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# UNIVERSITY OF CALGARY

## Understanding Depression Among Pregnant Aboriginal Women

by

Amrita Roy

A THESIS

# SUBMITTED TO THE FACULTY OF GRADUATE STUDIES IN PARTIAL FULFILMENT OF THE REQUIREMENTS FOR THE DEGREE OF DOCTOR OF PHILOSOPHY

# GRADUATE PROGRAM IN COMMUNITY HEALTH SCIENCES

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#### Abstract

Background: Prenatal depression is a significant maternal-child health concern.
Research on depression among pregnant Aboriginal women is limited. Given the unique historical and present-day societal context involved, targeted research is warranted.
Objectives: 1) To understand the risk factors, protective factors and societal context of prenatal depression in Aboriginal populations. 2) To examine accessibility and safety of clinical and social service systems used by pregnant Aboriginal women, and how they can be improved.

**Methods:** A multi-methods, community-based approach was taken. A qualitative constructivist grounded theory study (*Voices and PHACES*) was conceived and conducted in Calgary, in partnership with local health and social services and with involvement of Aboriginal community members and Elders. The study involved personal interviews with pregnant Aboriginal women (n=13) and service-providing professionals (n=12), and focus-groups with stakeholders (n=11). Additionally, secondary analysis was conducted of data from the *All Our Babies* study, a large epidemiological cohort study of n=3354 pregnant women in Calgary.

**Key results:** In this population, the individual-level risk factors commonly associated with depression (e.g., socioeconomic status, chronic life stress) appear to be mediators of the effects of more upstream, systemic factors related to historical and present-day societal context (e.g., racism, sexism, social exclusion, and intergenerational trauma from colonization). Substance abuse was found to be a common coping mechanism for stress,

trauma and depression, indicating that mental health issues need to be addressed in order to effectively manage addictions. Social support and traditional Aboriginal healing practices appear protective, and thus may be key intervention strategies. While services in Calgary appear to be working well in certain ways, a need was identified for more culturally-appropriate services, better networking among agencies, as well as strategies to increase accessibility, reduce stigma, and enhance a safe and empowering healing environment for patients and clients.

**Significance:** This dissertation contributes to a better understanding of the determinants of prenatal depression in Aboriginal women, and how the determinants may be addressed in health and social services. Moreover, it opens the door for further research on this important yet understudied topic, and also for the design of effective, evidence-based interventions targeted to this population's needs.

#### Preface

I entered my PhD program in fall 2008 after completing my MSc in Epidemiology & Biostatistics at Western University (Ontario). My MSc thesis examined nutrition, socioeconomic factors, and psychosocial stress as determinants of prenatal depressive symptoms, using epidemiological data from a pregnancy cohort study in Ontario. My MSc research inspired my enduring interest in perinatal mental health, and also in the role of chronic psychosocial stress in poor health. I thus decided to further examine these issues in my PhD research.

As I contemplated my PhD proposal, I had three broad training objectives in mind for myself. Firstly, I was interested in pursuing research in Aboriginal health, and in examining the role of marginalization in the social and health disparities facing Aboriginal populations in Canada and elsewhere. A few months before I started my PhD program, I watched on television the Canadian government's formal apology for the Indian Residential School system – the terrible legacy of which continues to impact Aboriginal peoples today. As a Canadian, I felt deep shame and anger at my country's treatment of Aboriginal peoples, both in the past and in the present. However, I also experienced a deep admiration for the strength, endurance and resilience that clearly exist among Aboriginal individuals and communities, which have allowed them to face centuries of colonization and oppression. I was accordingly inspired to bring an Aboriginal health focus to my PhD research, and to engage in the academic-community partnerships that must occur in order for such research to be ethical, meaningful and fruitful. Secondly, I was interested in expanding my methodological repertoire. My MSc program trained me in quantitative (epidemiological) methods. I was interested in also gaining training and experience in qualitative methods, and in how to integrate across quantitative and qualitative methods with mixed-methods and multi-methods approaches. Thirdly, I was interested in a PhD experience that would help me to transition from being an analyst (which my MSc prepared me to do) to being an investigator. I was thus interested in having at least one component of my PhD proposal be primary research, wherein I could experience the process of conceptualizing, designing and executing a study 'from scratch'. Thanks to the guidance and support of my supervisor and advisory committee, I have been able to meet all three of my objectives through the PhD research presented in this dissertation.

This PhD dissertation has been formulated as a manuscript-based dissertation. In lieu of traditional results chapters, the findings of the analyses have been presented as three manuscripts aimed at academic peer-reviewed journals. As first-author on the manuscripts, I took the lead in all aspects of the research design, analysis and writing. Co-authors contributed through assistance in data analysis and interpretation, and in providing feedback on manuscript drafts; permission from co-authors to include these manuscripts in my thesis are documented in Appendix J. The citations for these three manuscripts are as follow:

Roy, A., Patten, S., Thurston, W., Beran, T., Crowshoe, L., & Tough, S. Race as a determinant of prenatal depressive symptoms: Analysis of data from the "All Our Babies" study. (Manuscript in preparation).

Roy, A., Thurston, W., Patten, S., Tough, S., & Crowshoe, L. A framework for understanding prenatal depression in Aboriginal women: data from the "Voices and PHACES" study. (Manuscript in preparation).

Roy, A., Thurston, W., Patten, S., Tough, S., & Crowshoe, L. Towards barrier-free and culturally-safe services for pregnant Aboriginal women: data from the "Voices and PHACES" study. (Manuscript in preparation).

In addition to the three manuscripts reporting results, another three published

papers have been included as appendices, due to their direct relevance to the dissertation.

Citations are as follows:

Roy, A. (2014). Intergenerational trauma and Aboriginal women: implications for mental health during pregnancy. *First Peoples Child and Family Review*, 9(1), 7-21.

Roy, A., Thurston, W., Crowshoe, L., Turner, D., & Healy, B. (2014). Research with, not on: Community-based Aboriginal health research through the "Voices and PHACES" study. In Badry, D., Fuchs, D., Montgomery, H., & McKay, S. (Eds.), *Reinvesting in Families: Strengthening Child Welfare Practice for a Brighter Future: Voices from the Prairies* (pp.111–132). Regina, SK: University of Regina Press.

Roy, A., Thurston, W. E., & the "Voices and PHACES" Study Team. (2015). Depression and mental health in pregnant Aboriginal women: Key results and recommendations from the "Voices and PHACES" study (Final report). Calgary, AB: University of Calgary

The above have been reprinted in this dissertation with consent from the respective

publishers, as documented in Appendix J.

#### Acknowledgements

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In regards to the *Voices and PHACES* study, I express my sincere appreciation firstly to the pregnant women, the professionals, and the stakeholders who shared their experiences as participants. I hope that this dissertation has been able to meaningfully convey their stories. I am also grateful to the many individuals and organizations who were involved in the execution of the study, including the community partner agencies and other recruitment sites, the study team consisting of academic and community research team members as well as the Oversight Committee, the study staff, and various other individuals who supported the study. Specific organizations and individuals are named in Appendix E and Appendix I of this dissertation. In regards to the *All Our Babies* study, I similarly express my gratitude to the pregnant women who participated in the study, and to the study's research team and staff.

Throughout my time at the University of Calgary as an MD-PhD student, I have received immense support and assistance from numerous individuals (faculty members, administrators, and administrative assistants) in the Department of Community Health Sciences, the Undergraduate Medical Education program, and the Leaders in Medicine program. While there are too many individuals to name here, I am indebted to them all. I also gratefully acknowledge my funding support: Frederick Banting and Charles Best Canada Graduate Scholarship Doctoral Award from the Canadian Institutes of Health Research (CIHR); Izaak Walton Killam Memorial Scholarship from the Killam Trusts; MD-PhD Studentship from Alberta Innovates-Health Solutions (AIHS); Scobey Hartley Doctoral Award from the Alberta Centre for Child, Family & Community Research; Alberta Award for the Study of Canadian Human Rights and Multiculturalism (Doctoral Scholarship) from the Government of Alberta; Achievers in Medical Science doctoral scholarships from the University of Calgary; the Nat Christie Foundation Medical Entrance Award from the University of Calgary.

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# List of Abbreviations

Abbreviation	Definition
ANOVA	Analysis of Variance
CHREB	Conjoint Health Research Ethics Board
CI	confidence interval
CUPS	Calgary Urban Projects Society
DSM	Diagnostic and Statistical Manual of Mental
	Disorders
EPDS	Edinburgh Postnatal Depression Scale
FASD	foetal alcohol spectrum disorders
HPA	hypothalamic pituitary adrenal
IGT	intergenerational trauma
IPV	interpersonal violence
OCAP	Ownership, Control, Access and Possession
OLS	ordinary least squares
PAR	Participatory Action Research
PHACES	Prenatal Health for Aboriginal Communities
	and EnvironmentS
SIDS	sudden infant death syndrome
TRC	Truth and Reconciliation Commission

#### **Chapter One: Introduction**

Depression during pregnancy (prenatal depression) can carry significant repercussions for maternal, foetal and family health. Approximately 10% of pregnant women in Canada will experience depression (PHAC, 2005). Prevalence may be higher in disadvantaged and marginalized groups, such as Aboriginal populations (Bowen & Muhajarine, 2006a); however, there is a paucity of research on prenatal depression in Aboriginal women.

Various organizations in Canada have identified Aboriginal maternal-child health issues as being of particular concern (Government of Alberta, 2010; Health Council of Canada, 2011; Sheppard & Hetherington, 2012; Tough, 2009). As with Indigenous populations in other countries including the United States, Australia and New Zealand (Coughlin, Kushman, Copeland & Wilson, 2013; Watson, Hodson, Johnson & Kemp, 2002; Wu et al., 2013), Aboriginal populations in Canada experience greater health and social inequities relative to other Canadians. Moreover, many of the risk factors and health consequences associated with prenatal depression are more prevalent among Aboriginal populations (Bennett, 2005), suggesting that prenatal depression should be assessed. However, empirical research on the determinants of depression among pregnant Aboriginal women is limited. Population-level studies to date on all types of depression have found that socioeconomic disadvantage and chronic psychosocial stress are major risk factors (Bowen & Muhajarine 2006b). It is also clear, however, that the causal pathways for depression, both at the clinical and the population levels, are complex. Given the unique historical and present-day social context of Aboriginal peoples, it would be erroneous to assume that the results of studies in non-Aboriginal populations can be directly applied to Aboriginal populations. Aboriginal women experience intersecting stressors from race, gender, social exclusion and intergenerational trauma from the legacy of colonization (Bennett, 2005; Roy, 2014; Sotero, 2006; Thurston et al., 2014). A context-specific understanding is therefore crucial in order to develop effective and evidence-based policies, programs and services for this population (Semenya & Lane, 2006; Sutherns & Bourgeault, 2008).

#### **1.1 Background**

#### 1.1.1 Depression and prenatal depression

Depression is a mental health disorder involving biological, psychological and social factors in its aetiology and expression. Diverse theories explain the development of depression; a discussion of those theories in relation to Aboriginal women's mental health has been presented separately in Appendix A (Roy, 2014). In almost all of these theories, be they biologically or psychosocially focused, psychosocial stress plays a key role (Roy & Campbell, 2013; Roy & Roy, 2017). Accordingly, there is increasing emphasis on a biopsychosocial, diathesis-stress-based framework. This approach states that depression stems from a combination of biological and other predispositions and psychosocial stressors from social circumstances (Engel, 1977; Garcia-Toro & Aguirre, 2007; Schotte, et al., 2006; Sdorow & Rickabaugh, 2002). Risk factors associated with prenatal depression are similar to those for depression in non-pregnant populations (Bowen & Muhajarine, 2006b), and are diverse. Family and personal history of depression, and presence of other chronic and/or infectious disorders, may increase biological vulnerability to depression (Swaab, Bao, & Lucassen, 2005). However, the literature indicates that the most significant risk factors for depression are psychosocial stress and socioeconomic status. Chronic psychosocial stress, stemming from stressful life events, generates pathophysiology leading to depression (Swaab, Bao, & Lucassen, 2005; Roy & Campbell, 2013; Roy & Roy, 2017). Consistent with the lens of the social determinants of population health (CSDH, 2008), studies in pregnant women point to predictive factors such as low income, limited education, unemployed or underemployed status and occupation type, unmarried status, young age, high parity (Bowen & Muhajarine, 2006b; Fall et al., 2013; Field, Hernandez-Reif, & Diego, 2006; Gotlib, et al., 1989; Jeong et al., 2013; Jesse, et al., 2005; Le Strat et al., 2011; Marcus, et al., 2003; Ross et al., 2004; Roy, et al., 2010), unplanned pregnancy (Bowen, & Muhajarine, 2006b), poor diet (Bodnar & Wisner, 2005; Roy, et al., 2010), and childhood or adulthood experiences of domestic violence (Barnet, et al., 1996; Benedict, Paine, Paine, Brandt, & Stallings, 1999; Bowen & Muhajarine, 2006b; Campbell, 2002; Howard, Oram, Galley, Trevillion, & Feder, 2013; Robertson-Blackmore et al., 2013; Villar-Loubet et al., 2014). Protective factors are those that appear to buffer the impact of stress; these include social support, and psychological resilience via attitudes such as optimism, high self-esteem and hope (Santini et al., 2015; Southwick, Vythilingam, & Charney, 2005).

Depression carries impacts on physical and social wellbeing. The associated continuous elevation of stress-related hormones has far-reaching implications for

physical health, including impairing immune system and neurological function. Diverse chronic and infectious disorders are comorbidities with depression (Patten, et al., 2008), and similar pathophysiology likely partially accounts for the association (Schiepers, Wichers, & Maes, 2005; Swaab, Bao, & Lucassen, 2005). Corresponding stress-related endocrine mechanisms and pro-inflammatory immune activation have been implicated in preterm birth, low birthweight, and other adverse pregnancy outcomes (Bowen & Muhajarine, 2006b; Grigoriadis et al., 2013; Grote et al., 2010; Korebrits et al., 1998; Swaab, Bao, & Lucassen, 2005; Szegda et al., 2013; Wadhwa et al., 1996). Moreover, exposure in utero to increased levels of maternal stress hormones can alter a foetus' stress system, and can thereby predispose a baby to be at increased risk for depression and anxiety in the future (Swaab, Bao, & Lucassen, 2005). Depressed individuals are more likely to engage in unhealthy coping behaviours such as smoking, alcohol consumption and illicit drug use (Bowen & Muhajarine, 2006b). In the context of prenatal health, these behaviours yield further risk of harm to the foetus. Furthermore, pregnant women who are depressed are less likely than those without depression to use prenatal health services (Bowen & Muhajarine, 2006b) that may offer remediation for various risks to maternalfoetal health. Finally, prenatal depression increases the risk of women experiencing depression after childbirth (postpartum depression). Maternal depression can impact the mother's interactions with her infant, her partner and her other children, yielding negative effects on children's long-term cognitive and behavioural development (Bowen & Muhajarine, 2006b; Beck, 2006). Accordingly, good maternal mental health is important for the physical, mental and psychosocial health of the entire family. It carries ramifications for healthy child development and for the maintenance of a stable home

environment (Letourneau et al., 2012). In this regard, pregnancy is a meaningful earlyintervention point; programs, policies and services that enhance maternal mental health during pregnancy can serve as a preventive tool for many of the issues identified by Alberta's Ministry of Children and Youth Services in its 2010 Business Plan (Government of Alberta, 2010).

The American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders (DSM-5) lays out the criteria for clinical diagnosis of depressive disorders, based on the presence and severity of symptoms, such as, persistent depressed mood, lack of interest or pleasure, fatigue, irritability, problems in concentration and memory, problems in sleeping, changes in appetite, and changes in weight (APA, 2013). DSM-5 criteria are used by physicians to diagnose clinical depression by assessing somatic, cognitive-style and mood symptoms in a clinical interview. By contrast, the scales commonly used in epidemiological depression research generally measure and derive scores for the presence of depressive symptoms. Although these scales cannot be used to *diagnose* clinical depression, scores can identify probable clinical depression. Because many of the somatic symptoms of depression are also associated with expected physical experiences of pregnancy, mood and cognitive-style symptoms are the distinguishing factor between depressed and non-depressed pregnant women (Cox, Holden, & Sagovsky, 1987). The Edinburgh Postnatal Depression Scale (EPDS) (Cox, Holden, & Sagovsky, 1987), the most commonly used scale for examining perinatal depressive symptoms (Bowen et al., 2014), accordingly focuses heavily on cognitive-style and mood-related symptoms. The EPDS is a 10-item scale developed for use in pregnant and postpartum women (Cox, Holden, & Sagovsky, 1987). The validation study by the scale

developers found a sensitivity of 86% and a specificity of 78% relative to the Research Diagnostic Criteria for depression, as well as a split-half reliability of 0.88 and a standardized alpha-coefficient of 0.87 (Cox, Holden, & Sagovsky, 1987). The EPDS has been found to provide valid and reliable results in a wide range of populations, including in Aboriginal women (Bowen et al., 2014). A validation study among postpartum First Nations women in Saskatchewan found a correlation of 0.71 with Beck Depression Inventory II scores (Clarke, 2008).

