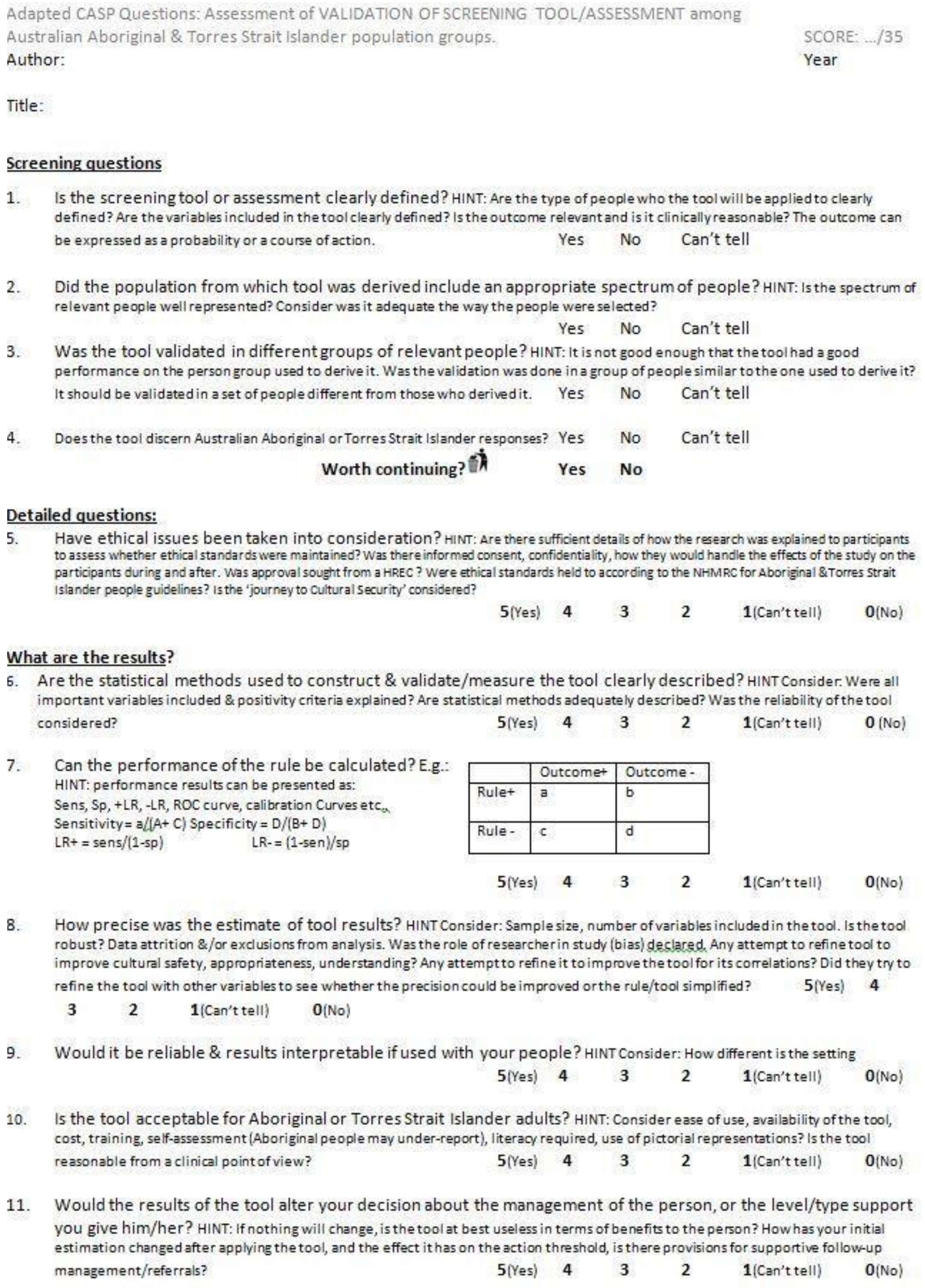
APPENDICES

Appendix A – Adapted CASP Screening Tool



Adapted CASP Questions: Assessment of VALIDATION OF SCREENING TOOL/ASSESSMENT among Australian Aboriginal & Torres Strait Islander population groups. SCORE: …/35

Author: Year

Title:

Screening questions

1. Is the screening tool or assessment clearly defined? HINT: Are the type of people who the tool will be applied to clearly defined? Are the variables included in the tool clearly defined? Is the outcome relevant and is it clinically reasonable? The outcome can be expressed as a probability or a course of action. Yes No Can't tell

2. Did the population from which tool was derived include an appropriate spectrum of people? HINT: Is the spectrum of relevant people well represented? Consider was it adequate the way the people were selected? Yes No Can't tell

3. Was the tool validated in different groups of relevant people? HINT: It is not good enough that the tool had a good performance on the person group used to derive it. Was the validation was done in a group of people similar to the one used to derive it? It should be validated in a set of people different from those who derived it. Yes No Can't tell

4. Does the tool discern Australian Aboriginal or Torres Strait Islander responses? Yes No Can't tell

Worth continuing? **Yes** **No**

Detailed questions:

5. Have ethical issues been taken into consideration? HINT: Are there sufficient details of how the research was explained to participants to assess whether ethical standards were maintained? Was there informed consent, confidentiality, how they would handle the effects of the study on the participants during and after. Was approval sought from a HREC ? Were ethical standards held to according to the NHMRC for Aboriginal &Torres Strait Islander people guidelines? Is the 'journey to Cultural Security' considered?
5(Yes) **4** **3** **2** **1**(Can't tell) **0**(No)

What are the results?

6. Are the statistical methods used to construct & validate/measure the tool clearly described? HINT Consider: Were all important variables included & positivity criteria explained? Are statistical methods adequately described? Was the reliability of the tool considered? **5**(Yes) **4** **3** **2** **1**(Can't tell) **0** (No)

7. Can the performance of the rule be calculated? E.g.:
HINT: performance results can be presented as:
Sens, Sp, +LR, -LR, ROC curve, calibration Curves etc.
Sensitivity = a/(A+ C) Specificity = D/(B+ D)
LR+ = sens/(1-sp) LR- = (1-sen)/sp

	Outcome+	Outcome -
Rule+	a	b
Rule -	c	d

5(Yes) **4** **3** **2** **1**(Can't tell) **0**(No)

8. How precise was the estimate of tool results? HINT Consider: Sample size, number of variables included in the tool. Is the tool robust? Data attrition &/or exclusions from analysis. Was the role of researcher in study (bias) declared. Any attempt to refine tool to improve cultural safety, appropriateness, understanding? Any attempt to refine it to improve the tool for its correlations? Did they try to refine the tool with other variables to see whether the precision could be improved or the rule/tool simplified? **5**(Yes) **4** **3** **2** **1**(Can't tell) **0**(No)

9. Would it be reliable & results interpretable if used with your people? HINT Consider: How different is the setting
5(Yes) **4** **3** **2** **1**(Can't tell) **0**(No)

10. Is the tool acceptable for Aboriginal or Torres Strait Islander adults? HINT: Consider ease of use, availability of the tool, cost, training, self-assessment (Aboriginal people may under-report), literacy required, use of pictorial representations? Is the tool reasonable from a clinical point of view? **5**(Yes) **4** **3** **2** **1**(Can't tell) **0**(No)

11. Would the results of the tool alter your decision about the management of the person, or the level/type support you give him/her? HINT: If nothing will change, is the tool at best useless in terms of benefits to the person? How has your initial estimation changed after applying the tool, and the effect it has on the action threshold, is there provisions for supportive follow-up management/referrals? **5**(Yes) **4** **3** **2** **1**(Can't tell) **0**(No)

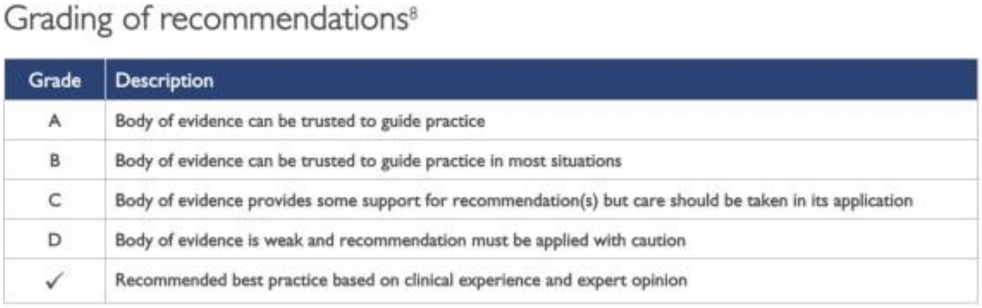
Appendix B - HINTS for Combined Studies Assessment. Adapted from CASP Checklists (2020)

Combined Studies Assessment. Not included are the 5 screening questions Adapted from CASP Checklists (2020).	
Q5. Was the research design appropriate to address the aims of the research?	HINT: consider has the research are justified the research design?
Q6. Was the recruitment strategy appropriate for the research aims?	HINT: did the research explain how the participants were selected? Were they the most appropriate to provide the knowledge sought by the study? Was their discussion around recruitment example why some people would choose not to take part?
Q7. Were the data collected in a way that addressed the research issue?	HINT: consider was the setting for data collection justified? Is it clear how the data were collected example focus groups interviews etc.? Did the research justify the methods chosen? Did the research and make methods explicit e.g.: for interview methods is there an indication of how interviews were conducted, or did they use a topic guide? If methods were modified during the study did the research explain why and how. Is the form of data clear e.g.: tape recordings, notes etc. did the research are discussed saturation of data?
Q8. Has relationship between researcher & participants been adequately considered?	HINT has the research are critically examined their own role, potential bias, influences during formulation of the research questions; data collection, including sample recruitment and location. How did the research respond to events during the study, did they consider the implications of changes in the research design?
Q9 Have ethical issues been taken into consideration?	HINT are there sufficient details of how the research was explained to participants to assess whether ethical standards were maintained? Did the researcher discuss issues raised by the study, e.g.: informed consent, confidentiality how they would handle the effects of the study on the participants during and after. Was approval sought from ethics committee?
Q10 Was the data analysis sufficiently rigorous?	HINT: is there an in-depth description of the analysis process. Is thematic analysis used? If so is it clear how categories and themes were derived? Did the research explain how the data presented was selected from the original sale to demonstrate the analysis process? Did

	the researcher critically examine their role, potential bias, influenced during analysis and selection of data for presentation?
Q11. Is there a clear statement of findings?	HINT: Consider if findings are explicit. Is there adequate discussion of evidence both for and against researchers arguments? Has researcher discussed credibility of the findings e.g.: triangulation, respondent validation, more than one analyst? Our findings discussed in relation to the original research question?
Q12. How valuable is the research?	HINT: Does researcher discuss contribution the study makes to existing knowledge or understanding? Do they consider findings in relation to current practice or policy? Or to the relevant research-based literature? Did they identify new areas where research is necessary? Have researchers discussed whether or how findings can be transferred to the population considered or other ways research may be used?
Q13. How valuable is the research application to the perinatal period?	Hint: consider somatic symptoms such as dizziness, indigestion, tiredness, breathing difficulties etc..

Appendix C – NHMRC Levels of Evidence

NHMRC (2009). NHMRC levels of evidence and grades of recommendations for developers of guidelines