#### 1.1.2 Prenatal depression in Aboriginal populations

Aboriginal populations experience notable health and social inequities (Bennett, 2005; First Nations Centre, 2005; Health Canada, 2014; Mikkonen & Raphael, 2010). Various studies indicate that significant proportions of Aboriginal men and women experience, at some point in life, depressive symptoms (Bennett, 2005; First Nations Centre, 2005). Correlates of prenatal depression, such as comorbid health conditions, alcohol consumption, smoking and illicit drug use, adverse pregnancy outcomes, and infant health concerns such as foetal alcohol spectrum disorders (FASD) and sudden infant death syndrome (SIDS), appear to occur at higher rates among Aboriginal populations relative to non-Aboriginal populations (Bennett, 2005; First Nations Centre, 2005). Despite the indication that prenatal depression may be a major concern for Aboriginal populations, very little research has been done. Only two studies in Canada could be found, both by the same authors. One study found higher mean scores on the Edinburgh Postnatal Depression Scale (EPDS) in Aboriginal women relative to non-Aboriginal sample sizes limited the statistical analyses (Bowen &

Muhajarine, 2006a). The other study compared prevalence rates of prenatal depression, based on EPDS score, between Aboriginal and non-Aboriginal women; the authors found a somewhat higher prevalence in the Aboriginal group, though the difference was not statistically significant (Bowen et al., 2009). These same authors also recently published a critical review of the literature concerning perinatal mental health concerns in Indigenous women in Canada, the United States, Australia and New Zealand (Bowen et al., 2014). In reviewing the literature, they offered the following four recommendations for future directions in this area: 1) the need for longitudinal, population-based studies; 2) the need to further validate and modify screening tools to make them appropriate for Indigenous populations; 3) the need for further research that explores cultural diversity and the meaning of the lived experiences of perinatal mental health concerns in these populations; and 4) the need to develop evidence-based practices for researchers and practitioners to better understand and address the mental health needs of Indigenous women of childbearing age, through collaborations with Indigenous communities (Bowen et al., 2014).

Aboriginal populations experience disadvantage along virtually all of the social determinants of population health (Adelson, 2005; Bennett, 2005; First Nations Centre, 2005; Health Canada, 2014; Mikkonen & Raphael, 2010). The greater socioeconomic disadvantage may partially explain higher rates of depression and other mental health issues. However, in order to address the socioeconomic disadvantage and consequent health disparities faced by Aboriginal populations, it is critical to understand the broader context that is driving both social inequities and health inequities.

#### 1.1.3 Oppression, social exclusion and structural violence

The theoretical framework for understanding oppression adopted in this research is that of Cudd (2006), supplemented by conceptualizations derived in the BIAS FREE framework of the Global Forum for Health Research (2006). Cudd (2006) defines oppression as a "harm through which groups of persons are systematically and unfairly or unjustly constrained, burdened, or reduced by any of several forces" (p. 23). Cudd states that four conditions need to be met for a harm to be oppressive: 1) the harm involves an institutional practice; 2) it is perpetuated through an institution or practice on a group whose identity exists apart from the harm that results; 3) the institutional practice in question benefits another social group; and, 4) there is coercion or force involved that cannot be shown to be justifiable. By institutional practice, Cudd signifies not only practices of physical institutions (such as governmental or economic organizations), but also social practices involving norms and beliefs that systemically pervade society. Cudd's definition of "force" is also broad, and includes both direct and indirect forces. Direct forces externally impact the choices and actions of individuals, such as unjust laws leading to certain behaviours, or unjust norms that explicitly deny equal opportunities to certain groups. Direct forces are "concrete and external" in nature (p. 52). Indirect forces, by contrast, influence the background social beliefs based on which we behave, such as the adoption of stereotypical beliefs. Indirect forces work through psychological processes that accommodate, rationalize or justify oppression, enabling its occurrence.

The "social groups" to which Cudd refers in her definition of oppression often stem from social hierarchies in place in society, based on factors such as race and/or ethnicity, religion, sex and gender, class and socioeconomic status, ability, sexual orientation, age, and other characteristics. Within these hierarchies are "dominant" and "non-dominant" groups; domination in this context is conceptualized according to the relative ability to accrue power and access to resources, and is a source of inequity (Burke, & Eichler, 2006). The maintenance of these social hierarchies through acts of oppression benefits the "dominant" groups, by concentrating power and resources in their hands.

Cudd distinguishes the outcomes of oppression as psychological and material. Psychological oppression involves manipulation of one's mental state, emotions or belief states, leading to stress, reduced self-image (such as loss of sense of identity or lowered self-esteem), or other psychological harm. Material oppression involves harm to one's physical being, or to one's material resources (e.g., wealth, income, access to services such as health and education, physical space). Cudd points out that either outcome of oppression may, or may not, be subjectively recognized by victims, and that psychological and material oppression are linked in that they "mutually cause and exacerbate the effects of each other" (p. 24). Cudd further argues that material oppression (i.e., physical harm and economic domination) is particularly powerful in setting "a vicious cycle of harm" (p. 26) that causes, and then further reinforces, subjugation of the oppressed group to one or more privileged groups. Cudd's argument on the importance of material factors in the establishment of this subjugation is similar to the concept of social exclusion, discussed below. Social exclusion is often conceptualized as the social disadvantage and subjugation associated with poverty, low social capital, low social integration and other forms of social and economic deprivation (Morgan, et al., 2007). Additionally, Cudd's argument above also links directly with the social determinants of health lens of population health. This lens points to the role of social, physical and

economic factors including income, education, employment, social support, social environment and physical environment in explaining the phenomenon of the social gradient of health, that is, the consistent observation of poorer health in socially and economically disadvantaged segments of the population (CSDH, 2008). Cudd separates objective and subjective forms of oppression: subjective oppression involves the judgement or perception by an individual or group that they are oppressed, whereas objective oppression is an act that fits the four criteria for oppression, regardless of whether it is subjectively perceived to be oppressive by the targeted group. Objective oppression can arguably impact health through multiple pathways involving the social determinants of health, even if it is not subjectively recognized by the oppressed group. When the oppression is recognized (i.e., subjectively perceived), it can additionally impact health directly through chronic psychosocial stress. Thus, it can be argued that oppression can account for much of both the socioeconomic disadvantage and the chronic psychosocial stress that are recognized as major risk factors for depression.

Galabuzi and Labonte (2003) discuss the concept of social exclusion, which "refers to the inability of certain groups or individuals to participate fully in Canadian life due to structural inequalities in access to social, economic, political and cultural resources". These inequalities are rooted in "oppression related to race, class, gender, disability, sexual orientation, immigrant status and religion" (p 1). The authors cite Aboriginal peoples as a group facing systematic social exclusion in Canadian society. Oppression and social exclusion can lead to poor health outcomes through pathways including disadvantage along the social determinants of health, barriers to health care access and healthy living, unhealthy coping behaviours, and stress pathophysiology from

chronic distress (Cudd, 2006; Elo, 2009; Galabuzi & Labonte, 2003). Thus, it can be argued that oppression and social exclusion may underlie much of both the socioeconomic disadvantage and the chronic psychosocial stress that are recognized as major depression risk factors.

A related framework that ties together oppression and social exclusion is that of structural violence, which brings together intersecting traumas of race, gender, class, and other "social locations", showing the "multidimensionality of oppression" (Dominguez & Menjivar, 2014, p.185; Williams, 2015). Structural violence encompasses the trauma imposed by "physical, economic, political, and cultural arrangements (public sector and private institutions) and legacies" that are power structures (Williams, 2015, p.5). These structures "stop individuals, groups, and societies from reaching their full potential" (Farmer et al., 2006, p.1686). Often normalized and thus "invisible", these structures yield "disparate access to resources, political power, education, health care, and legal standing [as] just a few examples" (Farmer et al., 2006, p.1686).

#### 1.1.4 Race and social exclusion

While they are overlapping constructs and often used interchangeably, there are key distinctions between the terms 'ethnicity' and 'race'. Ethnicity refers to one's affiliation with an identified group on the basis of similar cultural, linguistic, religious or other practices; geographic location; ancestry or heritage; or other related attributes. Race is an externally imposed categorization; while historically purported to be biological in nature, it actually references rank in society and the corresponding social outcomes and experiences. Thus, one's racial identification closely reflects one's position in racialized social hierarchies (Bhopal, 2004; Karlsen & Nazroo, 2006).

Ethnicity and race can affect health through many pathways. There may be biological influences on health through genetic predisposition to certain disorders within specific ethnic groups. There may also be psychosocial influences on health through, for example, cultural norms that impact health, or social experiences that impact health. In depression, the influences of ethnicity and race are likely largely social rather than biological. While certain genetic polymorphisms have been identified to be associated with depression, there is no compelling evidence to suggest their differential presence by ethnicity. Moreover, virtually all of the genetic polymorphisms identified appear to operate in the context of gene-environment interactions – that is, they only contribute to pathology in the context of stressful environments, and thus cannot be understood with consideration of psychosocial influences (Roy & Campbell, 2013; Roy & Roy, 2017). In public health, there is growing interest in the concept of social exclusion and its link with health, in light of the recognition of the social determinants of health (CSDH, 2008), and the systems and structures in society that drive them. As defined earlier, social exclusion refers to reduced access to power and resources in society, based on non-dominant positioning along one or more social hierarchies (Burke & Eichler, 2006; Galabuzi & Labonte, 2003). In this regard, race is a significant social hierarchy (Burke & Eichler, 2006; Galabuzi & Labonte, 2003; Karlsen & Nazroo, 2006). Social exclusion can be heightened when there is intersection between multiple non-dominant identities; for example, in racialized minority women, racial non-dominance intersects with gender nondominance. For Aboriginal women, there is moreover intersection with non-dominance

from Indigeneity (Burke & Eichler, 2006; Galabuzi & Labonte, 2003); in this regard, there is growing recognition of the intergenerational legacy of colonization and its impact on health (Adelson, 2005; Sotero, 2006). Social exclusion yields inequities along the social determinants of health – including income, food and housing security, education, employment and working conditions, social support, physical environments, social environments, and access to healthcare and health-promoting resources - which, in turn, yield the population-level health inequities seen among strata of society (Galabuzi & Labonte, 2003).

At the clinical level, social exclusion also leads to chronic stress, a key cause of depression. Socioeconomic deprivation and its consequences can yield significant psychosocial stress, leading to poorer mental and physical health. Constant exposure to discrimination, disrespect, unfair treatment, and other barriers that impede full economic, social and political participation, also can contribute to chronic stress and associated health outcomes. These barriers can be overt or implicit; it has been suggested that many of the present-day inequalities between dominant and non-dominant groups – in education, employment, housing, political involvement, and other areas - stem from implicit biases concerning non-dominant groups, rather than explicit acts of discrimination (Sue, 2010). For example, implicit biases are the basis of "microaggressions", which are the everyday stressors stemming from being of a nondominant social group, such as a non-dominant racial group. Microaggressions are different than overt acts of discrimination; whereas the latter are easily identifiable and, for the most part, socially unacceptable in the present day, microaggressions are subtle, pervasive, chronic and cumulative, and reflect unconscious and normalized biases in

society. These characteristics make microaggressions particularly challenging to address and counter, and, thus, quite distressing for individuals who experience them throughout life on a daily basis (Sue, 2010). Studies have linked microaggressions with poor physical and mental health in minorities, including chronic stress and depression; it has even been shown that day-to-day microaggressions generate more distress in individuals than overt acts of discrimination, and also more distress than other types of stressful life events (literature reviewed by Sue (2010)). Thus, the chronic stress generated by social exclusion is clinically significant; further attention is thus warranted of the structures that propagate exclusion, as well as the mediating pathways that yield its effects on health.

Race-based social exclusion is, therefore, relevant to understanding prenatal mental health among racialized minority women. Some studies in the United States and the United Kingdom have compared perinatal depressive symptoms and/or depression between racial groups; these studies show better mental health in White<sup>1</sup> women relative to racialized minority women, explained in part (though not fully) by more favourable social and socioeconomic circumstances (Gavin et al., 2011; Holden, McKenzie, Pruitt, Aaron, & Hall, 2012; Jesse, Walcott-McQuigg, Mariella, & Swanson, 2005; Liu & Tronick, 2013a; Liu & Tronick, 2013b; Melville, Gavin, Guo, Fan, & Katon, 2010; Prady et al., 2013; Redshaw & Henderson, 2013; Traviss, West, & House, 2012). Studies have also found an association between depression in pregnant racialized minority women in the United States and experiences of discrimination based on race, gender and/or class (Canady, Bullen, Holzman, Broman, & Tian, 2008; Dailey & Humphreys, 2011; Ertel et

<sup>&</sup>lt;sup>1</sup> "White" is used here to refer to the racialized category constructed based on European ancestry.

al., 2012; Walker, Ruiz, Chinn, Marti, & Ricks, 2012). Racialized and gendered stressors have been shown to predict depression even in well-educated African-American pregnant women (Jackson, Rowley, & Curry Owens, 2012), indicating explanatory pathways other than low socioeconomic status. Higher chronic stress and its association with depression in racialized minority women during pregnancy has also been examined in studies using biomarkers for HPA and immune dysregulation, providing mechanistic insight (Cassidy-Bushrow, Peters, Johnson, & Templin, 2012; Corwin et al., 2013). A 2010 study examining preterm birth (which has been identified as a possible consequence of stress and depression during pregnancy), found a three-way interaction effect between exposure to racism, stress during pregnancy, and depressive symptoms during pregnancy in prediction of preterm birth in African-American women (Misra, Strobino, & Trabert, 2010). Reflective of the microaggressions literature, a 2010 study found that chronic, everyday discrimination (rather than major incidents of discrimination) was independently associated with prenatal depressive symptoms in low-income, inner-city women (Bennett et al., 2010). Research in the United States and the United Kingdom accordingly point to the importance of understanding race and its associated stressors in examining the mental health of pregnant women.

In Canada, recent studies have examined immigration status in relation to perinatal depression and its determinants; these studies indicate that, relative to Canadianborn women, immigrant women experience poorer mental health during and after pregnancy, lower socioeconomic status, greater social isolation, higher stress and inadequate social support (Ballantyne, Benzies, & Trute, 2013; Miszkurka, Goulet, & Zunzunegui, 2010; O'Mahony, Donnelly, Raffin Bouchal, & Este, 2012; Peer, Soares,

Levitan, Streiner, & Steiner, 2013; Urquia, O'Campo, & Heaman, 2012; Zelkowitz et al., 2004). While these factors may be attributed to the migration experience, the question of ethnicity and race has been raised in two of these studies. In one study, in which authors examined differences in reproductive health indicators within immigrant women based on whether they were of European or non-European ethnicity; the authors found poorer health, including poorer mental health, in immigrants of non-European ethnic groups relative to immigrants of European ethnic groups (Urquia et al., 2012). Another study found that region of origin played a role in the extent of depressive symptomatology; the authors concluded that depression in pregnant minority women deserves more attention irrespective of length of time in Canada (Miszkurka et al., 2010). With no apparent studies in Canada about prenatal depression that examine race and/or ethnicity outside of immigration status, the scope of the research literature appears limited to questions of migration rather than questions of racial non-dominance. Similarly, studies that examine prenatal depression in Aboriginal women in Canada are similarly limited. As cited earlier, only two studies, both by the same authors, could be found (Bowen & Muhajarine, 2006; Bowen, Stewart, Baetz, & Muhajarine, 2009). Both studies compared Aboriginal and non-Aboriginal women within socially high-risk samples of pregnant women in Saskatchewan; thus, generalizability of findings may be limited to such a demographic. Canadian studies that look at determinants of prenatal depression among ethnic minority groups and Aboriginal groups are limited in number and in scope. Thus, despite their potential importance in understanding prenatal depression, race and associated social exclusion have received limited attention to date in the research literature concerning prenatal depression.

#### 1.1.5 Indigeneity: Colonization and intergenerational trauma

The history of colonization is integral to understanding the societal context of Aboriginal populations in Canada. Cudd (2006) highlights colonization and its long-term, intergenerational effects as vivid examples of oppression. Acts of colonization (e.g., genocide; seizure of land; attempts at assimilation; residential schools; the Indian Act and other colonial legislations; etc.) meet all four of Cudd's criteria for oppression discussed earlier, and thus are particularly salient in understanding oppression faced by Aboriginal populations in Canada. The concept of intergenerational trauma (IGT), also known as historical trauma, explains how historical oppression continues to affect future generations. IGT theory explains why populations subjected to long-term, mass trauma (e.g., colonization, genocide, slavery, war) show a higher prevalence of disease even several generations after the original events (Brave Heart & DeBruyn, 1998; Sotero, 2006). The symptoms of IGT "as a disease are the maladaptive social and behavioural patterns that were created in response to the trauma experience, absorbed into the culture and transmitted as learned behaviour from generation to generation" (Sotero, 2006, p. 96). Notably, there is elevation of psychological problems and destructive behaviour associated with maladaptive coping, such as addictions, suicide and violence (Brave Heart & DeBruyn, 1998; Sotero, 2006). Pathways through which IGT is transmitted over time include impaired capacity to parent. In this regard, the legacy of residential schools and the Sixties Scoop era of assimilatory child welfare policies are particularly pertinent to understanding IGT among Aboriginal populations in Canada, as has been discussed in detail separately in Appendix A (Roy, 2014). The resultant trauma caused many

survivors of these two systems to turn to substance abuse, criminal activity, self-harm, as well as domestic violence against partners and children. Children of survivors thus experienced abuse, neglect and the consequences of their parents' substance abuse and other self-destructive behaviour. As a result, survivors' children in turn were more likely than others to engage in substance abuse and other self-destructive behaviour and become involved in domestic violence or abuse. In this way, a vicious intergenerational cycle of violence, addictions, self-harm and trauma has been unleashed (ANAC et al., 2002; Chansonneuve, 2005; NWAC, 2007).

As discussed separately in Appendix A (Roy, 2014), IGT is critical to understanding mental health in Aboriginal populations, including in pregnant Aboriginal women. In IGT, historical grief mingles with grief, anger and trauma from present-day experiences such as loss of family members and friends to addictions, suicide and violence; personal experiences of violence; poverty and other social disparities; and personal experiences of oppression (including racism and sexism) which reinforce the stories of ancestral oppression (Niezen, 2009; Sotero, 2006). The multifaceted and intergenerational effects of colonization, including the legacy of residential schools, have played a key role in yielding the social and health inequities faced by Aboriginal peoples today (Chansonneuve, 2005; Sotero, 2006; Waldram, Herring, & Young, 2006).