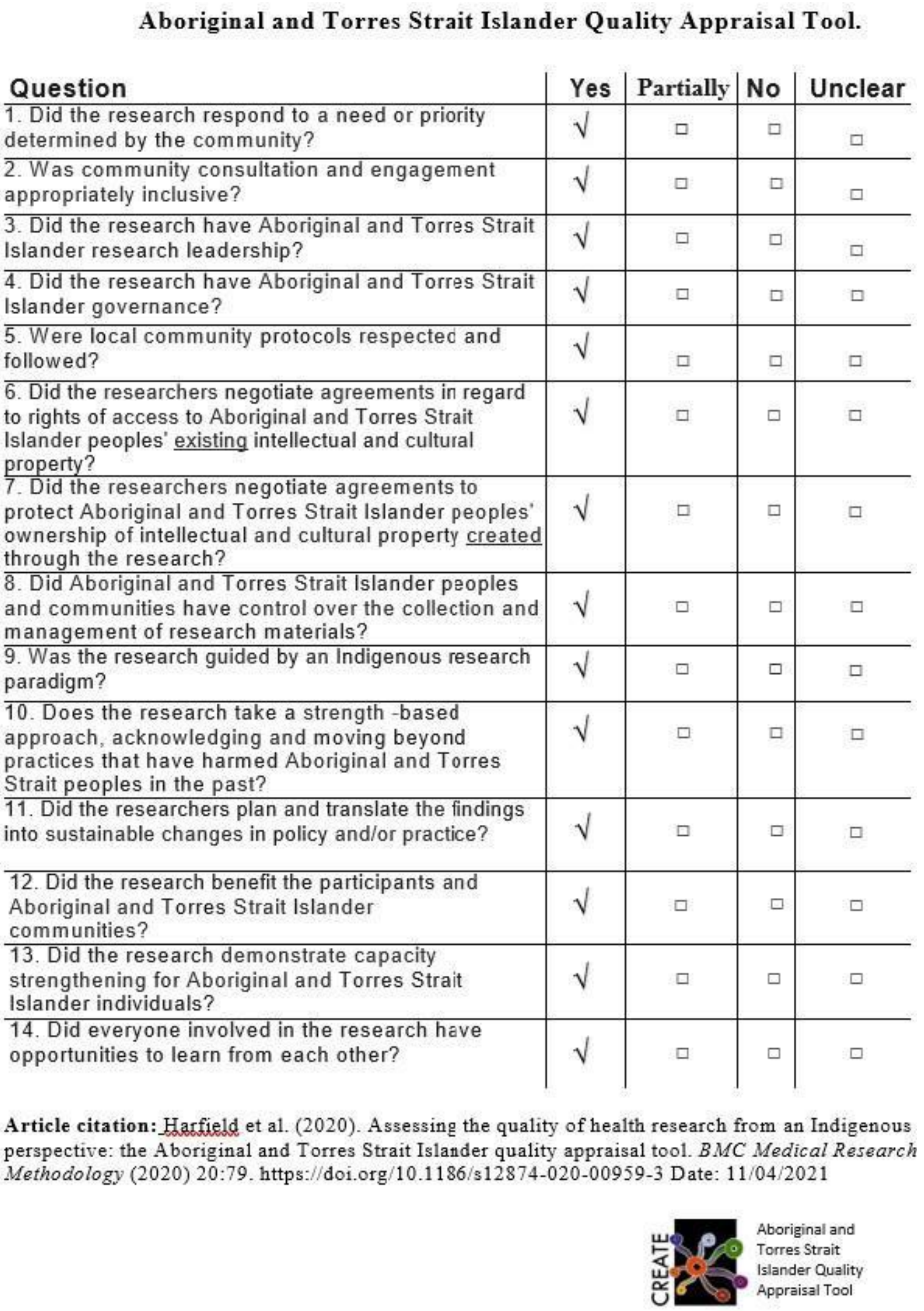
Grading of recommendations[8]

Grade	Description
A	Body of evidence can be trusted to guide practice
B	Body of evidence can be trusted to guide practice in most situations
C	Body of evidence provides some support for recommendation(s) but care should be taken in its application
D	Body of evidence is weak and recommendation must be applied with caution
✓	Recommended best practice based on clinical experience and expert opinion

Designations of levels of evidence according to type of research question[8]

Level	Intervention	Diagnosis	Prognosis	Aetiology	Screening
I	A systematic review of Level II studies	A systematic review of Level II studies	A systematic review of Level II studies	A systematic review of Level II studies	A systematic review of Level II studies
II	A randomised controlled trial	A study of test accuracy with an independent, blinded comparison with a valid reference standard, among consecutive patients with a defined clinical presentation	A prospective cohort study	A prospective cohort study	A randomised controlled trial
III-1	A pseudorandomised controlled trial (i.e. alternate allocation of some other method)	A study of test accuracy with an independent, blinded comparison with a valid reference standard, among consecutive patients with a defined clinical presentation	All or none	All or none	A pseudorandomised controlled trial (i.e. alternate allocation of some other method)
III-2	A comparative study with concurrent controls: • Non-randomised, experimental trial • Cohort study • Case-control study • Interrupted time series with a control group	A comparison with reference standard that does not meet the criteria required for Level II and III-1	Analysis of prognostic factors amongst untreated control patients in a randomised controlled trial	A retrospective cohort study	A comparative study with concurrent controls: • Non-randomised, experimental trial • Cohort study • Case-control study
III-3	A comparative study without concurrent controls: • Historical control study • Two or more single arm study • Interrupted time series without a parallel control group	Diagnostic case-control study	A retrospective cohort study	A case-control study	A comparative study without concurrent controls: • Historical control study • Two or more single arm study
IV	Case studies with either post-test or pre-test/post-test outcomes	Study of diagnostic yield (no reference standard)	Case series, or cohort study of patients at different stages of disease	A cross-sectional study	Case studies

Appendix D – Aboriginal and Torres Strait Islander Quality Appraisal Tool



Aboriginal and Torres Strait Islander Quality Appraisal Tool.