#### 1.1.6 Gender and its intersections with race and Indigeneity

Johnson and colleagues (2007, p.5) define gender as "the socially prescribed and experienced dimensions of 'femaleness' or 'maleness' in a society, ... [which is] manifested at many levels". Gender is not static, as the social prescriptions vary between

populations and change over time. Johnson and colleagues describe four dimensions of gender: gender roles, gender identity, gender relations and institutionalized gender (Johnson, Greaves, & Repta, 2007). Gender ideology is defined by Vespa (2009, p. 364) as the beliefs, attitudes and worldview that "perpetuate gender inequality while justifying 'natural' or assumed arrangements". These natural arrangements result in gender stereotypes defined as "characteristics that are generally believed to be typical for either men or women in a specific historical and cultural setting" (Johansson, et al., 2009, p. 634). Thus gender ideology and stereotypes are mechanisms for the formulation and maintenance of gender roles, identities, relations and the gendered nature of institutions. Gender ideology and gender stereotypes negatively impact both men and women; however, the patriarchal power imbalance between men and women has yielded a "patriarchal dividend" (Connell, 2002, p. 142) of advantage for men at the expense of systemic inequity for women. In order to understand oppression in the lives of Aboriginal women, an understanding of gender is thus crucial.

Aboriginal women find themselves at the intersection of various sources of oppression, including, but not limited to, gender, race, and Indigeneity. While traditional forms of analysis may consider these sources of oppression individually or additively, this approach has come under considerable criticism for not accurately conceptualizing the complex social experiences of women facing multiple sources of oppression (Andersen, 2005; Hankivsky, Cormier, & deMerich, 2009; Weber & Parra-Medine, 2003). Intersectionality is an approach that considers "simultaneous interactions between different aspects of social identity (e.g., race, ethnicity, Indigeneity, gender, class, sexuality, geography, age, ability, immigration status, religion) as well as the impact of

systems and processes of oppression and domination (e.g., racism, classism, sexism, ableism, homophobia)" (Hankivsky, Cormier, & deMerich, 2009, p. 3). Intersectionality is not prescriptive in terms of types of research methods that can be employed to assess it; rather, it is a paradigm that helps pursue knowledge that is useful for making change while ensuring that inequities are not inadvertently reinforced by the research process (Hankivsky, Cormier, & deMerich, 2009).

Gender, race and Indigeneity are three sources of oppression that are particularly important for understanding Aboriginal women's experiences. At the intersections of racism, sexism and the legacy of colonization, Aboriginal women's mental health is shaped both by present-day traumatic experiences as well as by historical (intergenerational) trauma. As articulated by Huhndorf and Suzack (2010), "for Indigenous women, colonization has involved their removal from positions of power, the replacement of traditional gender roles with Western patriarchal practices, and exertion of colonial control over Indigenous communities through management of women's bodies, and sexual violence" (p. 1). Examining the intersections of racism, sexism and colonization in the lives of Aboriginal women offers insight into, among other things, the disproportionately high levels of gender-based violence against women in Aboriginal populations. Racism and sexism, in concert with the normalization of violence and abuse in residential schools, have contributed to disproportionately high rates of gender-based violence against Aboriginal women. Relative to non-Aboriginal women, Aboriginal women are 3.5 times more likely to experience violence (Halseth, 2013). As discussed by LaRocque: "Sexual violence is related to racism in that racism sets up or strengthens a situation where Aboriginal women are viewed and treated as sex objects. The

objectification of women perpetuates sexual violence. Aboriginal women have been objectified not only as women but also as Indian women" (LaRocque, 1994, p. 73). The dehumanization of Aboriginal women as "squaws" for male sexual gratification is recognized as a primary motive for violence against Aboriginal women by non-Aboriginal men (Amnesty International, 2004). However, LaRocque also elaborates on how this racialized objectification of women has also contributed to violence perpetrated by Aboriginal men, notably in concert with the racist and sexist categorization of Aboriginal men as violent "savages". She explains that "one of the many consequences of racism is that, over time, racial stereotypes and societal rejection may be internalized by the colonized group. The internalization process is one of the most problematic legacies of long-term colonization" (LaRocque, 1994, p. 74). Cudd (2006) also addresses the issue of internalized oppression in her work. She points out that subjugation process of oppression involves the use of indirect forces (as defined earlier) that lead "the oppressed to act in ways that further their own oppression" (p. 26); these forces impact the social beliefs, desires and choices of individuals in the oppressed group. External colonial forces supporting gender-based violence within Aboriginal populations include the highly patriarchal Indian Act which creates gender inequity; among other issues, the Indian Act fails to give reserve-dwelling First Nations women matrimonial property rights, a major obstacle for women trying to flee domestic violence (NWAC, 2007). Domestic violence has been suggested to be a key reason for the much higher proportion of lone-parent, female-headed households among Aboriginal populations; such families, in turn, are at greater likelihood of facing poverty (LaRocque, 1994), which further intersects with present-day and historical trauma in women's lives. In recent years, the issue of violence

against Aboriginal women in Canada has received considerable media attention, culminating in calls for a national inquiry into the issue of the disproportionately high rates of missing and murdered Aboriginal women; such a call was also present in the final report released recently by the Truth and Reconciliation Commission (2015) in regards to moving forward from the legacy of residential schools in Canada. In late 2015, the Government of Canada announced that an inquiry would be launched (Government of Canada, 2015).

# 1.1.7 Tailoring services for pregnant Aboriginal women

While the risk factors for mental health that exist in Aboriginal women's lives are not limited to the pregnancy period, the stresses of pregnancy and parenting may further exacerbate Aboriginal women's mental health concerns. As such, pregnancy can be argued to be an especially important time to offer healing-oriented interventions. Additionally, given the key role that parenting has in transmitting trauma to the next generation (Sotero, 2006), pregnancy also offers a meaningful point of intervention for breaking the vicious cycle of IGT (Smith et al., 2006; Roy, 2014). Furthermore, because pregnancy often leads to contact with services (notably health services), pregnancy may also offer practical opportunities to intervene. However, interventions must be meaningful in order to be effective.

Access is defined by Levesque and colleagues (2013) as "the opportunity to reach and obtain appropriate health care services in situations of perceived need for care, ... resulting from the interface between the characteristics of persons, households, social and physical environments and the characteristics of health systems, organisations and providers" (p. 4). To this end, accessibility focuses on the *characteristics of services*: "the nature of services that provide [access]" (p.4). There are five dimensions to accessibility: 1) Approachability, such that those requiring services can identify and reach them; 2) Acceptability, based on social and cultural factors of prospective users; 3) Availability and accommodation, such that services can be physically reached by users in a timely manner, based on characteristics such as geography and hours of operation; 4) Affordability, reflecting the economic capacity of users to spend the resources (including money and time) to use services; and 5) Appropriateness, referring to the fit between services and the needs of users (Levesque, Harris, Russell, 2013). While referring to health services, the above conceptualization is arguably applicable to social services as well. Various challenges have been identified for Aboriginal patients and clients accessing health and social services. Issues in this regard include funding constraints; a lack of services that meet specific needs; geography-related barriers; multijurisdictional confusion about funding coverage and benefits; a lack of culturally-appropriate services; racism, stereotyping and a lack of cultural competence and cultural safety; and a lack of autonomy and self-determination over services by Aboriginal peoples (Adelson, 2005; Marrone, 2007; Oelke, 2010; Waldram, Herring & Young, 2006).

There is a need to create safe, stigma-free environments in service systems, where patients or clients, irrespective of sociocultural identity, can feel comfortable and respected. It is increasingly acknowledged that cultural awareness and cultural sensitivity – which focus on recognizing and tolerating differences – are insufficient for achieving such an environment; rather, they are early steps in a continuum of reflective practice

(Oelke et al., 2013). Cultural competence is the ability of service-providing professionals to effectively work across cross-cultural settings, by incorporating patients' and clients' cultural background, beliefs and values into the care provided (NAHO, 2008; Oelke et al., 2013). Cultural safety expands the goals of cultural competence by focusing on structural inequities stemming from various sociocultural factors, and the consequent power differentials in relationships – particularly that between service providing professionals and patients or clients. Cultural safety also highlights the value of a critical cultural perspective; such a perspective defines culture "as a relational process ... influenced by issues of racism, colonialism, historical circumstances, and the current political climate in which we live" (Browne & Varcoe, 2006, p. 164), rather than as a static set of customs or beliefs. Accordingly, the execution of cultural safety in service systems requires a broader commitment to anti-oppression and decolonization approaches. Cultural competence and cultural safety are particularly essential when working with Aboriginal patients and clients, given the lack of trust that stems from the fact that Aboriginal peoples' historical relationship with health and social services is entrenched in colonization (ANAC, 2009; NAHO, 2008; Oelke et al., 2013; Roy, 2014). Despite the recognition of their importance, training of service-providing professionals on cultural competence and safety appear to be limited (Oelke, 2010; Oelke et al., 2013). While some training programs and related interventions have been designed and implemented in countries around the world, reviews of the published literature in this area suggest varying levels of success in effectiveness, as well as a need for more rigorous and methodologically-sound evaluation methods that assess diverse meaningful outcomes (Clifford et al., 2015; Horvat et al., 2014; Truong et al., 2014). Additionally,

these reviews point to a dearth of intervention literature specific to Canada, given that the majority of intervention literature appears to be based in the United States (Clifford et al., 2015; Horvat et al., 2014; Truong et al., 2014).

The literature has suggested a number of best practices for health and social services for Aboriginal patients and clients, to ensure both safety and accessibility. The Society of Obstetricians and Gynaecologists of Canada, for example, offers a list of recommendations for health services in the area of Aboriginal women's health. These include: ensuring that professionals have an adequate understanding of the sociocultural, historical and population health context of Aboriginal peoples, notably the legacy of residential schools; embracing a holistic view of health and wellbeing, in line with Aboriginal worldviews; supporting community-directed services, programs and initiatives; and supporting health promotion and prevention (Smylie, 2000). In the context of pregnant and parenting Aboriginal people, Smith and colleagues (2006) found that participants of their study seek health care that is respectful, strengths-based, clientdirected, holistic, that permits healing and trust, that is culturally appropriate, that addresses the "mind, body and soul" (p E39), and that includes fathers and other family members.

Mental health issues in Aboriginal patients may be best addressed through a combination of mainstream therapies and culturally-entrenched healing practices (Brave Heart & DeBruyn, 1998; Brave Heart, 2003; McCormick, 2008; Menzies, 2008), as discussed in further detail separately in Appendix A (Roy, 2014). In addition to individual-level interventions, population health promotion interventions are also important, that address structural and community-level factors that influence healing.

Prevention at the population level lies in adequately addressing both downstream factors surrounding risk exposure, as well as upstream structural issues that impact health and wellbeing through the social determinants of health. Through an exploration of recent population-level interventions aimed at promoting maternal-perinatal health, it is apparent that there has been a greater emphasis on downstream factors than on upstream factors. This discussion has been presented separately in Appendix A (Roy, 2014). The lack of dramatic success observed with such interventions is likely because these interventions do essentially nothing to change the broader, structural factors impacting women's mental health. The health promotion function of public health suggests that a multi-pronged, multi-sectoral approach is required in the process of "enabling people [and populations] to increase control over, and to improve, their health" (WHO, 1986, p 1). Health promotion interventions use strategies of building healthy public policy, creating supportive environments, strengthening community action, developing personal skills, and reorienting health services (WHO, 1986). Because of the complexity of the determinants involved for mental health, health promotion interventions have been suggested to be especially effective for mental health (Herrman, Saxena, & Moodie, 2005). Because health promotion "focuses on achieving equity in health" (WHO, 1986, p 1), a health promotion approach to would advocate tailoring interventions for the specific needs of pregnant Aboriginal women. Furthermore, a health promotion approach focuses on action on the broader determinants of health beyond simply behavioural and biological factors - such as political, economic, social, cultural and environmental factors (WHO, 1986).

# 1.1.8 The need for further research

In recent years, there has been increased focus on ensuring that both clinical and population health interventions (including programs, services and policies) are based on evidence derived from research that is high quality, systematic, transparent and methodologically appropriate (Vollman, Anderson, & McFarlane, 2007; Oxman, et al., 2009). As summarized earlier, multiple and diverse risk and protective factors have been identified in the literature to be associated with prenatal depression. However, in order to plan appropriately tailored and effective population health interventions, further understanding is required on how these factors interrelate in causal pathways, as well as the relative importance of these factors and their causal pathways in predicting depression. For example, a randomized-control trial of a prenatal intervention involving in-home nurse visits showed different patterns of success among pregnant women in Calgary, based on whether they were high-risk or low-risk for poor maternal and perinatal health outcomes. Not surprisingly, the needs of high-risk women were not being fully met with a conventional prenatal intervention (Tough, et al., 2006). In the application of evidence-based practice, it is imperative to remember that evidence is inherently sensitive to context, given that the research observations that yield conclusions of evidence are inherently context-specific (Oxman, et al., 2009). A contextualized understanding is essential to tailor population health interventions, to ensure their effectiveness. Aboriginal populations arguably have a very different historical and present-day social context than other populations; therefore, research on (prenatal) depression in non-Aboriginal populations may not be adequate to inform the design of interventions for pregnant Aboriginal women.

As discussed above, current population health research on depression focuses largely on individual-level factors such as socioeconomic status and personal life stress. It is well documented that Aboriginal populations experience disadvantage in this regard; however, what is lacking is the targeted exploration of how the broader societal and institutional contexts influence these factors, and how they may impact depression through other pathways. Insight in this regard may help in the design of more effective interventions that take into account the broader, *upstream* issues faced by Aboriginal women. Furthermore, without this upstream insight, we risk falling, explicitly or implicitly, into a 'blame the victim' frame of mind, where population-level trends of individual-level characteristics become scapegoats for the broader realities of social inequities. This risk runs particularly high when discussing the health of pregnant and postpartum Aboriginal women, who are often portrayed as 'bad mothers' (Tait, 2009a, 2009b; Morrow, Hankivsky, & Varcoe, 2007). As prenatal depression does carry potentially serious consequences for child health, discussion of its determinants can easily end up endorsing this characterization, unless care is taken to contextualize the broader factors involved. Failure to consider the influence of upstream factors on health can result in the overlooking of key pathways to target for meaningful and enduring primary prevention; furthermore, failure to do so also runs the serious risk of reinforcing inequities.

#### **1.2 PhD dissertation objectives**

As discussed above, there is a paucity of studies on prenatal depression that include Aboriginal women among their participants. The two studies in Canada that we were able to locate, cited earlier, only examined sociodemographic factors and risk behaviours. It is well documented that Aboriginal populations experience disadvantage in this regard; however, what is lacking is the targeted exploration of how the unique historical and present-day social context of Aboriginal peoples influences these factors, and how it may impact depression through other pathways. Insight in this regard may help in the design of more effective interventions that take into account the broader, upstream issues faced by Aboriginal women.

To this end, this multi-method PhD dissertation had two broad objectives:

1) To understand the risk factors, the protective factors and the social context of prenatal depression in Aboriginal populations. In regards to social context, the dissertation had a particular focus in understanding the underlying societal and institutional context of Aboriginal women's health and wellbeing. Of particular interest were three sources of oppression, social exclusion and structural violence in the lives of Aboriginal women: race, gender and Indigeneity. The principle product for this objective was the creation of a theoretical framework for understanding the determinants of depression in pregnant Aboriginal women. Data from two studies (the *All Our Babies* study and the *Voices and PHACES* study) informed the creation of this theoretical framework, in addition to the existing research literature. Two journal articles present the results pertaining to this objective, as described further in the Methods chapter.

2) To examine experiences and perspectives on accessibility and safety of clinical and social service systems used by pregnant Aboriginal women, and how they can be improved in meeting the needs of this population. The product for this objective was a conceptualization of barriers to accessible and culturally safe service-provision for

pregnant Aboriginal women. Data from the *Voices and PHACES* study informed this conceptualization, in addition to the existing research literature, culminating in one journal article.

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# **Chapter Two: Methods**

The two dissertation objectives were met through data from two studies. Prenatal data from the *All Our Babies* longitudinal pregnancy cohort study served as a source of epidemiological data for secondary analysis as part of this dissertation. It contributed primarily to the first objective of deriving a theoretical framework for determinants of prenatal depression in Aboriginal women. While the small number of pregnant Aboriginal women in the study sample precluded in-depth analysis of that subgroup, the data permitted a detailed look at non-dominant race as a marker of social exclusion, and its interrelations in pathways with other risk and protective factors. One journal manuscript was produced to disseminate results of the analysis of the second study, described below.

The second study, the *Voices and PHACES* study, was a qualitative constructivist grounded theory study that was conceived, designed, and executed as part of this dissertation. Data from this study contributed to addressing both objectives of this dissertation. Two journal manuscripts were produced to disseminate the results of the analysis of this data - one for each objective. An additional book chapter (Appendix B) was also published that focussed on the community engagement methods used in the study (Roy et al., 2014).

The methods for the two studies and associated analyses are described below.

### 2.1 All Our Babies study

### 2.1.1 Research questions and hypotheses

This component of the dissertation involved analyzing data from a Canadian longitudinal pregnancy cohort study to answer the following research questions: A) How do pregnant Aboriginal women, women of non-Aboriginal ethnic minority groups and White women compare on identified major risk factors and protective factors for prenatal depression; levels of depressive symptoms; and, risk of possible clinical depression?

B) Is non-dominant race associated with higher depressive symptoms, and higher possibility of clinical depression, during pregnancy?

C) What factors mediate the relationship between race and depression?

There have been concerns around the use of race in health research, in light of its historic misidentification as a biological construct. As defined earlier, we are using the term 'race' as a social construct. The term 'racialized' is also used here, to further emphasize the socially constructed nature of 'race'. 'Aboriginal' refers collectively to the Indigenous peoples of Canada, and includes First Nations, Inuit and Métis groups. 'White' references the racialized category constructed based on European ancestry.

A number of hypotheses guided the analyses:

• Aboriginal and non-Aboriginal racialized minority women were hypothesized to have significantly higher mean depressive symptoms scale score estimates relative to White women; correspondingly, the proportion of women scoring as atrisk of clinical depression (according to identified low and high scale score cutoffs for possible clinical depression) was anticipated to be greater than in White women.