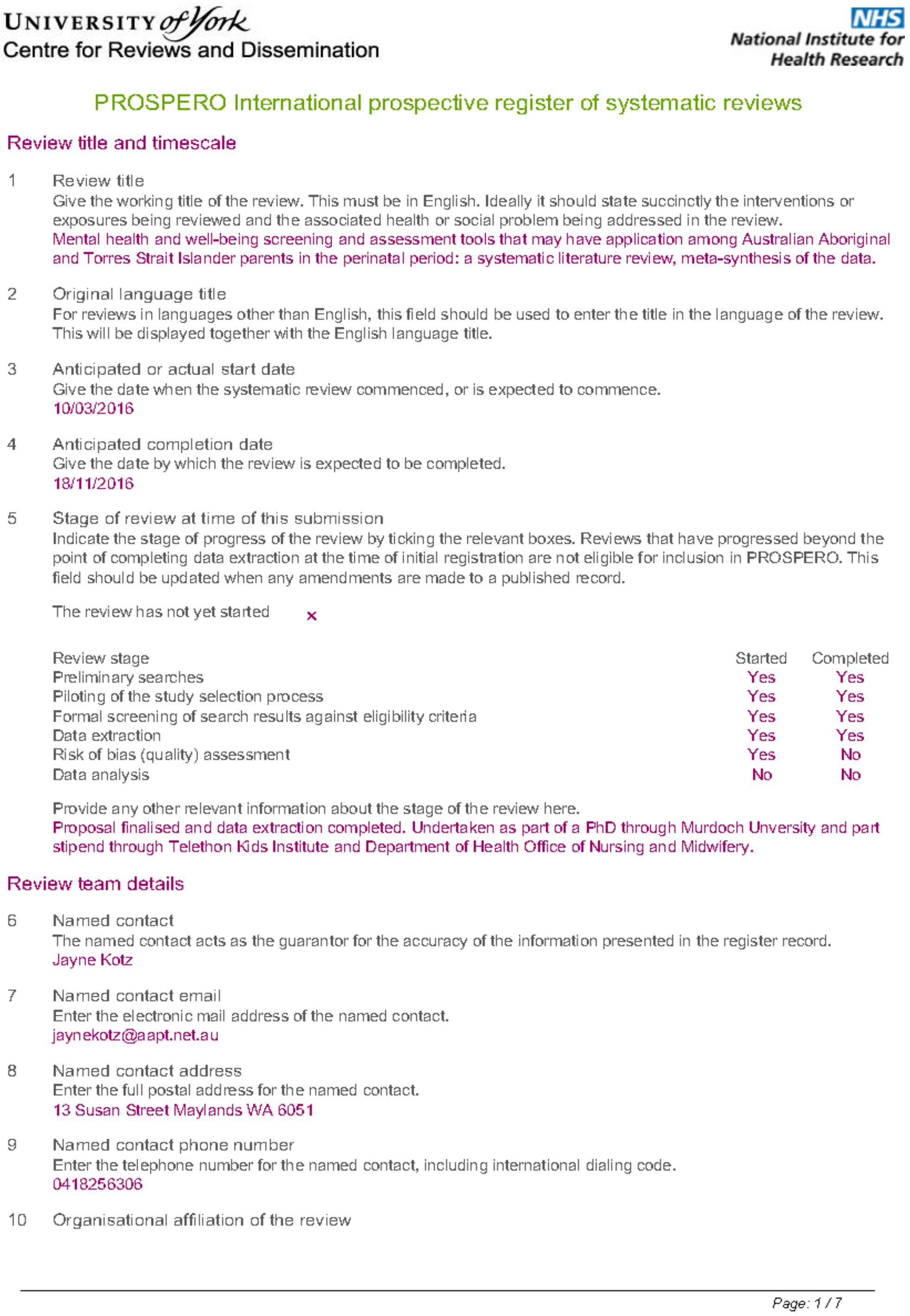
Question	Yes	Partially	No	Unclear
1. Did the research respond to a need or priority determined by the community?	√	☐	☐	☐
2. Was community consultation and engagement appropriately inclusive?	√	☐	☐	☐
3. Did the research have Aboriginal and Torres Strait Islander research leadership?	√	☐	☐	☐
4. Did the research have Aboriginal and Torres Strait Islander governance?	√	☐	☐	☐
5. Were local community protocols respected and followed?	√	☐	☐	☐
6. Did the researchers negotiate agreements in regard to rights of access to Aboriginal and Torres Strait Islander peoples' existing intellectual and cultural property?	√	☐	☐	☐
7. Did the researchers negotiate agreements to protect Aboriginal and Torres Strait Islander peoples' ownership of intellectual and cultural property created through the research?	√	☐	☐	☐
8. Did Aboriginal and Torres Strait Islander peoples and communities have control over the collection and management of research materials?	√	☐	☐	☐
9. Was the research guided by an Indigenous research paradigm?	√	☐	☐	☐
10. Does the research take a strength -based approach, acknowledging and moving beyond practices that have harmed Aboriginal and Torres Strait peoples in the past?	√	☐	☐	☐
11. Did the researchers plan and translate the findings into sustainable changes in policy and/or practice?	√	☐	☐	☐
12. Did the research benefit the participants and Aboriginal and Torres Strait Islander communities?	√	☐	☐	☐
13. Did the research demonstrate capacity strengthening for Aboriginal and Torres Strait Islander individuals?	√	☐	☐	☐
14. Did everyone involved in the research have opportunities to learn from each other?	√	☐	☐	☐

Article citation: Harfield et al. (2020). Assessing the quality of health research from an Indigenous perspective: the Aboriginal and Torres Strait Islander quality appraisal tool. *BMC Medical Research Methodology* (2020) 20:79. https://doi.org/10.1186/s12874-020-00959-3 Date: 11/04/2021

CREATE

Aboriginal and
Torres Strait
Islander Quality
Appraisal Tool

Appendix E - PROSPERO Register for Systematic Reviews



UNIVERSITY *of York*
Centre for Reviews and Dissemination

NHS
National Institute for
Health Research

PROSPERO International prospective register of systematic reviews

Review title and timescale

1 Review title
Give the working title of the review. This must be in English. Ideally it should state succinctly the interventions or exposures being reviewed and the associated health or social problem being addressed in the review.
Mental health and well-being screening and assessment tools that may have application among Australian Aboriginal and Torres Strait Islander parents in the perinatal period: a systematic literature review, meta-synthesis of the data.

2 Original language title
For reviews in languages other than English, this field should be used to enter the title in the language of the review. This will be displayed together with the English language title.

3 Anticipated or actual start date
Give the date when the systematic review commenced, or is expected to commence.
10/03/2016

4 Anticipated completion date
Give the date by which the review is expected to be completed.
18/11/2016

5 Stage of review at time of this submission
Indicate the stage of progress of the review by ticking the relevant boxes. Reviews that have progressed beyond the point of completing data extraction at the time of initial registration are not eligible for inclusion in PROSPERO. This field should be updated when any amendments are made to a published record.

The review has not yet started ×

Review stage	Started	Completed
Preliminary searches	Yes	Yes
Piloting of the study selection process	Yes	Yes
Formal screening of search results against eligibility criteria	Yes	Yes
Data extraction	Yes	Yes
Risk of bias (quality) assessment	Yes	No
Data analysis	No	No

Provide any other relevant information about the stage of the review here.
Proposal finalised and data extraction completed. Undertaken as part of a PhD through Murdoch Unversity and part stipend through Telethon Kids Institute and Department of Health Office of Nursing and Midwifery.

Review team details

6 Named contact
The named contact acts as the guarantor for the accuracy of the information presented in the register record.
Jayne Kotz

7 Named contact email
Enter the electronic mail address of the named contact.
jaynekotz@aapt.net.au

8 Named contact address
Enter the full postal address for the named contact.
13 Susan Street Maylands WA 6051

9 Named contact phone number
Enter the telephone number for the named contact, including international dialing code.
0418256306

10 Organisational affiliation of the review

Full title of the organisational affiliations for this review, and website address if available. This field may be completed as 'None' if the review is not affiliated to any organisation.
Murdoch University

Website address:
www.murdoch.edu.au

11 Review team members and their organisational affiliations
Give the title, first name and last name of all members of the team working directly on the review. Give the organisational affiliations of each member of the review team.