- The association between race and depressive symptoms was hypothesized to be partially mediated by risk factors such as social and economic factors, health background, negative life experiences including discrimination and domestic violence, and chronic psychosocial stress. Potential confounders in this regard were hypothesized to be age, marital status, and parity.
- Protective factors such as prenatal vitamin use and social support were hypothesized as buffers between stress and depressive symptoms.

These guiding hypotheses, based on the literature, are depicted in the conceptual framework proposed in Figure 2.1.

# 2.1.2 Dataset

The *All Our Babies* longitudinal pregnancy cohort study served as the source of data for this analysis. Between 2008 and 2011, pregnant women were recruited through clinical and community settings in Calgary, Alberta. Most (69%) were recruited from Calgary Laboratory Services (the public, city-wide single-provider clinical laboratory service in Calgary, from where pregnant women complete all clinical laboratory investigations including tests involved in routine prenatal care). To be eligible to participate, women had to be at least 18 years of age; at a gestational age of less than 25 weeks at recruitment; receiving prenatal care in Calgary; and able to complete the questionnaire in English. Women completed two mail-in, paper-based questionnaires (Appendix C) during pregnancy. To facilitate response, trained research staff followed up

by phone with completion reminders, and also to seek clarification in cases of missing or unclear answers in submitted questionnaires. The development of the questionnaire involved stakeholder and expert input. Validated scales were used wherever possible, and the questionnaire was pilot-tested for clarity and acceptability. Data collected include pregnancy history, sociodemographic factors, health status, diet, and psychosocial factors (Gracie et al., 2010; McDonald et al., 2013). Of the 3354 pregnant women in the study, 3134 had prenatal depressive symptoms scores and, thus, were included in this paper's analyses.

The assessment of ethnicity was done by asking participants to choose one of a possible 16 options in response to the question "How would you identify your ethnic background?". Psychosocial stress was measured with the 10-item Cohen Perceived Stress Scale (Cohen, Kamarck, & Mermelstein, 1983). Social support adequacy was assessed with the 20-item Medical Outcomes Study Social Support Survey (Sherbourne & Stewart, 1991). Both scales are widely used, with good psychometric properties. Sociodemographic, socioeconomic, dietary, life events and health background variables were assessed through categorical questions (Appendix C).

The Edinburgh Postnatal Depression Scale (EPDS) was used to measure depressive symptoms (Cox, Holden & Sagovsky, 1987). The most widely used depressive symptoms measure in pregnant and postpartum women, the EPDS has good psychometric properties, and good utility and accessibility across population groups. It has 10 questions, with answer options ranging in value from 0 to 3 points. To score, points are added, with a maximum possible score of 30 points; the higher the score, the higher the level of depressive symptoms. While a clinical diagnosis of depression cannot be determined from EPDS score alone, clinical depression is likely at 10 points or higher, and very likely at 13 points or higher (Bowen & Muhajarine, 2006; Cox, Holden & Sagovsky, 1987).

#### 2.1.3 Ethics approval and funding

The *All Our Babies* study was approved by the Conjoint Health Research Ethics Board (CHREB) of the University of Calgary (Ethics ID 22128 in June 2007; Ethics ID 20821 in February 2009). The secondary analysis of its data as part of this PhD dissertation was approved by CHREB in August 2013 (modification to Ethics ID 24158). The *All Our Babies* study is funded by Alberta Innovates – Health Solutions, the Alberta Children's Hospital Foundation, and Alberta Health Services.

# 2.1.4 Analysis

To decide how each variable would be treated in the analyses, preliminary data checks were conducted for each variable. In light of the focus on race in the identified research questions, extensive exploratory examination of the ethnicity variable categories was conducted, to ensure that the collapsing of groups into broad racialized categories was justified. EPDS scores, in both continuous and categorical fashion, were examined across the original fifteen ethnicity categories, to explore the justifiability of collapsing into broader racial categories. The effect of Aboriginal identity was compared to the effect of non-Aboriginal racial minority identity through ordinary least squares (OLS) linear regression (continuous EPDS score as outcome), and binomial regression using a generalized linear modelling approach involving the binomial family and identity link (EPDS score dichotomized to a categorical outcome indicating low or high possibility of clinical depression).

EPDS data were collected twice during pregnancy and averaged to generate the outcome variable. Support for the decision to average EPDS scores into a single score per participant included the very similar mean score estimates between the two time points noted during preliminary data checks, with estimates of 5.2 [95% CI: 5.1, 5.4] and 5.1 [4.9, 5.2] respectively. Moreover, there was a lack of clinically significant change in scores across the two time points for the majority (69.7%) of the sample. A change of at least 4 points in EPDS score is deemed to be clinically significant (i.e. reflecting a genuine change in mood); a change of less than 4 points may simply be due to measurement error (Matthey, 2004). To give greater credibility to a pregnancy assessment, the scores were accordingly averaged to create a stable estimate.

Descriptive test statistics (t-tests, Pearson chi-square tests, prevalence ratios and prevalence differences, as appropriate) were used to conduct comparisons between racialized groups (categorized into three groups and two groups). To assess the joint effect of race with other variables, on mean EPDS score estimates, two-way Analyses of Variance (ANOVA) were used.

The guiding hypotheses, outlined earlier and shown in Figure 2.1, were tested through multivariable OLS linear regression modelling, using a stepwise approach combining of forward and backward selection processes. To permit higher statistical power, the outcome variable (EPDS score) was kept continuous. The forward selection process involved the insertion of variables in blocks according to their positioning on Figure 2.1. The backward selection rule involved, for all stages but the final model,

removal of variables for which the beta coefficient's p-value was less than 0.2 (Lee & Koval, 1997); for the final model, the p-value was lowered to the conventional cut-off of 0.05. Possible multicollinearity was assessed by examining Variance Inflation Factor values for variables for each of the regression models, which proved non-concerning with all variable values <14, and most variable values <2. The hypotheses of partial mediation were assessed with the three-step process outlined by Baron and Kenny, who stated that a variable may be defined as a partial mediator between an initial variable and an outcome variable if the following conditions are met: 1) The initial variable is associated with the outcome variable; 2) The initial variable is associated with the proposed mediator; and 3) The association between the initial variable and the outcome variable is attenuated with adjustment for the proposed mediator (Baron & Kenney, 1986). The third condition was assessed in the multivariable regression modelling by looking for an attenuation of greater than 15% of the beta coefficient for race.

To examine whether the findings of the OLS regression were sustained when EPDS scores were dichotomized along possible clinical depression, binomial regression modelling was done using the predictor variables that were statistically significant in the OLS regression modelling process. The generalized linear modelling approach used involved the binomial family and identity link; beta coefficients were thus prevalence differences.

The results of the above were reported in a manuscript included in this dissertation as Chapter 3. The results of the exploratory analyses involving the original ethnicity variable were not reported in the manuscript due to space constraints. Those results are being reported in this dissertation in Appendix D.

### 2.2 Voices and PHACES study

This component of the dissertation involved a qualitative constructivist grounded theory study called *Voices and PHACES* (with PHACES standing for Prenatal Health for Aboriginal Communities and EnvironmentS). We interviewed both pregnant Aboriginal women, and health and social services professionals who work with pregnant Aboriginal women. The study itself had two objectives, which correlated with the objectives of the broader dissertation: 1) to develop a theoretical framework on determinants of prenatal depression in Aboriginal women, and 2) to examine experiences and perspectives on accessibility and safety of clinical and social service systems used by pregnant Aboriginal women, and how they can be improved.

# 2.2.1 Ethics approval and funding

The study was approved by CHREB in October 2011 (Ethics ID 24158), and was funded by an Investigator-driven Grant from the Alberta Centre for Child, Family and Community Research.

### 2.2.2 Academic-community partnerships

The study involved a community-based approach consisting of academiccommunity partnerships between University of Calgary researchers, community organizations (social services agencies and health clinics) in the Calgary area, and members of local Aboriginal communities. Such an approach was used to with the goal of ensuring that the research would be valid, ethical, meaningful for knowledge translation, and respectful of the principles of Ownership, Control, Access and Possession (OCAP) in Aboriginal research (First Nations, 2007).

Five Calgary-based community organizations were core partners in the research: Inn from the Cold, Calgary Urban Projects Society (CUPS), Awo Taan Healing Lodge, Elbow River Healing Lodge of Alberta Health Services, and the Adult Aboriginal Mental Health program of Alberta Health Services. Along with assisting with recruitment of participants, representatives from these organizations served on the study's Research Team, alongside University of Calgary researchers. Twelve other organizations in the Calgary area chose to be involved as recruitment sites only:

- Northeast Calgary Women's Clinic
- Isis Women's Health Clinic
- Riley Park Maternity Clinic
- Tsuu T'ina Health Centre
- Closer to Home and its prenatal program Kiwehtata
- Brenda Strafford Centre for the Prevention of Domestic Violence
- University of Calgary Native Centre
- Mount Royal University Iniskim Centre
- AHS Calgary and Area Aboriginal Hospital Liaisons program
- EFW Radiology's maternal-fetal medicine clinics in Calgary
- AHS Community Health Centres
- Metis Child and Family Services Aboriginal Parent Link Centre

In addition to the involvement of community partners on the Research Team, the study also had a separate Oversight Committee involving four Aboriginal community members (two of whom were Elders), and a representative from Alberta's Ministry of Human Services (Appendix E). A project governance structure, involving regular meetings and consultations, was implemented to ensure a collaborative approach throughout all stages of the study. The methods used have been discussed in detail separately in Appendix B (Roy et al., 2014). The three general study team meetings described in this regard (Roy et al., 2014) occurred in December 2011, August 2013, and February 2014.

### 2.2.3 Study design

Grounded theory methodology is suited to questions about process, or a situation that involves stages or changes over time, and to a topic that has little theoretical development (Glaser & Strauss, 1967). The researcher seeks a rich description of the characteristics of the phenomenon in a way that permits drawing together the characteristics into an integrated theory (Morse & Richards, 2002). Thus, the theory emerges from the data that is derived from multiple sources (Glaser & Strauss, 1967; Stern, 2009). Initially described by Glaser and Strauss (1967), grounded theory methodology has developed over time into various branches. In *constructivist* grounded theory, the researcher seeks the standpoints of the participants, in addition to the historical circumstances and social experiences that shape their opinions. A constructivist approach recognizes the existence of multiple interpretations of a situation according to social context (Charmaz, 2009; Charmaz, 2014). As argued in the background, the unique historical and present-day social context of Aboriginal women's health is crucial to understanding their needs, and shaping policy and programs accordingly. Furthermore, a large proportion of the health and social services professionals who serve pregnant Aboriginal women come from a different social context than that of their patients and clients. As such, in order to better understand the construction of prenatal depression, we felt it important to interview both Aboriginal pregnant women and the service providers who work with them, to compare and contrast their viewpoints on the issues.

### 2.2.4 Recruitment, data gathering and ethical considerations

Participants (pregnant women and professionals) were recruited from partner community organizations (see Appendix F for recruitment posters and pamphlet). Pregnant women were eligible to participate if they were 18 years of age or older, in the second or third trimester of pregnancy, lived in the Calgary area, and self-identified as Aboriginal. Professionals were eligible to participate if they worked in relevant positions in the Calgary area. Purposeful and theoretical sampling guided recruitment, initially based on characteristics identified from the literature (Charmaz, 2009; Charmaz, 2014) and later, following the grounded theory tradition, to deliberately seek out participants based on gaps in the emerging theory (Charmaz, 2014; Glasser & Strauss, 1967; Glaser, 1978; Strauss & Corbin, 1990; Stern, 2009). Data gathering and analysis were conducted iteratively, until saturation was reached; that is, no new information was being identified (Glasser & Strauss, 1967; Creswell, 1998; Crabtree & Miller, 1999; Charmaz, 2014).

Trained interviewers conducted personal, face-to-face interviews with participants. Interviews took place in mutually convenient locations where participants

felt comfortable and safe; in many cases, the organizations from which participants were recruited were able to provide space. Consent to participate was first sought. As part of the consent process, participants were informed of their rights to ask questions, make comments, refuse to answer certain questions, or withdraw participation completely, at any point in the study. The legal obligation to report any revelations of child abuse or child neglect during the interviews was also explained. Interviewers reviewed the consent form, and participants indicated consent either by signing the form (Appendix G), or by stating verbal consent on audio-tape. Interviews were audio-recorded with participants' permission. A \$25 subject fee was given to thank participants for their time and to cover any expenses they may have incurred as result of their participation (e.g., parking, childcare, time away from work, etc.). At the conclusion of the first interview, participants were asked for consent to recontact them for a second (member-checking) interview.

In regards to the legal obligation to report suspected child abuse or neglect, some of our community partner organizations requested that we approach them first with any disclosures, and seek their help in addressing the issue. The point was made that it would be highly likely that the abuse or neglect in question was already well documented, and already known by the social worker or case manager working with the woman. Other community partner organizations and recruitment sites indicated that they wanted us to complete the reporting requirements directly in cases of disclosures, without their involvement. Interviewers were thus trained and provided organization-specific instructions on how to address disclosures. No disclosures occurred over the course of the study; thus no reporting was ultimately required.

By design, this research broached issues that were sensitive and potentially distressing; we had an ethical obligation to ensure support for our participants. As part of the interview preamble, pregnant participants were given a list of services to which they could reach out for support if required. Interviewers were also trained to observe and offer to terminate the interview if a participant became distressed. All of our community partners offer counselling and/or other support services as part of their facilities; as part of their partnership in this research, they agreed to facilitate support to participants, who, by their responses or other comments, indicated presence of significant emotional distress, threats of self-harm or harm to others, or current exposure to domestic or intimate partner violence. Interviewers were trained and provided organization-specific instructions on how to address the above, including the name and contact information of designated point-persons at each recruitment organization, as well as general emergency contacts in the city. Ultimately, no incidents of participant distress occurred over the course of the study.

Confidentiality of participants and their responses were ensured in a number of ways. Interviewers were trained about their obligations in this regard. Identifiers were removed from data and replaced with participant codes. Forms, interview notes, survey sheets, audio recordings and all participant information were secured at the University, and all computer files were password-protected.

# 2.2.5 Interviews

Interviewers used semi-structured interview guides (Appendix H) to conduct the interviews, which averaged about an hour in length. Interviews with the women began

with a series of open-ended questions; interviewers were trained to probe according to the flow of the conversation. Broadly speaking, the women were asked to reflect on their sense of wellbeing during the current pregnancy, what sorts of factors they felt contributed in this regard, their experiences with existing programs and services in Calgary, and whether (and how) their social context may be impacting their prenatal mental health. The open-ended questions were followed by administration of the Edinburgh Postnatal Depression Scale (EPDS), to assess the current level of depressive symptoms of the women. The EPDS is a 10-item scale developed for use in pregnant and postpartum women (Cox, Holden, & Sagovsky, 1987). The EPDS has been found to provide valid and reliable results in a wide range of populations, including in Aboriginal women in Canada (Bowen & Muhajarine, 2006a; Cox, Holden, & Sagovsky, 1987). As the final component of the interviews, a brief section of closed-ended sociodemographic questions were presented to participants.

The professionals' interviews began with brief general questions about the professional's job and experience with pregnant Aboriginal women, and then proceeded with open-ended questions. Broadly speaking, professionals were asked to reflect on their experiences working with pregnant Aboriginal women, what they felt are the factors impacting the mental health of pregnant Aboriginal women, how they felt issues of social context impact pregnant Aboriginal women's health, their reflections on the adequacy and appropriateness of existing programs and services in Calgary, and what they felt needs to be changed or improved in this regard.

Personal interviews were conducted with 13 pregnant women and 12 professionals between March 2012 and August 2013, at which point it was determined that saturation was reached in the data.

# 2.2.6 Member-checking interviews and community gathering

Member-checking interviews were conducted as a step towards ensuring rigour and trustworthiness; that is, the preliminary results derived from the analysis of the initial interviews were shared with the original participants who were interested and available for a second interview. The member-checking interviews (Appendix H) involved seeking confirmation that the analysis made sense in light of the participants' experiences and perspectives, and seeking any additional reflections that participants may offer. Memberchecking interviews were also audio-recorded with participants' permission, and transcribed. Participants were again given a \$25 subject fee for their time. Memberchecking interviews were conducted with seven of the 25 participants (three women and four professionals), between September 2013 to February 2014.

Following completion of member-checking interviews, a community gathering was held in Calgary on March 20, 2014. Invitees included study participants, other Aboriginal community members, staff and management of clinical and social service agencies in the Calgary area, and other stakeholders. A total of eleven individuals attended. The preliminary results of the study were shared at the event, followed by a presentation by one of the study participants (an Aboriginal woman) about her experiences. These presentations were followed by focus-group-style discussions to seek audience reactions and reflections on the study results, and on possible recommendations for policies and programs. The three questions that guided these discussions were as follows:

- Based on the results of the study, what recommendations for programs, services and policies would you suggest?
- What role do you see for your organization or your profession vis-à-vis the implementation of these recommendations?
- What barriers does your organization or profession face in the implementation of these recommendations? What would your organization or profession require to overcome these barriers?

## 2.2.7 Analysis

Interview transcripts were analyzed using the software NVivo 9 (QSR International, 2010). Preliminary open coding was conducted to form initial categories, followed by axial coding to cluster categories and selective coding to develop themes and concepts (Strauss & Corbin, 1990). The constant comparative method (Glasser & Strauss, 1967) was used, where initial interviews were revisited as analysis proceeded to compare results from subsequent interviews. Memos were written on reflections on emerging themes and concepts, the relationships between them, and points stemming from comparison between groups. As permitted and encouraged in constructivist grounded theory (Charmaz, 2009; Charmaz, 2014), the existing literature was referenced during the above process, to stimulate analysis, and contrast data with existing accounts and perspectives in the literature. The themes emerging from the interviews with the women and the themes emerging from the interviews with the professionals were analyzed separately, to account for the fact that the knowledge of professionals on this domain will be socially constructed in a different manner than that of the women themselves (Charmaz, 2009; Charmaz, 2014). The data from the professionals were compared with that of the women, to explore similarities and differences. Closed-ended demographic data were entered and analyzed using Microsoft Excel.