Title	First name	Last name	Affiliation
Ms	Jayne	Kotz	Murdoch University
Professor	Rhonda	Marriott	Murdoch University
Dr	Corinne	Reid	Murdoch Unversity
Dr	Tracy	Reibel	Telethon Kids Institute
Ms	Amanda	May	Murdoch Unversity

12 Funding sources/sponsors
Give details of the individuals, organizations, groups or other legal entities who take responsibility for initiating, managing, sponsoring and/or financing the review. Any unique identification numbers assigned to the review by the individuals or bodies listed should be included.
Murdoch University. PhD Candidature.Student number: 32311237

13 Conflicts of interest
List any conditions that could lead to actual or perceived undue influence on judgements concerning the main topic investigated in the review.
Are there any actual or potential conflicts of interest?
None known

14 Collaborators
Give the name, affiliation and role of any individuals or organisations who are working on the review but who are not listed as review team members.

Title	First name	Last name	Organisation details

Review methods

15 Review question(s)
State the question(s) to be addressed / review objectives. Please complete a separate box for each question.
What culturally relevant screening or assessment tools have been developed for use among Aboriginal and Torres Strait Islander Australians that may inform safe effective mental health and wellbeing screening in the perinatal period?

16 Searches
Give details of the sources to be searched, and any restrictions (e.g. language or publication period). The full search strategy is not required, but may be supplied as a link or attachment.
We searched the following electronic bibliographic databases: Scopus, PsychINFO, BioMed Central, EbscoHost-CINAHL, ProQuest, PubMed, OVID/PROQUEST. Grey literature was accessed via Marcé Conference Proceedings, Australian Bureau of Statistics, Telethon Kids Institute and the Australian Indigenous Health InfoNet website. Eligible studies were original empirical studies pertaining to mental health, social and emotional wellbeing assessments or screening among Australian Aboriginal people; those written in English, published in peer-reviewed journals or in the above mentioned key grey literature sources. The search terms were adapted for use with bibliographic databases in combination with database-specific filters where these are available.Studies published between January 1996 and July 2016 were sought.

17 URL to search strategy
If you have one, give the link to your search strategy here. Alternatively you can e-mail this to PROSPERO and we will store and link to it.

I give permission for this file to be made publicly available
No

18 Condition or domain being studied
Give a short description of the disease, condition or healthcare domain being studied. This could include health and wellbeing outcomes.
The context of current social and emotional wellbeing and mental health screening and assessment of Australian Aboriginal and Torres Strait Islander parents in the perinatal period (from conception through until age 4).

19 Participants/population
Give summary criteria for the participants or populations being studied by the review. The preferred format includes details of both inclusion and exclusion criteria.
Inclusion: Australian Aboriginal and Torres Strait Islander people of reproductive age (adolescent through until middle age) where their mental health and or their social and emotional wellbeing is being considered. Exclusion Criteria: Australian Aboriginal and Torres Strait Islander Adolescents under the age of 13 years and adults over the age of 55 years.

20 Intervention(s), exposure(s)
Give full and clear descriptions of the nature of the interventions or the exposures to be reviewed
There is no evidence that current perinatal mental health screening protocol in Australia is appropriate or effective for use among Aboriginal and Torres Strait Islander Australians. The focus for this review is the nature, extent and effectiveness social and emotional well-being and mental health screening of Aboriginal and Torres Strait Islander mothers and fathers in perinatal period (from conception through until age 4). Given the dearth of literature and research available within this context, we elected to extend our review to include the context of social and emotional well-being screening and assessment of Aboriginal and Torres Strait Islander people during their reproductive years. Our inclusion criteria included three or more of the following: mother* OR maternal OR antenatal OR postnatal OR perinatal OR paternal OR father* AND "mental health" OR wellbeing OR "social and emotional wellbeing" OR psych* AND aborig* OR indigenous AND screen* OR assess* OR tool* OR scale. Exclusion criteria anywhere in text: NOT cancer NOT hepatitis NOT infect* NOT cardi* NOT heart NOT educat* NOT audi* NOT infant OR paed* OR child* NOT diabet* NOT immigrant*. Geographical inclusion: Australia only.

21 Comparator(s)/control
Where relevant, give details of the alternatives against which the main subject/topic of the review will be compared (e.g. another intervention or a non-exposed control group).
Publications will be screened and assessed using CASP (Critical Appraisal Skills Program) tools that have been amended for this purpose. Finally we will be comparing research to assess: • Psychometric properties and the validation criteria for each tool • Cultural considerations and cultural bias • Deficit versus strength focus • Capacity for application of each tool in the perinatal period among Aboriginal parents and across disciplines • Key emergent minimum set of criteria for perinatal mental health and wellbeing screening among Aboriginal parents.

22 Types of study to be included
Give details of the study designs to be included in the review. If there are no restrictions on the types of study design eligible for inclusion, this should be stated.
To inform future mental health and/or social and emotional well-being screening in the perinatal period, we included all empirical research publications (qualitative and quantitative) that reported the results of utilizing existing, adapted or new mental health social and emotional well-being screening or assessment tools or strategies. We sought to determine the extent of the cultural considerations, the acceptability and the effectiveness of various screening and assessment strategies that have been used among Australian Aboriginal and Torres straight Islander adults. This study design by necessity needed to include cultural considerations beyond statistical analysis and data sets alone.Therefore we included: 1. Screening tool validation studies 2. Mixed methods research 3. Literature reviews 4. Outcome, cohorts, needs analysis, audits

23 Context
Give summary details of the setting and other relevant characteristics which help define the inclusion or exclusion criteria.
We are aware that true comparisons cannot be drawn between different studies. However in order to deepen understanding of the contextual dimensions of perinatal mental health screening among Aboriginal parents within the complex cultural interface of differing world views, a review that considered diverse studies was considered necessary. Therefore we included evaluations and reports following social and emotional well-being interventions within the target group.

24 Primary outcome(s)
Give the most important outcomes.
Solid evidence to recommend changes to the current National guidelines for perinatal mental health screening among Aboriginal and Torres Strait Islander women.

Give information on timing and effect measures, as appropriate.
The current National Perinatal Mental Health Screening Guidelines are about to be reviewed (2017). It is intended that this review will be completed before the end of the 2016 and report completed to inform this process.

25 Secondary outcomes
List any additional outcomes that will be addressed. If there are no secondary outcomes enter None.
Outcomes from this research will additionally inform the first author's PhD which has been assessing the acceptability and effectiveness of current perinatal mental health screening practices among Aboriginal and Torres Strait Islander parents in Western Australia.

Give information on timing and effect measures, as appropriate.
It is anticipated that this secondary outcome will be completed by mid 2017

26 Data extraction (selection and coding)
Give the procedure for selecting studies for the review and extracting data, including the number of researchers involved and how discrepancies will be resolved. List the data to be extracted.
Four researchers are involved in this review. The first author (JK) undertook the complete data extraction; author two (AM) undertook an inter-rater reliability data extraction with one data base for comparison. Once saturation was reached ie: no new publications emerging that met our initial criteria for potential relevance, all abstracts were read and screened for search terms and relevance by the first author (JK), and independently verified by the second (AM) and third (TR) authors. If publications contained three or more of the selection criteria search terms and were deemed relevant they were selected and uploaded into Endnote. An inclusion rather than exclusion approach was taken. In Endnote, publications were grouped twice: initially into the overall search group, secondly into individual search engine categories. Duplicates were removed and the remaining publications included for the systematic screening process and analysis using the adapted CASP criteria.This was undertaken independently by three researchers (JK, AM, TR). The final inclusion of screened and assessed publications were then uploaded into Nvivo for coding and thematic analysis. The initial search located many articles and reports. However the majority of these were excluded following either a reading of the abstract or a review of the full text. Article exclusions were due to not meeting the inclusion criteria in particular, the articles were not empirical research or were repeated versions of the same research.

27 Risk of bias (quality) assessment
State whether and how risk of bias will be assessed, how the quality of individual studies will be assessed, and whether and how this will influence the planned synthesis.
Inter-rater reliability: Four authors were employed for this review and data metasynthesis in order to establish rigor and trustworthiness. Data analysis was undertaken by the first three researchers (JK, AM, TR). The first author (JK) independently read all papers a number of times, undertaking an appraisal, coding and drawing out emergent themes and constructs from each paper. The second author (AM) similarly read thematically analysed, appraised and coded the validation studies only; the third author (TR) undertook the same process with all papers except the validation studies. All results were compared. Ratings were considered acceptable if the overall score variance was less than four out of a total 32 or 36 points within 10 criteria. Emergent themes and constructs was undertaken for all research papers, initially independently by each reviewer, then collectively compared and synthesized. Should consensus could not be easily reached in the appraisal or analysis then remaining authors (CR) a psychologist/researcher and (RM) an Aboriginal midwife/researcher were consulted with weighting preferenced to the Aboriginal researcher. Where a selected publication was authored by one of the researchers, eg: Kotz et al. (2016); Reibel et al. (2014), two unrelated authors appraised these papers.

28 Strategy for data synthesis
Give the planned general approach to be used, for example whether the data to be used will be aggregate or at the level of individual participants, and whether a quantitative or narrative (descriptive) synthesis is planned. Where appropriate a brief outline of analytic approach should be given.
We will provide a narrative synthesis of the findings from the included studies, structured around the type of intervention, target population characteristics, type of outcome and intervention content. We will provide summaries of intervention effects for each study by calculating risk ratios (for dichotomous outcomes) or standardised mean differences (for continuous outcomes). We anticipate that there will be limited scope for meta-analysis because of the

range of different outcomes measured across the small number of existing trials. However, where studies have used the same type of intervention and comparator, with the same outcome measure, we will pool the results using a random-effects meta-analysis, with standardised mean differences for continuous outcomes and risk ratios for binary outcomes, and calculate 95% confidence intervals and two sided P values for each outcome. In studies where the effects of clustering have not been taken into account, we will adjust the standard deviations for the design effect. Heterogeneity between the studies in effect measures will be assessed using both the ?2 test and the I2 statistic. We will consider an I2 value greater than 50% indicative of substantial heterogeneity. We will conduct sensitivity analyses based on study quality. We will use stratified meta-analyses to explore heterogeneity in effect estimates according to: study quality; study populations; the logistics of intervention provision; and intervention content. We will also assess evidence of publication bias.

29 Analysis of subgroups or subsets

Give any planned exploration of subgroups or subsets within the review. 'None planned' is a valid response if no subgroup analyses are planned.

A mixed methods approach has been drawn upon in data selection and analysis. In order to deepen understanding of the contextual dimensions of perinatal mental health screening among Aboriginal parents against the backdrop of the cultural complexities of differing world views, a review that considered diverse studies was considered necessary. There is limited scope for a meta-analysis because of the range of different outcomes measured and we are aware that true comparisons cannot be drawn between different studies. However, care has been taken to ensure that a systematic replicable meta-synthesis be undertaken to integrate the results from different but interrelated studies. The CASP (Critical Appraisal Skills Programme) tools were selected and adapted for the purpose of final stage screening and assessment. Adaptations were considered necessary to ensure strong inter-rater reliability and replicability. The selected CASP checklists categories selected for adaption were: Systematic Reviews, Qualitative Research and the Clinical Prediction Rule. Questions on the qualitative CASP checklist, for example, focus on three broad areas: 1. Are the results of the review valid? 2. What are the results? 3. Will the results help locally? If the answers are 'Yes' the publication is selected and a further 10-12 subcategories of analysis are undertaken. These include assessments related to the aim of the research, methodology suitability, recruitment fitting, the appropriateness and adequacy of data collection, the relationship between researcher and participants, ethics, clarity of findings, and the value of the research generally. Modifications to the CASP Checklist tools included: 1.Responses for each of the subcategories in each Checklist were modified from 'Yes', 'Can't tell' or 'No', to a numerical rating: 'Yes absolutely'=+4, 'Yes predominantly'=+3, 'Yes moderately'=+2, 'Yes a little'=+1, 'Can't tell' =0, 'No'= -4. 2. Additional subcategory questions were added to each Checklist category. These were: a. An additional Screening question: 'Does the research distinguish between Aboriginal populations/responses?" b. Additional question specific to Ethical Considerations ensuring unambiguous assessment of the integrity and beliefs afforded the research within the complex cultural context of mental health assessments among Aboriginal Australians. This considered: Human Research Ethics Committee (HREC) approvals, Informed Consent, Aboriginal input into development of research/ tool, local input, participant follow-up ect... Inclusion of this question was not required in the Literature Review Checklist. c. A column for the Numerical Score out of 32 for the Literature Review Checklist or 36 for all other Checklists. This enabled a systematic quantitative assessment of research quality and applicability that was inclusive of all categories of research. d. A column for the Key Emergent Themes or Constructs. This provided a framework to assess emergent thinking and constructs from quality research for consideration as they relate to mental health screening among Aboriginal women and men (see Appendix 2). 3.The Qualitative Research Checklist was adapted to become the Mixed-Methods Checklist. An additional subcategory was added: 'How valuable is the research? a) to the perinatal period for assessing mental health/wellbeing & b) for use among Aboriginal mothers &/or fathers' 4. Additional Checklist was created specifically for: Outcome/Cohort/Evaluations, Needs Analysis and Audits. This was drawn from the Validation Checklist and the Mixed Methods Checklist. All publications will be categorised, screened and appraised according to these four Checklists (see Appendix One). An additional assessment stage was added to the Validation Assessment (the adaptation of the original CASP Clinical Prediction Rule). This was drawn from key psychological assessment evaluation criteria (Groth-Marnat, 2009) and determined the psychometric properties in each validation study. All publications will be thematically analysed and key emergent themes and constructs drawn from each publication. Final analysis will be undertaken through matrix data triangulation.