Reflective of the collaborative nature of the study, group analysis was also conducted, involving academic and community partner representatives on the Research Team and community members on the Oversight Committee. Two group meetings were devoted to analysis (August 2013 and February 2014); at these meetings, results from the coding process were presented to the group by the lead researcher (A.R.) and group members' interpretations were solicited.

The results of the study have been documented in two journal manuscripts which have been prepared for submission to academic journals. The manuscripts are included in this dissertation document (Chapters 4 and 5). Additionally, key results and recommendations have been disseminated to stakeholders and community members through a final report (Roy et al., 2015) released in November 2015 (Appendix I).

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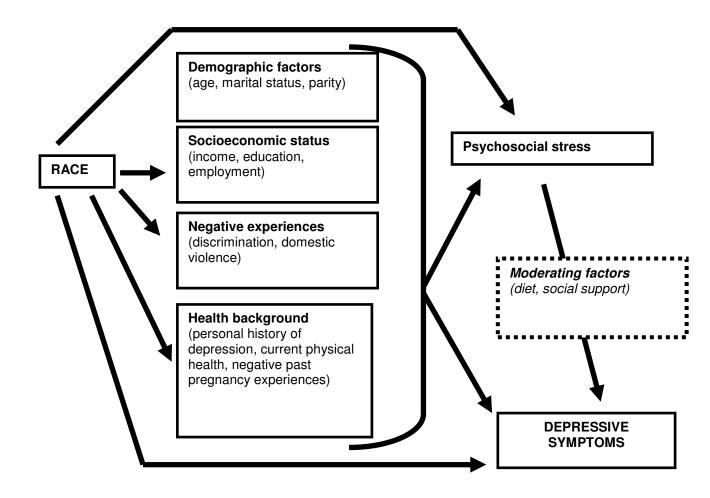


Figure 2.1: Proposed pathways through which race may be related to prenatal depressive symptoms (hypotheses tested with the *All Our Babies* data)

# Chapter Three: Race as a determinant of prenatal depressive symptoms: Analysis of data from the All Our Babies study

#### 3.1 Background

Depression during pregnancy carries serious maternal, fetal and family consequences. In addition to impaired psychosocial wellbeing, the pathophysiology associated with depression can interfere with proper immune, cognitive and neurological functioning (Bowen & Muhajarine, 2006a; Cohen & Herbert, 1996; Roy & Campbell, 2013; Roy & Roy, 2017). In the context of pregnancy, depression is further linked to increased risk of preterm birth, low birthweight, and other adverse pregnancy outcomes (Bowen & Muhajarine, 2006a; Grigoriadis et al., 2013; Grote et al., 2010; Korebrits et al., 1998; Szegda, Markenson, Bertone-Johnson, & Chasan-Taber, 2013; Wadhwa, Dunkel-Schetter, Chicz-DeMet, Porto, & Sandman, 1996). Prenatal depression is also associated with maternal smoking, drinking, illicit drug use, and less use of prenatal health services (Bowen & Muhajarine, 2006a; Le Strat, Dubertret, & Le Foll, 2011). Moreover, there is increased risk of postpartum depression, which can hamper child behavioural and cognitive development (Beck, 2006; Bowen & Muhajarine, 2006a; Clare & Yeh, 2012; Koutra et al., 2013; Liu & Tronick, 2013a; Nunes & Phipps, 2013). Prenatal depression is, thus, both a clinical and a public health concern.

Studies from the United States and the United Kingdom suggest that racialized minorities may be at higher risk for prenatal depression. Studies in Canada in this regard, however, are relatively limited. This paper presents an analysis of Canadian data to examine the role of race as a predictor of prenatal depressive symptoms, in relation to other risk and protective factors, in a sample of pregnant women from Alberta.

## 3.1.1 Risk and protective factors for prenatal depression

The risk and protective factors for prenatal depression are similar to that of depression in non-pregnant populations. The aetiology of depression is complex, multifactorial, and biopsychosocial in nature (Roy & Campbell, 2013; Roy & Roy, 2017; Schotte, Van Den Bossche, De Doncker, Claes, & Cosyns, 2006). The most significant risk factor for depression appears to be chronic psychosocial stress; the term "psychosocial" is used here to emphasize the importance of cognitive appraisal of the social environment as a determinant of perceived stress. Through deregulation of the hypothalamic-pituitary-adrenal (HPA-) axis, chronic psychosocial stress is at the interface between the pathophysiology of depression and its predominantly social risk factors (Roy & Campbell, 2013; Roy & Roy, 2017).

Women who experience depression during pregnancy are more likely to have experienced depression at an earlier point in their lives (Bernazzani, Saucier, David, & Borgeat, 1997; Bowen, Stewart, Baetz, & Muhajarine, 2009; Bowen, Bowen, Butt, Rahman, & Muhajarine, 2012; Jeong et al., 2013; Marcus, Flynn, Blow, & Barry, 2003; Ross, Sellers, Gilbert Evans, & Romach, 2004; Schmied et al., 2013). The existence of other health conditions also appears to be associated with increased risk of depression (Cohen & Herbert, 1996; Roy & Campbell, 2013), including prenatal depression (Fall, Goulet, & Vezina, 2013). Deficiencies in several micronutrients contribute to increased physiological vulnerability to depression (Roy & Campbell, 2013), including in pregnant women (Barker, Kirkham, Ng, & Jensen, 2013; Bodnar & Wisner, 2005; Leung & Kaplan, 2009; Roy, Evers, Avison, & Campbell, 2010), who may face heightened risk of deficiencies without regular consumption of a prenatal supplement (Pick, Edwards, Moreau, & Ryan, 2005; Roy, Evers, & Campbell, 2012; Shuaibi, House, & Sevenhuysen, 2008). One study showed that zinc intake moderated the association between stress and prenatal depressive symptoms (Roy et al., 2010), suggesting greater vulnerability to the effects of stress with low levels of intake.

Various socioeconomic and sociodemographic factors appear to be associated with depression – both generally, and specifically during pregnancy. In pregnant women, younger age has been shown to be associated with higher risk of depression (Bowen et al., 2012; Field, Hernandez-Reif, & Diego, 2006; Gotlib, Whiffen, Mount, Milne, & Cordy, 1989; Meltzer-Brody, Boschloo, Jones, Sullivan, & Penninx, 2013). Not being married, having low income, having low levels of education, and being unemployed also appear to contribute to risk of depression (Fall et al., 2013; Field et al., 2006; Gotlib et al., 1989; Jeong et al., 2013; Le Strat et al., 2011; Marcus et al., 2003; Ross et al., 2004; Roy et al., 2010). At the population level, these factors tie in to the social determinants of health and the social gradient of health (CSDH, 2008); their associations with depression are likely in part explained by the chronic stress and strain they cause (Corwin et al., 2013; Roy et al., 2010; Roy & Campbell, 2013; Roy & Roy, 2017). In addition to social and economic stressors (Barnet, Joffe, Duggan, Wilson, & Repke, 1996; Bernazzani et al., 1997; Bowen et al., 2009; Bowen et al., 2012; Dayan et al., 2010; Fall et al., 2013; Jesse, Walcott-McQuigg, Mariella, & Swanson, 2005; Ross et al., 2004; Roy et al., 2010), other negative life events that may contribute to depression include domestic and

sexual violence, traumatic events, unfair treatment and discrimination (Benedict, Paine, Paine, Brandt, & Stallings, 1999; Canady, Bullen, Holzman, Broman, & Tian, 2008; Dailey & Humphreys, 2011; Ertel et al., 2012; Howard, Oram, Galley, Trevillion, & Feder, 2013; Jeong et al., 2013; Le Strat et al., 2011; Meltzer-Brody et al., 2013; Miszkurka, Goulet, & Zunzunegui, 2010; Robertson-Blackmore et al., 2013; Silverman & Loudon, 2010; Stewart, Umar, Tomenson, & Creed, 2013; Sue, 2010; Villar-Loubet et al., 2014; Walker, Ruiz, Chinn, Marti, & Ricks, 2012). Stressors related to pregnancy or parenting are also relevant: Negative experiences with a previous pregnancy (miscarriage, pregnancy or birth complications, etc.), for example, can impact mental health during a subsequent pregnancy (Dayan et al., 2010; Stewart et al., 2013), as can the stress and strain associated with already having other children (Gotlib et al., 1989; Redshaw & Henderson, 2013). Finally, social support has been shown to be protective (Barnet et al., 1996; Bowen et al., 2009; Bowen et al., 2012; Fall et al., 2013; Jeong et al., 2013; Stewart et al., 2013), likely as a coping mechanism against stress (Southwick, Vythilingam, & Charney, 2005). As can be seen, the factors associated with prenatal depression in the literature are numerous and diverse. The multifactorial aetiology underscores the need to understand how factors interrelate in causal pathways, to develop effective interventions.

### 3.1.2 Ethnicity, race and health

The terms "ethnicity" and "race" are often used interchangeably; however, while they are overlapping constructs, there are key distinctions between them. Ethnicity pertains to one's association with an identified group based on similar cultural, linguistic, religious or other practices; geographic location; ancestry or heritage; or other related attributes. By contrast, race is an externally imposed categorization; while it has historically been purported to be biological in nature, it actually has more to do with rank in society and the corresponding social outcomes and experiences. Thus, one's racial identification is tied closely to one's place in racialized social hierarchies (Bhopal, 2004; Karlsen & Nazroo, 2006).

Ethnicity and race can impact health through many pathways. In depression, the influences of ethnicity and race are likely largely social rather than biological. With public health's present focus on the social determinants of health (CSDH, 2008), and the systems and structures in society that drive the social determinants, there is growing interest in the concept of social exclusion and its link with health. Social exclusion has been defined as "the inability of certain groups or individuals to participate fully in [society] due to structural inequalities in access to social, economic, political and cultural resources" (p.1) (Galabuzi & Labonte, 2003). Social exclusion thus refers to diminished access to power and resources in society, based on one's position of non-dominance along one or more social hierarchies (Burke & Eicher, 2006; Galabuzi & Labonte, 2003). Race is a significant social hierarchy in this regard (Burke & Eicher, 2006; Galabuzi & Labonte, 2003; Karlsen & Nazroo, 2006). Social exclusion can be exacerbated when there is intersection between multiple identities of non-dominance; for example, in racialized minority women, there is intersection of racial non-dominance with gender non-dominance. For Aboriginal women, there is additionally intersection with nondominance from indigeneity (Burke & Eicher, 2006; Galabuzi & Labonte, 2003); in this regard, there is growing recognition that the intergenerational legacy of colonization

continues to impact Aboriginal peoples' health (Adelson, 2005; Sotero, 2006). Social exclusion drives inequities along the social determinants of health, which in turn drive the health inequities seen at the population level among strata of society (Galabuzi & Labonte, 2003).

At the clinical level, social exclusion also contributes to chronic stress, which, as discussed previously, is one of the key risk factors for depression. Socioeconomic deprivation and its consequences can cause considerable psychosocial stress, contributing to poorer mental and physical health. Moreover, constant exposure to unfair treatment and other barriers that impede full economic, social and political participation, also can lead to chronic stress and associated health outcomes. These barriers can be overt or implicit; it has been argued that many of the present-day inequalities between dominant and non-dominant groups are likely the result of implicit biases concerning non-dominant groups, more so than overt acts of discrimination (Sue, 2010). Among other manifestations, implicit biases are the basis of "microaggressions", which are the everyday stressors associated with being of a non-dominant social group. Unlike overt acts of discrimination, microaggressions are subtle, pervasive, chronic and cumulative, and reflect unconscious and normalized biases in society. These characteristics make microaggressions more difficult to address and counter, and thus particularly distressing for individuals who experience them daily throughout life (Sue, 2010). Studies have linked microaggressions with poorer physical and mental health in minorities, including chronic stress and depression (Sue, 2010). Overall, it can be stated that the chronic stress generated by social exclusion is clinically significant; further examination of the

structures that propagate exclusion, as well as the mediating pathways that lead to its health impacts, is thus warranted.

Accordingly, race-based social exclusion is relevant to understanding prenatal mental health among racialized minority women. Some studies in the United States and the United Kingdom have compared perinatal depressive symptoms and/or depression between racialized groups; these studies show better mental health in White women, explained in part (though not fully) by more favourable social and socioeconomic circumstances (Gavin et al., 2011; Holden, McKenzie, Pruitt, Aaron, & Hall, 2012; Jesse et al., 2005; Liu & Tronick, 2013a; Liu & Tronick, 2013b; Melville, Gavin, Guo, Fan, & Katon, 2010; Prady et al., 2013; Redshaw & Henderson, 2013; Traviss, West, & House, 2012). Studies have also found an association between depression in pregnant racialized minority women in the United States and experiences of discrimination based on race, gender and/or class (Canady et al., 2008; Dailey & Humphreys, 2011; Ertel et al., 2012; Walker et al., 2012); the above extends even to well-educated African-American pregnant women (Jackson, Rowley, & Curry Owens, 2012), pointing to explanatory pathways other than low socioeconomic status. Consistent with the microaggressions literature, a 2010 study found that chronic, everyday discrimination (rather than major incidents of discrimination) was independently associated with prenatal depressive symptoms in low-income, inner-city women (Bennett et al., 2010). Thus, research in the United States and the United Kingdom indicate that race and its associated stressors are important for understanding the mental health of pregnant women.

In Canada, a number of recent studies have examined immigration status in its relationship with perinatal depression and its determinants; the overarching conclusions

from these studies is that immigrant women experience poorer mental health during and after pregnancy, lower socioeconomic status, greater social isolation, higher stress and inadequate social support relative to Canadian-born women (Ballantyne, Benzies, & Trute, 2013; Miszkurka et al., 2010; O'Mahony, Donnelly, Raffin Bouchal, & Este, 2012; Peer, Soares, Levitan, Streiner, & Steiner, 2013; Urquia, O'Campo, & Heaman, 2012; Zelkowitz et al., 2004). While these factors may be conceptualized as part of the migration experience, the question of ethnicity and race has been raised in a couple of these studies. In one study examining differences in reproductive health indicators within immigrant women, the authors found poorer health, including poorer mental health, in immigrants of non-European ethnic groups relative to immigrants of European ethnic groups (Urquia et al., 2012). Another study found that region of origin played a role in determining the extent of depressive symptomatology; the authors concluded that depression in pregnant minority women deserves more attention irrespective of length of time in Canada (Miszkurka et al., 2010). There do not appear to be studies in Canada about prenatal depression that examine race and/or ethnicity outside of immigration status, limiting the scope of the research literature to questions of migration rather than questions of racial non-dominance. Similarly, studies that examine prenatal depression in Aboriginal women in Canada, too, are limited. Only two studies, both by the same authors, could be located. One study found higher mean scores on the Edinburgh Postnatal Depression Scale (EPDS) in Aboriginal women relative to non-Aboriginal women, though small sample sizes limited the statistical analyses (Bowen & Muhajarine, 2006b). The other study compared prevalence rates of prenatal depression, based on EPDS score, between Aboriginal and non-Aboriginal women; the authors found a

somewhat higher prevalence in the Aboriginal group, though the difference was not statistically significant (Bowen et al., 2009). Both studies compared Aboriginal and non-Aboriginal women within socially high-risk samples of pregnant women, and thus generalizability may be limited. Overall, Canadian studies looking at determinants of prenatal depression among ethnic minority groups and Aboriginal groups in Canada are limited in number and in scope.

#### **3.2 Research questions and hypotheses**

This paper presents analyses of data from a Canadian longitudinal pregnancy cohort study to answer the following research questions: A) How do pregnant Aboriginal women, women of non-Aboriginal ethnic minority groups and White women compare on identified major risk factors and protective factors for prenatal depression; levels of depressive symptoms; and, risk of possible clinical depression? B) Is non-dominant race associated with higher depressive symptoms, and higher possibility of clinical depression, during pregnancy? C) What factors mediate the relationship between race and depression?

A number of hypotheses guided the analyses. Firstly, Aboriginal and non-Aboriginal racialized minority women were hypothesized to have significantly higher mean depressive symptoms scale score estimates relative to White women; correspondingly, the proportion of women scoring as at-risk of clinical depression (according to identified low and high scale score cut-offs for possible clinical depression) was anticipated to be greater than in White women. The association between race and depressive symptoms was hypothesized to be partially mediated by risk factors such as social and economic factors, health background, negative life experiences including discrimination and domestic violence, and chronic psychosocial stress. Potential confounders in this regard were hypothesized to be age, marital status, and parity. Protective factors such as prenatal vitamin use and social support were hypothesized as buffers between stress and depressive symptoms. These guiding hypotheses, based on the literature, are depicted in the conceptual framework proposed in Figure 3.1.

The historic misidentification of race as a biological construct has led to concerns around its use in health research, as discussed later in this paper. In this paper, the term "race" is used as a social construct, as defined earlier. The term "racialized" is also used in this paper, to further emphasize the socially constructed nature of "race". "Aboriginal" is an umbrella term for the Indigenous peoples of Canada, and includes First Nations, Inuit and Métis groups. "White" is used in this paper to refer to the racialized category constructed based on European ancestry.

#### **3.3 Methods**

## 3.3.1 Dataset

The data for the analyses stem from the *All Our Babies* longitudinal pregnancy cohort study. Details on study design, questionnaire development, sampling, recruitment and sample characteristics have been reported elsewhere (Gracie et al., 2010; McDonald et al., 2013), and are summarized here in brief: Pregnant women were recruited between 2008 and 2011 through clinical and community settings in Calgary, Alberta, with the

majority (69%) recruited from Calgary Laboratory Services (the public, city-wide singleprovider clinical laboratory service in Calgary, from where pregnant women complete all clinical laboratory investigations including tests involved in routine prenatal care). Women were eligible to participate if they were at least 18 years of age; at a gestational age of less than 25 weeks at recruitment; receiving prenatal care in Calgary; and able to complete the questionnaire in English. Women answered two mail-in, paper-based questionnaires during pregnancy; trained research staff followed up by phone with completion reminders, and also to seek clarification in cases of missing or unclear answers in submitted questionnaires. Stakeholder and expert input was sought in the development of the questionnaire, for which validated scales were used wherever possible, and which was pilot-tested to ensure clarity and acceptability. Data collected include pregnancy history, sociodemographic factors, health status, diet, and psychosocial factors. Of the 3354 pregnant women in the study, 3134 have prenatal depressive symptoms scores and thus could be included in this paper's analyses.

Ethnicity was assessed by asking participants to choose one of a possible 16 options in response to the question "How would you identify your ethnic background?". Psychosocial stress was measured with the 10-item Cohen Perceived Stress Scale (Cohen, Kamarck, & Mermelstein, 1983). Social support adequacy was assessed with the 20-item Medical Outcomes Study Social Support Survey (Sherbourne & Stewart, 1991). Both scales are widely used, with good psychometric properties. Sociodemographic, socioeconomic, dietary, life events and health background variables were assessed through categorical questions, as described elsewhere (Gracie et al., 2010; McDonald et al., 2013). Depressive symptoms were measured with the Edinburgh Postnatal Depression Scale (EPDS) (Cox, Holden, & Sagovsky, 1987). The EPDS is the most widely used depressive symptoms measure in pregnant and postpartum women. It has good psychometric properties, and good utility and accessibility across population groups. It has 10 questions, with answer options ranging in value from 0 to 3 points. To score, points are summed, with a maximum possible score of 30 points; the higher the score, the higher the level of depressive symptoms. While a clinical diagnosis of depression cannot be ascertained from EPDS score alone, clinical depression is likely at 10 points or higher, and very likely at 13 points or higher (Bowen & Muhajarine, 2006b; Cox et al., 1987).

#### 3.3.2 Analysis

Preliminary data checks were conducted for each variable, to decide how each would be treated in the analyses. Given the focus on race in the guiding research questions, extensive exploratory examination<sup>2</sup> of the ethnicity variable categories was conducted, to ensure justification for the collapsing of groups into broad racialized categories.

EPDS data were collected twice during pregnancy; for the purposes of this analysis, the two scores were averaged to create the outcome variable. The decision to average EPDS scores into a single score per participant was supported by the very similar mean score estimates between the two time points noted during preliminary data checks, with estimates of 5.2 [95% CI: 5.1, 5.4] and 5.1 [4.9, 5.2] respectively. Additionally,

<sup>&</sup>lt;sup>2</sup> Reported in Appendix D

there was a lack of clinically significant change in scores across the two time points for the majority (69.7%) of the sample. A change of at least 4 points in EPDS score is considered to be clinically significant (i.e. likely reflecting a real change in mood); a change of less than 4 points may simply be due to measurement error (Matthey, 2004). Accordingly, averaging the scores was done in this analysis to enable more stability in the estimates, thus giving greater credibility to an assessment during pregnancy.

Comparisons between racialized groups (categorized into three groups and two groups) were conducted through descriptive test statistics (t-tests, Pearson chi-square tests, prevalence ratios and prevalence differences, as appropriate). Two-way Analysis of Variance (ANOVA) was used to assess the joint effect of race with other variables, on mean EPDS score estimates.

The hypotheses outlined earlier and depicted in Figure 3.1 were tested through multivariable OLS linear regression modelling, using a stepwise approach combining forward and backward selection processes. The outcome variable (EPDS score) was kept continuous for this purpose, to permit higher statistical power. The forward selection process involved the insertion of variables in blocks according to their positioning on Figure 3.1. The backward selection rule involved, for all stages but the final model, removal of variables for which the beta coefficient's p-value was less than 0.2 (Lee & Koval, 1997); for the final model, the p-value was lowered to the conventional cut-off of 0.05. The possibility of multicollinearity was assessed by examining Variance Inflation Factor values for variables for each of the regression models, which proved non-concerning with all variable values <14, and most variable values <2. The hypotheses of partial mediation were assessed by checking whether the following conditions were met:

1) The initial variable is associated with the outcome variable; 2) The initial variable is associated with the proposed mediator; and 3) The association between the initial variable and the outcome variable is attenuated with adjustment for the proposed mediator (Baron & Kenny, 1986). The third condition was assessed in the multivariable regression modelling by looking for an attenuation of greater than 15% of the beta coefficient for race.

To assess whether the findings of the OLS regression remained in place when EPDS scores were dichotomized along possible clinical depression, binomial regression modelling was conducted using the predictor variables that were statistically significant in the OLS regression modelling process. The generalized linear modelling approach used involved the binomial family and identity link, resulting in prevalence differences as beta coefficients.

#### **3.4 Results**

The preliminary exploratory analyses showed, firstly, that mean EPDS score estimates, and proportions facing possible clinical depression, were significantly lower in the White category than in the rest of the original ethnicity categories. Secondly, the effects of Aboriginal identity (in reference to White identity) and non-Aboriginal racialized minority identity (in reference to White identity) on depressive symptoms and possible clinical depression, alone and adjusted for other variables, appeared relatively similar to each other overall, though the 95% Confidence Intervals (CIs) were wide for the Aboriginal category's values due to its small sample size. In concert with conceptual arguments, these exploratory analyses supported the collapsing of the original ethnicity categories into tricategorical and dichotomous race variables for the main analyses presented in this paper.

The characteristics of the sample are summarized in Table 3.1. EPDS score and stress score were kept continuous for most of the analyses, though they were both dichotomized for the binomial regression analyses. All other variables were categorized at appropriate cut-offs. Footnotes to Table 3.1 explain how variables were defined and which cut-offs were used.

Table 3.1 also depicts the characteristics of the sample stratified into three racialized groups: White women, Aboriginal women, and non-Aboriginal racialized minority women. Relative to women of the other two race categories, White women had higher income, higher levels of employment, lower levels of stress (measured in both continuous and dichotomous forms), lower levels of depressive symptoms and lower proportion of possible clinical depression (at both score cut-offs), and higher levels of social support. Relative to non-Aboriginal racialized minority women, a higher proportion of White women reported a personal history of depression, and experiences of domestic violence. Relative to White and non-Aboriginal racialized minority women, greater proportions of Aboriginal women were in the lowest category for income, in the lowest category for education, in the not-working category for employment, in the "other" category for marital status, and in the youngest category for age. A higher proportion of Aboriginal women reported experiencing domestic violence. Similar proportions in all three race categories reported experiences of discrimination during pregnancy.

Table 3.2 summarizes EPDS scores for the three racialized groups. White women had the lowest mean EPDS score estimates. The difference in mean score estimates between the White group and the non-Aboriginal racialized minority group was statistically significant. The Aboriginal group's mean EPDS estimate was similar to that of the non-Aboriginal racialized minority group. However, the 95% CIs were large, and thus statistical significance could not be established. The proportions facing possible clinical depression were significantly lower in the White group relative to the other two groups. Table 3.3 summarizes EPDS scores by dichotomized race. Compared to women of all other ethnicities, White women had significantly lower mean EPDS scores, and significantly lower proportions facing possible clinical depression. For the latter, the prevalence ratios for the other ethnic groups category relative to the White category were 1.8 [CI: 1.5, 2.1] and 2.4 [CI: 1.8, 3.3] at score cut-offs of 10 and 13 respectively.

Table 3.4 depicts mean EPDS score estimates along key risk and protective factors for depression, with the sample stratified into two racialized groups. The last column summarizes the p-values of the F-tests of the two-way ANOVAs run to assess the joint effect of race with each of the other variables of interest. In almost all strata, the White category had statistically significant lower mean EPDS score estimates relative to the category of all other ethnic groups. One exception was current physical health, for which the strata of not-good health had similar mean EPDS estimates between the two racialized groups. The other exception was stress as a continuous variable; the Pearson correlation coefficient between stress score and EPDS score was 0.8 in both racialized groups. As part of the ANOVAs, interaction effects between race and each variable was assessed; the only interaction term to be statistically significant at the 5% level of

significance was between race and domestic violence (p=0.04), indicating that the association between domestic violence and depressive symptoms was stronger in the White group. As that interaction was deemed conceptually plausible, it was applied in the multivariable modelling done subsequently.

Table 3.5 shows the results of each stage of the multivariable OLS linear regression modelling process. Race was entered as a dichotomous variable. Beta coefficients were number of points increase on estimated mean EPDS score for being in a given category of a variable, relative to the reference category for that variable. Key results are as follows: Firstly, addition of demographic variables and health background variables did not yield any change in the beta coefficient for race. By contrast, addition of socioeconomic variables caused a significant (more than 15%) attenuation of the beta coefficient for race. Addition of stress (continuous variable) yielded a major increase in the value of the adjusted  $R^2$ ; the beta coefficient for stress remained robust throughout all stages of the modelling, and suggested a very strong association (0.5 point increase on the EPDS scale for every 1-point increase on the stress scale). Moreover, addition of stress yielded a major attenuation of the beta coefficient for race. Beta coefficients for physical health, personal depression history and employment also attenuated meaningfully, and discrimination and income were rendered statistically non-significant. The main effect term for domestic violence was rendered statistically non-significant with the addition of stress; however, the interaction term between race and domestic violence remained highly statistically significant, and so the domestic violence variable was kept in the subsequent stages of the modelling. The interaction term between stress and regular vitamin use was not statistically significant; however, the interaction term between stress and social

support was statistically significant, indicating that the association between stress and depressive symptoms was weaker in women with good social support relative to women with lower social support.

Finally, Table 3.6 shows the results of each stage of the binomial regression modelling process, in which the outcome variable was possibility of clinical depression, with high possibility defined as a score of 10 or more on the EPDS. Beta coefficients were risk differences relative to a variable's reference category. As the objective of this phase of the analyses was to confirm whether the results of the OLS linear regression model process remained in place when EPDS score was categorized to a more clinically meaningful measure, only the variables found to be statistically significant in the previous modelling were used. As can be seen in the first column, each variable remained highly statistically significant on its own; however, the interaction term between race and domestic violence was not significant. In the second stage of modelling (race, current physical health, personal history of depression and history of domestic violence), all variables retained their statistical significance, and the beta coefficient for race did not change from the adjustments. By contrast, addition of stress as a dichotomous variable (third stage of modelling) resulted in attenuations of the beta coefficients of race, current physical health and personal history of depression; history of domestic violence became statistically non-significant. In the last stage of the modelling (addition of social support), the interaction between stress and social support was found to be statistically significant; that is, the association between high stress and possible clinical depression was weaker in women with good social support relative to women with lower social support.

## 3.5 Discussion and conclusions

While the word "race" is used throughout this paper, it is acknowledged that the term can have problematic connotations and interpretations. The misconception of race as a biological phenomenon, the heterogeneity found within commonly racialized groups, and the complexity surrounding questions of identity and of the labelling of individuals and groups, have led various scholars to suggest avoiding the term "race" altogether and using the term "ethnicity" instead (Bhopal & Donaldson, 1998; Bradby, 2003). Moreover, various scholars have suggested that the focus of health disparities research should be on more specific ethnic categories (rather than broad racial categories) (Bhopal & Donaldson, 1998; Bradby, 2003), and/or on the specific constructs along which race and ethnicity data are often interpreted, such as socioeconomic status (Krieger, 2000). Other scholars, however, have countered such arguments, pointing out that simply eliminating the term or the idea of "race" from research aggravates rather than addresses the problems identified. Concerns around using the term "ethnicity" as a replacement term for race center around the widespread association of the term "ethnicity" with affiliation to cultural groups, which can lead to a focus on cultural norms and practices as predictors of health disparities, rather than on racialization-based social exclusion processes (Thomas, 2001; Williams, 1997). Various scholars point out that racial categories remain entrenched in society as a key social hierarchy, and must be acknowledged and examined in order for racism to be detected and understood; examining socioeconomic status in lieu of race ignores that racial hierarchies drive the

disparities along socioeconomic variables experienced by ethnic minorities, perpetuating the blaming of ethnic groups for their poorer health (Krieger, 2000; Thomas, 2001; Williams, 1997). Undoubtedly, more work needs to be done to advance the appropriate measurement in epidemiological research of the various complex processes involved in race, ethnicity, racism and social exclusion (Karlsen & Nazroo, 2006; Williams, 1997). However, analyses such as those presented in this paper, which depict the inequalities faced by non-dominant racialized groups relative to dominant racialized groups, remain useful to draw attention to the issue of race-based disparities in health.

The analyses presented in this paper sought to examine the predictors of prenatal depressive symptoms and the role of race in this regard. The cross-sectional nature of the analyses is recognized as a limitation, since the direction of causation cannot be assured. Indeed, some of the identified risk factors for depression are also among its consequences. For example, negative socioeconomic circumstances, low social support, and high stress can all lead to depression; but, depression can in turn worsen these same factors in one's life, setting off a potentially vicious cycle. Since pre-pregnancy life-course data were not available for the variables of interest for this analysis, it was not possible to fully establish temporality around the statistical associations found. However, the mechanistic arguments of causality for the pathways in Figure 3.1 are strong. The results have accordingly been interpreted in the context of the directed, acyclic causal diagram in Figure 3.1, which was proposed based on an extensive literature review of both the epidemiological and the conceptual literature.

Like all studies, the *All Our Babies* study has limitations in its design. The potential for selection bias exists in terms of women who were approached for

recruitment, who consented to participate, and who subsequently completed all questionnaires. A wide array of clinical and community venues related to prenatal services were targeted for recruitment; while a strength of the study, it still meant that women not accessing *any* prenatal care or services (including for reasons of social marginalization) were unlikely to be approached for inclusion. Only women who could communicate sufficiently in English to complete the written questionnaire were included, again pointing to the potential exclusion of certain socially marginalized pregnant women. While response rates for each questionnaire were high (ranging between 76%-84%), analysis of the characteristics of the 123 women who discontinued participation after the first questionnaire showed that women who dropped out were more likely to be younger, non-White, report lower income, report lower education, report lower psychosocial health, and were also less likely to be married or common-law (Gracie et al., 2010). Indeed, the final sample characteristics suggest that the sample overall was fairly socially advantaged compared to the general population from which the women were drawn. However, despite the above, the sample has been shown to be relatively similar vis-à-vis socioeconomic characteristics to the parenting population in Calgary, and also to contain enough variability along key socioeconomic and sociodemographic variables to permit analysis of their effects (Gracie et al., 2010; McDonald et al., 2013). Moreover, the analyses presented here reveal that the health impact of being in a nondominant racialized group persists even within a relatively more socioeconomically advantaged sample, confirming other research on racialization (Karlsen & Nazroo, 2006; Sue, 2010).

Fairly similar proportions in all three race categories reported experiences of discrimination during pregnancy. The above likely stems from the fact that the question from which the variable was derived asked about discrimination "of any kind" in broad terms. Moreover, only "yes" and "no" answer options were offered, meaning that frequency or severity of experiences also were not distinguished. Furthermore, the question was limited to the pregnancy period only, meaning chronic, lifetime exposure could not be distinguished from isolated recent incidents. While these limitations to the discrimination measure used in this study are noteworthy, it is still of interest that about 5% of women answered "yes" to the question, and that an association was detected with depressive symptoms in multivariable analyses that remained highly statistically significant prior to adjustment for stress.

There is considerable diversity between the multitude of ethnic groups within the White and minority categories. Given the recognized importance of tailoring clinical and health promotion interventions to the needs and context of specific groups, further research is warranted on prenatal mental health in specific ethnic groups, as well as specific socioeconomic and sociocultural circumstances. The health of Aboriginal women, in particular, involves unique determinants related to the ongoing legacy of colonization. Intergenerational trauma from residential schools and from the assimilatory child welfare policies of the "Sixties Scoop" era, for example, creates unique challenges to mental health (Adelson, 2005; Sotero, 2006). Examination of specific ethnic groups in this dataset was difficult due to small sample sizes and corresponding concerns of inadequate power and Type II error.

Indeed, the analyses involving race as a tricategorical variable, with a separate category for the Aboriginal women, were limited by the small sample size of the Aboriginal category (just n=26 with available EPDS scores). The small sample size also made it difficult to ascertain the meaningfulness of the differences noted in sample characteristics between the Aboriginal category and the other two race categories. It is of note, however, that the trends found are consistent with other research which suggests lower position on socioeconomic indicators, poorer scores on psychosocial wellbeing measures, and higher reported domestic violence rates among Aboriginal groups relative to other groups in the Canadian population (Adelson, 2005).

While understanding the diversity among individual ethnic groups is important, so too is understanding the role of dominant versus non-dominant racial characterization. Such insight is meaningful for both public health and clinical approaches, given the role of social exclusion on the social determinants of health generally, and on chronic psychosocial stress specifically. From the analyses, it is clear that racialized minority women experienced greater depressive symptoms, and greater proportions had possible clinical depression. The differences in these regards were both statistically and clinically significant. Moreover, even within strata of other known risk and protective factors for depression, racialized minority women experienced elevated depressive symptoms relative to the White dominant women. That is, when examining race jointly with another variable, race had an additive effect over and above the effect of the other variable, suggesting that race was an independent predictor of depressive symptoms. The latter was also confirmed in the multivariable regression analyses, in which race retained strong statistical significance even after adjustment for multiple other variables. While the beta

coefficient for race was attenuated significantly with adjustment for socioeconomic variables, and very significantly with adjustment for stress, it remained as an independent predictor in the respective final models of the OLS linear and binomial regressions. The above suggests that socioeconomic status and stress cannot fully explain the negative health impact of non-dominant race categorization – at least, not as these constructs are standardly conceptualized and measured. Given the sheer complexity of the social and economic inequities faced by ethnic minority groups, Karlsen and Nazroo (2006) caution against assuming that any remaining effect following adjustments can simply be attributed to genetic or cultural characteristics of ethnic groups. Further research on how to better measure and understand the complex nature and impacts of social exclusion is thus required, with the goal of addressing these issues in policies, programs, and services.