Review general information

30 Type and method of review

Select the type of review and the review method from the drop down list.

Systematic review

Mental health and behavioural conditions

31 Language

Select the language(s) in which the review is being written and will be made available, from the drop down list. Use the control key to select more than one language.

English

Will a summary/abstract be made available in English?

Yes

32 Country

Select the country in which the review is being carried out from the drop down list. For multi-national collaborations select all the countries involved. Use the control key to select more than one country.

Australia

33 Other registration details

Give the name of any organisation where the systematic review title or protocol is registered together with any unique identification number assigned. If extracted data will be stored and made available through a repository such as the Systematic Review Data Repository (SRDR), details and a link should be included here.

na

34 Reference and/or URL for published protocol

Give the citation for the published protocol, if there is one.

Give the link to the published protocol, if there is one. This may be to an external site or to a protocol deposited with CRD in pdf format.

I give permission for this file to be made publicly available

No

35 Dissemination plans

Give brief details of plans for communicating essential messages from the review to the appropriate audiences.

In addition to producing a report for the Centre of Perinatal Excellence (COPE) who is undertaking the next National Review of Perinatal Mental Health Screening Guidelines, a paper will be submitted to a leading journal in this field. Furthermore, should the findings of the review warrant a change in practice, a one page summary report will be prepared and sent to lead clinicians and healthcare professionals in the Department of Health Office of Nursing and Midwifery.

Do you intend to publish the review on completion?

Yes

36 Keywords

Give words or phrases that best describe the review. (One word per box, create a new box for each term)

Aboriginal and Torres Strait Islander

Social and emotional well-being

Mental health

Perinatal

Screening

Systematic review

Meta-synthesis

37 Details of any existing review of the same topic by the same authors

Give details of earlier versions of the systematic review if an update of an existing review is being registered, including full bibliographic reference if possible.

NA

Appendix F – Anonymous midwives statewide online questionnaire

1. Are you from Aboriginal or Torres Strait Islander decent?	**None / 50% / 100%**
2. Type of Service in which you generally practice:	Aboriginal Medical Services / Community Services / Hospital based services /Private Practice /Other
3. Postcode where your service is located:	
4. Professional background, choose as many options as are relevant:	Midwife / Maternal & Child Health Nurse / Community Nurse / Nurse Practitioner / Clinical Health Nurse / Aboriginal Health Worker / Other
5. What is your main current role?	Management / Service Delivery / Research / Consultancy / Other (please specify)
6. What proportion of your clients are Aboriginal or Torres Strait Islander?	100%/90%/80%/70%/60%/50%/40%/30%/20%/10%
7. When screen for perinatal mental health, which tool do you most frequently use?	EPDS / PASS / KMMS / Kessler / Other (please specify)
8. How often do you screen using the EPDS according to National guidelines?	
Among your Non-Indigenous clients	None /A little /Some /Most / All the time
Among your Indigenous clients	None /A little /Some /Most / All the time
9. Do you modify the EPDS for use with your Indigenous clients?	Yes/No
10. If you answer YES to Q9, how do you modify it? Choose the most frequent response	Re-word questions / Read the questions & complete it for her / Screen only if at risk / Other (please specify)
11. Which works best describe your overall experience using the EPDS among your NON-Indigenous clients? NB: Please mark as many as you like, AT LEAST 4	useless /useful / appreciated / unappreciated / valuable / waste of time /important / predictable /easy / difficult / tedious / interesting / helpful/ routine challenging / practical / other (please specify)
12. Which words best describe your overall experience using the EPDS amongst your INDIGENOUS clients? NB: Please mark as many as you like, BUT LEAST 4	Useless /Useful / Appreciated / Unappreciated / Valuable/Waste of time/Important/Predictable/Easy /Difficult/Tedious/Interesting/Helpful/Routine Challenging / Practical / Other (please specify)
13. Please rate your level of confidence and competence while administering the EPDS:	*Competence:* None/50%/100% *Confidence:* None/50%/100%
14. PSYCHOSOCIAL ASSESSMENT	
As part of your routine perinatal screening, how often do you undertake a psychosocial assessment with your INDIGENOUS clients?	None / A Little / Some / All of the Time
Why?	
15.a From the following, please select how frequently you include the following in your psychosocial assessment	
Mental Health State Examination	Routinely / Occasionally / Never
Current physical supports	Routinely / Occasionally / Never
Current emotional supports	Routinely / Occasionally / Never
Recent life stressors	Routinely / Occasionally / Never
Level Self Esteem	Routinely / Occasionally / Never
Anxiety Levels	Routinely / Occasionally / Never
Exposure to psychological abuse (partner) past or current	Routinely / Occasionally / Never
Exposure to physical abuse (partner) past or current	Routinely / Occasionally / Never