The number of two-way ANOVA tests conducted raises the question of whether adjustment for multiple comparisons should have been used to reduce the risk of a Type I error. Adjustment options in this regard include the Bonferonni correction, which lowers the accepted alpha for declaring statistical significance proportionally to the number of tests being conducted. However, the need to adjust for multiple comparisons has been questioned by Rothman (1990) and others, who point out that adjustment increases Type II error and interferes with the detection of meaningful research findings. Given that the associations tested in this analysis are all conceptually supported, the need for adjustment in this case can be debated. Moreover, given that the p-value for the test statistics for race in most of the ANOVAs was <0.001, applying a Bonferonni correction would not meaningfully change the overall conclusions. The results of the multivariable OLS linear regression modelling suggested that the association between race and depressive symptoms was partially mediated by socioeconomic status and by stress, as hypothesized. The attenuating effect of stress was particularly pronounced, and persisted even in the binomial regression where both depressive symptoms and stress were defined in the more clinically-interpretable form of dichotomous variables. The significant attenuation of the beta coefficient for race after insertion of stress may reflect differential exposure among racialized minority women to sources of stress, likely through racialization-based stressors that would not be a part of the experiences of White women. Further research, using specific measures for racialization-based stressors, would be required to assess this hypothesis.

The strong and robust association of stress with both depressive symptoms and possible clinical depression supports an already-large body of research evidence, transcending multiple disciplines, indicating that chronic psychosocial stress may be the most significant risk factor for depression (Roy & Campbell, 2013; Roy & Roy, 2017). In addition to race, the beta coefficients for a number of other variables either attenuated or were rendered statistically non-significant following insertion of stress, suggesting that stress may be a partial mediator along a number of other pathways leading to depression. The interaction term between stress and social support was highly statistically significant, in both the OLS linear regression modelling and the binomial regression modelling. This finding, too, supports existing research that points to social support as a meaningful intervention strategy for buffering the impact of stressful life circumstances on mental health. The statistical significance, in both the OLS linear regression modelling and the binomial intervention strategy for buffering the impact of stressful life circumstances on mental health. The statistical significance, in both the OLS linear regression modelling and the binomial regression and current

physical health, also is consistent with existing research. In clinical and social service provision, the documented existence of a personal history of depression and/or of chronic health conditions in a pregnant patient or client may thus suggest a heightened need to screen for current depression.

The binomial regression modelling was conducted with the objective of confirming whether the results of the OLS linear regression (involving depressive symptoms as a continuous variable) remained in place when depressive symptoms scores were dichotomized into a more clinically-interpretable variable of possible clinical depression. The results did indeed persist – with the exception of the domestic violence variable, which lost statistical significance upon insertion of stress in the binomial regression modelling. Here, too, it can be speculated that high stress likely explains much of the association between experiences of domestic violence and poor mental health.

The hypotheses of partial mediation were assessed using the classical causalsteps approach proposed by Baron and Kenny (1986). The advantage of this approach is its simplicity; it is easy to execute and to interpret. However, it has come under scrutiny recently due to its lower power to detect mediation effects, and also because it fails to conceptualize and detect mediation phenomena more complex than simple partial mediation (Fritz & Mackinnon, 2007; Hayes, 2009; Zhao, Lynch & Chen, 2010). Despite these identified shortcomings, the causal-step approach was deemed appropriate for the purposes of this specific analysis, which was seeking to test hypotheses of simple partial mediation. That hypothesized mediation effects were detected even using this lowerpowered approach arguably speaks to the statistical and clinical robustness of the findings.

Traditional epidemiological approaches to modelling have focused on confounding as an issue of interest, rather than mediation. Although statistically similar, they are conceptually different; a confounder by definition cannot be on the causal path between two variables, whereas a mediator by definition is on the causal path (MacKinnon, Krull, & Lockwood, 2000). Given the importance in public health of taking a multi-pronged and multi-sectoral approach, mediation analyses are useful. In this regard, the stepwise approach taken in the regression modelling in this paper is a strength, as it allowed the potential detection of partial mediation at various stages of the proposed conceptual framework. In interpreting mediation analyses, however, one should keep in mind the importance of addressing both proximal and distal determinants in intervention strategies. While downstream (proximal) factors such as perceived stress and social support are undoubtedly important to target (particularly in individual-level interventions), upstream (distal) factors also need to be addressed for ultimate primary prevention. In the context of racial differences in health, these would include the structural and systemic sources of social exclusion. Given the paucity of research on race and perinatal depression in Canada, the analyses presented in this paper are a meaningful addition to the perinatal health literature. Further research to untangle the complex impact of race and other axes of social exclusion may help in the design of effective psychosocial, clinical and public health interventions, to facilitate good mental health during pregnancy across groups.

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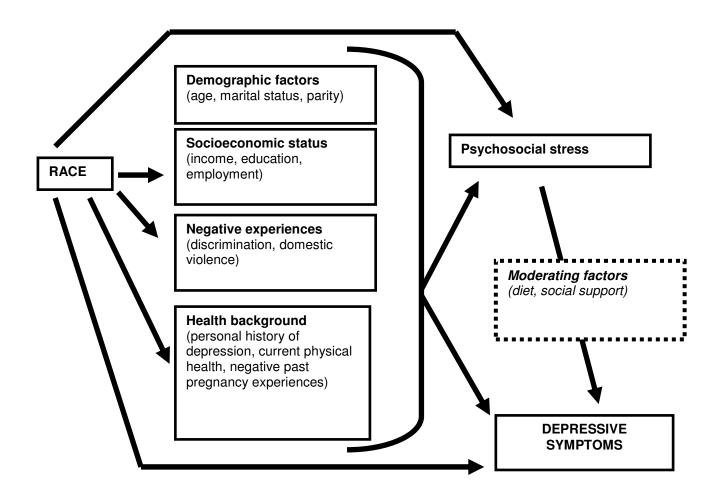


Figure 3.1: Proposed pathways through which race may be related to prenatal depressive symptoms.

# Table 3.1: Characteristics of sample (n=3134 women with an EPDS score available) Particular

VARIABLE – Categorical		FREQU	UENCY (PERCENT)	)
	FULL SAMPLE	WHITE	ABORIGINAL <sup>a</sup>	NON-ABORIGINAL
				RACIALIZED MINORITY <sup>b</sup>
Race (3 categories)		2481 (79.34%)	26 (0.83%)	620 (19.83%)
Age				
Less than 25 years	256 (8.36%)	198 (8.11%)	8 (30.77%)	49 (8.28%)
25-34 years	2202 (71.91%)	1755 (71.93%)	15 (57.69%)	430 (72.63%)
35 years or older	604 (19.73%)	487 (19.96%)	3 (11.54%)	113 (19.09%)
Income				
Less than \$40,000	252 (8.31%)	122 (5.07%)	9 (37.50%)	120 (19.97%)
\$40,000 to less than \$80,000	657 (21.65%)	497 (20.68%)	5 (20.83%)	152 (25.29%)
\$80,000 or more	2125 (70.04%)	1785 (75.25%)	10 (41.67%)	329 (54.74%)
Education				
High school or less	319 (10.20%)	251 (10.12%)	11 (42.31%)	56 (9.08%)
Some or completed postsecondary	2808 (89.80%)	2229 (89.88%)	15 (57.69%	561 (90.92%)
Employment				
Working	1832 (58.59%)	1496 (60.40%)	8 (30.77%)	327 (53.00%)
Not working	1295 (41.41%)	981 (39.60%)	18 (69.23%)	290 (47.00%)
Marital status				
Married/common-law	2964 (94.79%)	2353 (94.92%)	20 (80.00%)	587 (94.83%)
Other	163 (5.21%)	126 (5.08%)	5 (20%)	32 (5.17%)
Parity				
No previous births	1525 (48.96%)	1197 (48.50%)	11 (42.31%)	314 (51.14%)
At least one previous birth	1590 (51.04%)	1271 (51.50%)	15 (57.69%)	300 (48.86%)
Negative experiences with a past pregnancy <sup>c</sup>				
No	1963 (62.64%)	1556 (62.72%)	18 (69.23%)	384 (61.94%)
Yes	1171 (37.36%)	925 (37.28%)	8 (30.77%)	236 (38.06%)
Current physical health				
Good	2996 (95.66%)	2374 (95.73%)	25 (96.15%)	590 (95.32%)
Not good <sup>d</sup>	136 (4.34%)	106 (4.27%)	1 (3.85%)	29 (4.68%)
Experiences of discrimination during this pregnancy <sup>e</sup>				
No	2940 (95.77%)	2339 (96.18%)	24 (92.31%)	571 (94.38%)
Yes	130 (4.23%)	93 (3.82%)	2 (7.69%)	34 (5.62%)
History of domestic violence <sup>f</sup>				
No	2263 (72.93%)	1770 (71.75%)	14 (53.85%)	476 (78.68%)
Yes	840 (27.07%)	697 (28.25%)	12 (46.15%)	129 (21.32%)

2123 (67.78%)	1643(66.22%)	18 (72.00%)	457 (73.83%)
1009 (32.22%)	838 (33.78%)	7 (28.00%)	162 (26.17%)
412 (13.16%)	311 (12.55%)	5 (19.23%)	95 (15.35%)
2719 (86.84%)	2168 (87.45%)	21 (80.77%)	524 (84.65%)
2473 (86.23%)	2055 (89.97%)	14 (70.00%)	402 (71.79%)
395 (13.77%)	229 (10.03%)	6 (30.00%)	158 (28.21%)
	· · · ·		
2717 (86.69%)	2196 (88.51%)	18 (69.23%)	498 (80.32%)
417 (13.31%)	285 (11.49%)	8 (30.77%)	122 (19.68%)
2976 (94.96%)	2385 (96.13%)	21(80.77%)	564 (91.00%)
158 (5.04%)	96 (3.87%)	5 (19.23%)	56 (9.00%)
2243 (78.59%)	1825 (80.47%)	12 (60.00%)	404 (71.76%)
611 (21.41%)	443 (19.53%)	8 (40.00%)	159 (28.24%)
	MEA	N (SD) [95 % CI]	
FULL SAMPLE	WHITE	ABORIGINAL	NON-ABORIGINAL
			RACIALIZED MINORITY
5.2 (3.9) [5.0, 5.3]	4.9 [4.7, 5.0]	6.3 [4.3, 8.3]	6.2 [5.8, 6.5]
		15.5 [12.0,18.9]	14.6 [14.1,15.0]
	1009 (32.22%) 412 (13.16%) 2719 (86.84%) 2473 (86.23%) 395 (13.77%) 2717 (86.69%) 417 (13.31%) 2976 (94.96%) 158 (5.04%) 2243 (78.59%) 611 (21.41%) FULL SAMPLE 5.2 (3.9) [5.0, 5.3]	1009 (32.22%)       838 (33.78%)         412 (13.16%)       311 (12.55%)         2719 (86.84%)       2168 (87.45%)         2473 (86.23%)       2055 (89.97%)         395 (13.77%)       229 (10.03%)         2717 (86.69%)       2196 (88.51%)         417 (13.31%)       285 (11.49%)         2976 (94.96%)       2385 (96.13%)         158 (5.04%)       96 (3.87%)         2243 (78.59%)       1825 (80.47%)         611 (21.41%)       443 (19.53%)         MEA         FULL SAMPLE	1009 (32.22%)       838 (33.78%)       7 (28.00%)         412 (13.16%)       311 (12.55%)       5 (19.23%)         2719 (86.84%)       2168 (87.45%)       21 (80.77%)         2473 (86.23%)       2055 (89.97%)       14 (70.00%)         395 (13.77%)       229 (10.03%)       6 (30.00%)         2717 (86.69%)       2196 (88.51%)       18 (69.23%)         417 (13.31%)       285 (11.49%)       8 (30.77%)         2976 (94.96%)       2385 (96.13%)       21(80.77%)         158 (5.04%)       96 (3.87%)       5 (19.23%)         2243 (78.59%)       1825 (80.47%)       12 (60.00%)         611 (21.41%)       443 (19.53%)       8 (40.00%)         MEAN (SD) [95 % CI]         FULL SAMPLE         WHITE       ABORIGINAL         5.2 (3.9) [5.0, 5.3]       4.9 [4.7, 5.0]       6.3 [4.3, 8.3]

<sup>a</sup>reported ethnicity categories: First Nations registered, First Nations not registered, Métis

<sup>b</sup>reported ethnicity categories: Black/African North American, Chinese, South Asian, Filipino, Latin American, Southeast Asian, Arab, West Asian, Korean, Japanese, Mixed/Other

<sup>c</sup>answered yes to at least one of: miscarriage, stillbirth, abortion, neonatal death, low birthweight baby, preterm baby

<sup>d</sup>answered "fair" or "poor" to question about perceived health status on *both* the 2<sup>nd</sup> and 3<sup>rd</sup> trimester questionnaires (other answer options for the question were "good", "very good" and "excellent")

<sup>e</sup>answered "yes" to the question "During this pregnancy, have you experienced discrimination of any kind (age, sex, race, sexual orientation, disability etc.)?"

<sup>f</sup>answered yes to at least one of : physical abuse, emotional abuse, sexual abuse, financial abuse, neglect

gdefined as 4-7 times per week

<sup>h</sup>defined as a score of 69 or less <sup>i</sup>defined as top 20<sup>th</sup> percentile of scores

\*average of scale scores at 2<sup>nd</sup> and 3<sup>rd</sup> trimesters

RACIALIZED CATEGORY	SAMPLE SIZE	MEAN EPDS SCORE [95% CI]	PROPORTION SCORING 10 OR ABOVE ON EPDS <sup>1</sup>	PROPORTION SCORING 13 OR ABOVE ON EPDS <sup>2</sup>
White	2481	4.9 [4.7, 5.0]	0.11	0.04
Aboriginal <sup>a</sup>	26	6.3 [4.3, 8.3]	0.31	0.20
Non-Aboriginal racialized minority <sup>b</sup>	620	6.2 [5.8, 6.5]	0.20	0.09

 Table 3.2: EPDS scores by 3 racialized categories (White, Aboriginal, non-Aboriginal racialized minority)

<sup>a</sup>reported ethnicity categories: First Nations registered, First Nations not registered, Métis

<sup>b</sup>reported ethnicity categories: Black/African North American, Chinese, South Asian, Filipino, Latin American, Southeast Asian, Arab, West Asian, Korean, Japanese, Mixed/Other

<sup>1</sup>  $\overline{P}$ earson chi-square for tabulation: 35.9 (p<0.001)

<sup>2</sup> Pearson chi-square for tabulation: 38.8 (p<0.001)

# Table 3.3: EPDS scores by dichotomous race (White compared to all other women)

RACIALIZED CATEGORY	SAMPLE SIZE	MEAN EPDS SCORE [95% CI] <sup>1</sup>	PROPORTION SCORING 10 OR ABOVE ON EPDS <sup>2</sup>	PROPORTION SCORING 13 ORABOVE ON EPDS <sup>3</sup>
White	2481	4.9 [4.7, 5.0]	0.11	0.04
All other ethnic	646	6.2 [5.8, 6.5]	0.20	0.09
groups				

<sup>1</sup> Two-sample t-test: 7.6 (p<0.001)

<sup>2</sup> Prevalence difference [95% CI]: 0.08 [0.05, 0.12] Prevalence ratio [95% CI]: 1.8 [1.5, 2.1] Pearson chi-square for tabulation (p-value): 33.2 (<0.001)

<sup>3</sup> Prevalence difference [95% CI]: 0.06 [0.03, 0.08] Prevalence ratio [95% CI]: 2.4 [1.8, 3.3] Pearson chi-square for tabulation (p-value): 33.4 (<0.001)

VARIABLE - Categorical	MEAN EPDS SCORE [95% CI]		TWO-WAY ANOVA F-test p-values
	WHITE/ CAUCASION	ALL OTHER ETH GROUPS	<b>.</b>
Age			model: <0.001
Less than 25 years	6.1 [5.6,6.7]	6.7 [5.5,7.9]	race: <0.001
25-34 years	4.8 [4.6,4.9]	6.1 [5.7,6.5]	age: 0.005
35 years or older	4.9 [4.5,5.2]	6.0 [5.2,6.7]	interaction (ix): 0.468
Income			model: <0.001
Less than \$40,000	6.5 [5.7,7.2]	7.7 [6.9,8.5]	race: <0.001
\$40,000 to less than \$80,000	5.6 [5.3,6.0]	7.0 [6.3,7.6]	income: <0.001
\$80,000 or more	4.6 [4.4,4.8]	5.0 [4.7,5.5]	ix: 0.064
Education			model: <0.001
High school or less	5.6 [5.1,6.1]	6.7 [5.6,7.9]	race: <0.001
Some or completed postsecondary	4.8 [4.7,5.0]	6.1 [5.8,6.5]	educ: 0.010
			ix: 0.733
Employment			model: <0.001
Working	4.5 [4.4,4.7]	5.5 [5.1,6.0]	race: <0.001
Not working	5.4 [5.2,5.7]	6.9 [6.4,7.3]	empl: <0.001
8	[·]		ix: 0.210
Marital status			model: <0.001
Married/common-law	4.8 [4.6,4.9]	6.1 [5.8,6.4]	race: 0.008
Other	6.9 [6.1,7.6]	7.5 [6.2,8.8]	marital: <0.001
	015 [011,710]		ix: 0.351
Parity			model: <0.001
No previous births	4.9 [4.6,5.1]	5.9 [5.4,6.3]	race: <0.001
At least one previous birth	4.9 [4.7,5.1]	6.4 [6.0,7.0]	parity: 0.052
The least one previous on the	1.9 [1.7,5.1]	0.1[0.0,7.0]	ix: 0.135
Negative experiences with a past			model: <0.001
pregnancy			race: <0.001
No	4.8 [4.6,5.0]	6.1 [5.7,6.6]	past preg: 0.360
Yes	5.0 [4.8,5.3]	6.3 [5.7,6.8]	ix: 0.859
Current physical health	5.0 [7.0,5.5]	0.5 [5.7,0.0]	model: $< 0.001$
Good	4.7 [4.6,4.8]	6.0 [5.7,6.4]	race: 0.120
Not good	9.2 [8.4,10.1]	9.1 [7.3,10.8]	phys health: <0.001 ix: 0.073