Exposure to family violence past or current	Routinely / Occasionally / Never
Adverse childhood experiences (sexual/physical abuse)	Routinely / Occasionally / Never
Smoking	Routinely / Occasionally / Never
Alcohol	Routinely / Occasionally / Never
Other substances	Routinely / Occasionally / Never
Mental health issues-past / current	Routinely / Occasionally / Never
Comments	
15.b What are your usual 'lead questions' or 'openers' to inquire about domains you selected?	
16. Thinking about your routine inquiry.	Supports - or lack thereof / Major stressors current life specifics / Couples relationship / Exposure to Family violence-current or past / Adverse childhood experiences past / Smoking / Alcohol consumption / Other substances abuse or use / Mental health issues
17. If you left out any domains in Q15, what factors contribute to stopping you from including them in routine assessments? Select as many as apply.	Experience-lack of / Fear-of being invasive / Concern you may disclose something too difficult to deal with / Time / Scope of practice / Relevance / Clients may stop engaging with me or the service / Confidence
Provide comments about domain/s you do not cover	
18. How CONFIDENT are you in undertaking a psychosocial assessment with your clients?	*With Aboriginal clients:* Not at all / 50% / 100% *With NON-Aboriginal clients*: Not at all /50% / 100%
Comments:	
19. How COMPENTANT are you in undertaking a psychosocial assessment with your clients? Comments:	*With Aboriginal clients*: Not at all/50% Confident/100% Confident *With NON-Aboriginal clients:* Not at all/50% Confident/100% Confident
20: How easy is it to engage your Aboriginal clients in a meaningful mental health screening process?	Not at all easy / Moderately easy / Extremely easy
21. What in your opinion would assist in making this engagement easier? Please state each option.	Longer Assessment Time Training - Dealing with Disclosure FDV & Sexual Assault Training cultural training Support - Regular support for me from *trusted* mental health professional Resources: Culturally safe screening tool Resources: Culturally safe screening tool Better Resources: Culturally safe screening tool that includes prompters for psychosocial domains Better Resources- e.g. Visual Prompters Better Resources- Online or mobile app to initiate screening Aboriginal Health Worker to do assessment Visual prompters for psychosocial domain Flip Charts to serve as prompts
22. Have you had specific training around mental health and dealing with social and emotional wellbeing and mental health issues for women in the perinatal period?	Yes/No-please go to Q24
23. If so, please describe the type of training and indicate whether it was useful/relevant? Was there anything else you would like to have covered?	
24. How supported do you feel by your organization to undertake the perinatal mental screening process? Why:	not supported/50% supported/100% supported

25. Approximately how long does it take you to administer the perinatal mental health screening process?	<15 mins/15-30 mins/30-45 mins/45-60 mins/>60 mins
26. FATHERS: Do you think Fathers should be routinely offered screening for depression and/or anxiety?	Yes/No
27. Who do you think should screen Fathers?	Midwife / Child Health Worker / Aboriginal Health Worker / Counsellor / Self-administered screening tool / Other (please specify)
28. COLLABORATION: After administering the EPDS, how often do you make contact with other service providers, internally or externally, to support the case management of any of your clients?	Never / 50% of the time / 100% of the time
What factors influence your choice of referrals?	
29. COLLARBORATION: What type of service providers do you usually contact or refer to?	
30. Of the referrals that you make: Do you think they are generally acted on by women and their families? Why?	Yes / No
31. Thank you so much for you time. Your input is greatly valued. NB: Should you wish to add any further input, please leave your phone number and email address below and Jayne Kotz will contact you shortly to set up a convenient time for a confidential chat.	

Incomplete (more questions to add

Appendix G – Moose Guidelines

MOOSE Guidelines for Meta-Analyses and Systematic Reviews of Observational Studies*{Marriott, 2014 #1493}

Title

Identify the study as a meta-analysis (or systematic review)

Abstract

Use the journal's structured format

Introduction

Present

- The clinical problem
- The hypothesis
- A statement of objectives that includes the study population, the condition of interest, the exposure or intervention, and the outcome(s) considered

Sources Describe

- Qualifications of searchers (eg, librarians and investigators)
- Search strategy, including time period included in the synthesis and keywords
- Effort to include all available studies, including contact with authors
- Databases and registries searched
- Search software used, name and version, including special features used (eg, explosion)
- Use of hand searching (eg, reference lists of obtained articles)
- List of citations located and those excluded, including justification
- Method of addressing articles published in languages other than English
- Method of handling abstracts and unpublished studies
- Description of any contact with authors

Study

Selection

Describe

- Types of study designs considered
- Relevance or appropriateness of studies gathered for assessing the hypothesis to be tested
- Rationale for the selection and coding of data (e.g., sound clinical principles or convenience)
- Documentation of how data were classified and coded (e.g., multiple raters, blinding, and interrater reliability)
- Assessment of confounding (eg, comparability of cases and controls in studies where appropriate)
- Assessment of study quality, including blinding of quality assessors; stratification or regression on possible predictors of study results

- Assessment of heterogeneity
- Statistical methods (eg, complete description of fixed or random effects models, justification of whether the chosen models account for predictors of study results, dose-response models, or cumulative meta-analysis) in sufficient detail to be replicated

RESULTS: present

- A graph summarizing individual study estimates and the overall estimate
- A table giving descriptive information for each included study
- Results of sensitivity testing (eg, subgroup analysis)
- Indication of statistical uncertainty of findings

Discussion (MOOSE guidelines)

- Strengths and weaknesses
- Potential biases in the review process (eg, publication bias)
- Justification for exclusion (eg, exclusion of non–English-language citations)
- Assessment of quality of included studies
- Consideration of alternative explanations for observed results
- Generalization of the conclusions (ie, appropriate for the data presented and within the domain of the literature review)
- Guidelines for future research
- Disclosure of funding source

Appendix H

Known factors impacting risk/severity of perinatal depression or anxiety.

1. Biological	2. Psychological	3. Social
Family history of anxiety, depression	Poor relationship with own parents	Lack of emotional and practical support from partner and/or others
Alcohol abuse	Limited coping strategies	Domestic violence
Neurotransmitter imbalance	Poor sense of self / Low self-esteem	History of abuse (including childhood sexual assault)
History of depression	Feelings of failure	Many recent stressful life events
Hormonal changes	Dependent personality	Low socioeconomic status
Caesarean section	Cognitive vulnerability	Unplanned or unwanted pregnancy
	Anxious, worrier	Expecting first child or has many children already
	Negative perception of labour/birth	Childcare stresses
	Feeling trapped or out of control	Depressed parents during one's own childhood
	Perfectionist personality traits	Unemployment or excessive work demands
		Financial constraints
		Poor living condition
		Social and geographical isolation
		Single parenthood or marital separation
		Recent bereavement

Source: Pope et al. (2006)

Emergent factors faced by Aboriginal mothers that impact risk/severity of perinatal depression or anxiety.

Psychological	Service provider	Institutional
Fear of child removal	Racism	Institutional racism
Fear of being labelled 'mad' 'loopy'	Culturally unsafe practices	Culturally unsafe services and practices
Fear of being judged or ostracised by Family and/or Community	Cultural bias, prejudice, discrimination	Output based funding
Fear of being seen as 'weak' or as *not* being a 'strong' Mother'.	Cultural insensitivity or inflexibility	Automated electronic or paper-based referrals without follow-up/two-way communication
Fear of consequences of stigma for their children in the	Failure to work within a trauma informed practice	Undervaluing role of Aboriginal Health Workers

future		
Disconnection from Family / Culture	Biomedical damage-centered approach to perinatal care	
Complex trauma (intergeneration / present)	Failure to recognise the value of SEWB guiding principles (Gee et al, 2013)	