 Table 3.4: Mean EPDS score along risk and protective factors for depression, with sample stratified into 2 racialized groups

Experiences of discrimination			model: <0.001
during this pregnancy			race: <0.001
No	4.8 [4.7,5.0]	6.0 [5.7,6.3]	discrim: <0.001
Yes	6.8 [6.0,7.6]	9.0 [7.1,10.8]	ix: 0.180
History of domestic violence			model: <0.001
No	4.4 [4.2,4.6]	5.9 [5.6,6.3]	race: <0.001
Yes	6.1 [5.8,6.4]	6.9 [6.2,7.6]	dom viol: <0.001
			ix: 0.040
Personal history of depression			model: <0.001
No	4.0 [3.9,4.2]	5.4 [5.0,5.7]	race: <0.001
Yes	6.6 [6.3,6.9]	8.4 [7.7,9.1]	hist depr: <0.001
			ix: 0.187
Regular prenatal vitamin use			model: <0.001
No	5.5 [5.1,6.0]	6.9 [6.0,7.8]	race: <0.001
Yes	4.8 [4.6,5.0]	6.1 [5.7,6.4]	vit: 0.001
			ix: 0.836
Social support			model: <0.001
Adequate	4.5 [4.3,4.6]	5.2 [4.8,5.5]	race: 0.030
Not adequate	8.5 [8.0,9.1]	8.7 [8.0,9.4]	social support: <0.001
1	[-/*,/]	···· [····/···]	ix: 0.244

VARIABLE – Continuous	PEARSON CORRELATION COEFFICIENT WITH EPDS SCORE				
	WHITE/	ALL OTHER ETHNIC GROUPS			
	CAUCASION				
Psychosocial stress	0.8	0.8			

VARIABLE	β coefficient <sup>a</sup> (p-value)							
	Univariable model (each variable considered separately as the predictor)	Multivariable model with race, significant demographic variables and significant health background variables	Multivariable model with variables significant in last step, plus socioeconomic variables	Multivariable model with variables significant in last step, plus discrimination and domestic violence	Multivariable model with variables significant in last step, plus psychosocial stress	Multivariable model with variables significant in the last step, plus diet and social support	Final multivariable model	
		$R^2 = 0.1634$ Adj $R^2 = 0.1616$	R <sup>2</sup> = 0.1821 AdjR <sup>2</sup> =0.1795	R <sup>2</sup> = 0.1964 Adj R <sup>2</sup> = 0.1937	R <sup>2</sup> =0.6553 Adj R <sup>2</sup> =0.6539	R <sup>2</sup> =0.6591 Adj R <sup>2</sup> =0.6573	R <sup>2</sup> =0.6579 AdjR <sup>2</sup> =0.6569	
Race			*	*	*	*	*	
White <sup>1</sup>	[ref]	[ref]	[ref]	[ref]	[ref]	[ref]	[ref]	
All other ethnic groups	1.3 (<0.001)*	1.4 (<0.001)*	1.1 (<0.001)*	<sup>2</sup> 1.3 (<0.001)*	<sup>2</sup> 0.5 (<0.001)*	<sup>2</sup> 0.4 (<0.001)*	<sup>2</sup> 0.5 (<0.001)*	
Age	1.2 ( 0.001)*	0.0.(0.001)#	0.0.40.40.40					
Less than 25 years 25-34 years <sup>1</sup>	1.2 (<0.001)*	0.8 (0.001)*	0.2 (0.424)					
35 years or older	[ref] 0.04 (0.802)	[ref] -0.07 (0.657)	[ref] -0.03 (0.854)					
Marital status	0.04 (0.802)	-0.07 (0.037)	-0.03 (0.834)					
Married/common-law <sup>1</sup>	[ref]	[ref]	[ref]	[ref]	[ref]			
Other	2.0 (<0.001)*	1.0 (0.001)*	0.7 (0.025)*	0.4 (0.195)*	-0.1 (0.577)			
Parity	2.0 ((0.001)	1.0 (0.001)	0.7 (0.023)	0.1 (0.195)	0.1 (0.577)			
No previous births <sup>1</sup>	[ref]							
At least one previous birth	0.2 (0.249)							
Negative experiences with a past								
pregnancy								
No <sup>1</sup>	[ref]	[ref]						
Yes	0.2 (0.182)*	-0.005 (0.968)						
Current physical health								
Good <sup>1</sup>	[ref]	[ref]	[ref]	[ref]	[ref]	[ref]	[ref]	
Not good	4.2 (<0.001)*	3.5 (<0.001)*	3.3 (<0.001)*	3.2 (<0.001)*	0.8 (<0.001)*	0.8 (<0.001)*	0.8 (<0.001)*	
Personal history of depression								

# Table 3.5: OLS linear regression modelling (EPDS score as continuous)

No <sup>1</sup>	[ref]	[ref]	[ref]	[ref]	[ref]	[ref]	[ref]
Yes	2.6 (<0.001)*	2.5 (<0.001)*	2.4 (<0.001)*	2.2 (<0.001)*	0.8 (<0.001)*	0.7 (<0.001)*	0.7 (<0.001)*
Income							
Less than \$40,000	2.4 (<0.001)*	n/a	1.6 (<0.001)*	1.6 (<0.001)*	0.1 (0.316)		
\$40,000 to less than \$80,000	1.2 (<0.001)*		0.8 (<0.001)*	0.8 (<0.001)*	0.2 (0.199)		
\$80,000 or more <sup>1</sup>	[ref]		[ref]	[ref]	[ref]		
Education							
High school or less	0.8 (0.001)*	n/a	0.02 (0.930)				
Some/completed postsecondary <sup>1</sup>	[ref]						
Employment							
Working <sup>1</sup>	[ref]	n/a	[ref]	[ref]	[ref]	[ref]	
Not working	1.1 (<0.001)*		0.4 (0.004)*	0.4 (0.005)*	0.2 (0.088)*	0.2 (0.076)	
Experiences of discrimination							
during this pregnancy		n/a	n/a				
No <sup>1</sup>	[ref]			[ref]	[ref]	[ref]	
Yes	2.4 (<0.001)*			1.2 (<0.001)*	0.3 (0.195)*	0.3 (0.264)	
History of domestic violence	, , , , , , , , , , , , , , , , , , ,				. ,	. ,	
No <sup>1</sup>	[ref]	n/a	n/a	[ref]	[ref]	[ref]	[ref]
Yes	1.5 (<0.001)*			20.8 (< 0.001)*	$^{2}0.1(0.307)$	$^{2}0.1(0.403)$	$^{2}0.1(0.443)$
Race*domestic violence interaction	n/a	n/a	n/a	-0.9 (0.021)*	-0.6 (0.030)*	-0.6 (0.031)*	-0.5 (0.049)*
Psychosocial stress (continuous)	0.6 (<0.001)*	n/a	n/a	n/a	0.5 (<0.001)*	<sup>2</sup> 0.5 (<0.001)*	<sup>2</sup> 0.5 (<0.001)*
Regular prenatal vitamin use	. ,					· · · ·	. ,
No	0.8 (<0.001)*	n/a	n/a	n/a	n/a	$^{2}$ -0.3 (0.705)	
Yes <sup>1</sup>	[ref]					[ref]	
Social support							
Adequate <sup>1</sup>	[ref]	n/a	n/a	n/a	n/a	[ref]	[ref]
Not adequate	4.1 (<0.001)*					$\frac{1}{2}$ -0.8 (0.071)	<sup>2</sup> -0.9 (0.049)*
Vitamin <sup>*</sup> stress interaction	n/a	n/a	n/a	n/a	n/a	0.01 (0.631)	
Social support * stress interaction	n/a	n/a	n/a	n/a	n/a	0.1 (<0.001)*	0.1 (<0.001)*

<sup>a</sup> β coefficients are the number of points difference in estimated mean EPDS score relative to the variable's reference category
 <sup>1</sup> reference group for indicator variables in regression models (for categorical variables)
 <sup>2</sup> note inclusion of interaction effects in the model involving this variable
 \* Statistically significant. For all but the final model, the cut-off for significance was at p=0.2; if not significant in a model, the variable was taken out of subsequent model(s). For the final model, the cut-off for significance was p=0.05.

	Risk difference <sup>a</sup> (p-value)						
VARIABLE <sup>b</sup>	Each variable separately	Model with race, current physical health, personal history of depression and history of domestic violence	Model with race, current physical health, personal history of depression, history of domestic violence, and psychosocial stress	Model with race, curren physical health, persona history of depression, history of domestic violence, psychosocial stress and social suppor			
Race							
White <sup>1</sup>	[ref]	[ref]	[ref]	[ref]			
All other ethnic groups	<sup>2</sup> 0.1 (<0.001)*	0.1 (<0.001)*	0.03 (0.008)*	0.02 (0.037)*			
Current physical health							
Good <sup>1</sup>	[ref]	[ref]	[ref]	[ref]			
Not good	0.3 (<0.001)*	0.3 (<0.001)*	0.1 (0.001)*	0.1 (0.004)*			
Personal history of depression							
No <sup>1</sup>	[ref]	[ref]	[ref]	[ref]			
Yes	0.2 (<0.001)*	0.2 (<0.001)*	0.04 (<0.001)*	0.04 (<0.001)*			
History of domestic violence	· · · · ·						
No <sup>1</sup>	[ref]	[ref]	[ref]				
Yes	20.1 (< 0.001)*	0.1 (<0.001)*	0.009 (0.270)				
Race*domestic violence interaction	-0.05 (0.202)						
Psychosocial stress (dichotomized)	(,						
Low stress <sup>1</sup>	[ref]	n/a	[ref]	[ref]			
High stress	$^{2}0.4 (< 0.001)*$	*	0.5 (<0.001)*	$^{2}0.4 (< 0.001)*$			
Social support	(	n/a	n/a	(			
Adequate <sup>1</sup>	[ref]	*		[ref]			
Not adequate	$^{2}0.1 (< 0.001)*$			$^{2}0.1 (0.005)*$			
Social support * stress interaction	0.1 (0.039)*	n/a	n/a	0.1 (0.042)*			

# Table 3.6: Binomial regression modelling (EPDS score dichotomized at cut-off of 10)

<sup>a</sup> β coefficients are the risk differences relative to the variable's reference category, for possible clinical depression (defined as EPDS score 10 or above)

<sup>b</sup> only variables statistically significant in the OLS linear regression modelling were included <sup>1</sup> reference group for indicator variables in regression models (for categorical variables)

<sup>2</sup> note inclusion of interaction effects in the model involving this variable

\* Statistically significant. For all but the final model, the cut-off for significance was at p=0.2; if not significant in a model, the variable was taken out of subsequent model(s). For the final model, the cut-off for significance was p=0.05.

# Chapter Four: A framework for understanding prenatal depression in Aboriginal women: data from the Voices and PHACES study

## 4.1 Introduction

Prenatal depression can have serious consequences for maternal, foetal and family health. It is estimated that 10% of pregnant women in Canada will experience depression during pregnancy (PHAC, 2005); but, prevalence may be higher in populations that experience structural violence (Dominguez, & Menjivar, 2014; Farmer, 2008) such as Aboriginal populations (Reibel & Walker, 2010; Bowen et al., 2006a). There is, however, a paucity of research, as reflected in a recent critical review of the literature concerning perinatal mental health in Indigenous women in Canada, the United States, Australia and New Zealand (Bowen et al., 2014). Correspondingly, a framework appears to be lacking to conceptualize the complex determinants of prenatal depression in Aboriginal women.

Various Canadian organizations and researchers have identified Aboriginal maternal-child health as a particular concern (Health Council of Canada, 2011; Sheppard & Hetherington, 2012; Government of Alberta, 2010; Tough, 2009). As with Indigenous populations in the United States, Australia and New Zealand (Coughlin, Kushman, Copeland & Wilson, 2013; Watson, Hodson, Johnson & Kemp, 2002; Wu et al., 2013), Aboriginal populations in Canada experience greater health inequities relative to others groups. Moreover, many of the risk factors and health consequences associated with prenatal depression are more prevalent among Aboriginal populations (Bennett, 2005), suggesting that rates of prenatal depression may be higher and should be a concern for care providers and population health promotion. Given that approximately half of the Aboriginal population is currently under the age of 25 years (Statistics Canada, 2011) and that Aboriginal birthrates are higher, attention to Aboriginal maternal-child health issues is critical (Health Council of Canada, 2011).

Population-level studies to date on all types of depression have found that socioeconomic disadvantage and chronic psychosocial stress are major risks (Bowen & Muhajarine 2006b); however, causal pathways for depression, both at the clinical and the population levels, are complex. Given the historical and present-day societal context of Aboriginal peoples, it would be erroneous to assume that the results of studies in non-Aboriginal populations can be generalized to Aboriginal populations. Notably, Aboriginal women experience intersecting stressors associated with race, gender, social exclusion, and intergenerational trauma overlaid with historical and current colonization (Bennett, 2005; Roy, 2014; Sotero, 2006; Thurston et al., 2014). A context-specific understanding of prenatal depression is therefore crucial for the development of effective and evidence-based policies, programs, and services (Semenya & Lane, 2006; Sutherns & Bourgeault, 2008). A framework that reflects this context is thus warranted, in order to understand and address depression in this population.

Using data from a qualitative constructivist grounded theory study (*Voices and PHACES*) conducted in Calgary, Canada, this paper proposes a theoretical framework for understanding the determinants of depression in pregnant Aboriginal women.

#### 4.1.1 Background

#### 4.1.1.1 Depression and prenatal depression

Depression is a mental health disorder that involves biological, psychological and social factors in its aetiology and manifestation. While different theories explain the development of depression, in almost all, whether biologically or psychosocially focused, psychosocial stress plays a major role (Roy & Campbell, 2013; Roy & Roy, 2017); the term "psychosocial" is used here to refer to the cognitive appraisal of the social environment. Accordingly, an increasing emphasis is being placed on a biopsychosocial, diathesis-stress-based framework for understanding depression. This framework states that depression develops from a combination of biological and other predispositions and psychosocial stressors (Engel, 1977; Garcia-Toro & Aguirre, 2007; Schotte, et al., 2006; Sdorow & Rickabaugh, 2002). Risk factors associated with prenatal depression are similar to those associated with depression in non-pregnant populations (Bowen & Muhajarine, 2006b), and are quite diverse. The literature indicates that the most significant risk factors for depression are psychosocial stress and socioeconomic status. Chronic psychosocial stress, stemming from stressful life events, unleashes pathophysiology that yields depression (Swaab, Bao, & Lucassen, 2005; Roy & Campbell, 2013; Roy & Roy, 2017). In line with a social determinants of population health lens (CSDH, 2008), studies in pregnant women have suggested that factors such as lower income, less education, unemployed or underemployed status and occupation type, unmarried status, younger age, higher parity (Bowen & Muhajarine, 2006b; Fall et al., 2013; Field, Hernandez-Reif, & Diego, 2006; Gotlib, et al., 1989; Jeong et al., 2013;

Jesse, et al., 2005; Le Strat et al., 2011; Marcus, et al., 2003; Ross et al., 2004; Roy, et al., 2010), unplanned pregnancy (Bowen, & Muhajarine, 2006b), poor diet (Bodnar & Wisner, 2005; Roy, et al., 2010), and domestic violence experienced in childhood or in adulthood (Barnet, et al., 1996; Benedict, Paine, Paine, Brandt, & Stallings, 1999; Bowen & Muhajarine, 2006b; Campbell, 2002; Howard, Oram, Galley, Trevillion, & Feder, 2013; Robertson-Blackmore et al., 2013; Villar-Loubet et al., 2014) are predictive of prenatal depression. Factors that appear to buffer the impact of stress on the likelihood of developing depression include social support, and psychological resilience via attitudes such as optimism, high self-esteem and hope (Santini et al., 2015; Southwick, Vythilingam, & Charney, 2005; Roy et al., 2015).

Depression impacts physical and social wellbeing. The associated continuous elevation of stress-related hormones has implications for physical health, including compromising the immune system and impairing neurological function. A wide range of chronic and infectious disorders are comorbidities with depression (Patten, et al., 2008), and similar pathophysiology likely partially accounts for the association (Swaab, Bao, & Lucassen, 2005; Schiepers, Wichers, & Maes, 2005). Both stress-related endocrine mechanisms and pro-inflammatory immune activation have been implicated in preterm birth, low birthweight, and other adverse pregnancy outcomes (Bowen & Muhajarine, 2006b; Korebrits et al., 1998; Swaab, Bao, & Lucassen, 2005; Szegda et al., 2013; Wadhwa et al., 1996). Furthermore, exposure to increased levels of maternal stress hormones in utero can predispose a baby to be at increased risk for depression and anxiety later in life (Swaab, Bao, & Lucassen, 2005). Depressed individuals are more likely to engage in unhealthy coping behaviours, such as smoking, alcohol consumption, and illicit drug use (Bowen & Muhajarine, 2006b). In the context of prenatal health, this yields further risk of harm to the foetus. Depressed pregnant women are also less likely to use prenatal health services (Bowen & Muhajarine, 2006b), which may have consequences for both maternal and fetal health. Finally, depressed pregnant women are more likely to experience depression after childbirth (postpartum depression), which carries potential negative effects on children's long-term cognitive and behavioural development (Bowen & Muhajarine, 2006b; Beck, 2006). Thus, good maternal mental health is critical for the physical, mental and psychosocial health of the entire family; it has ramifications for healthy child development and for the maintenance of a stable home environment (Letourneau et al., 2012).

## 4.1.1.2 Aboriginal women's health

Aboriginal populations face considerable health and social inequities. Studies suggest significant proportions of Aboriginal men and women experience depressive symptoms at some point in life (First Nations Centre, 2005; Bennett, 2005). Many of the correlates of prenatal depression appear to occur at higher rates among Aboriginal populations, such as comorbid health conditions, alcohol consumption, smoking, illicit drug use, adverse pregnancy outcomes, and infant health concerns such as foetal alcohol spectrum disorders and sudden infant death syndrome (First Nations Centre, 2005; Bennett, 2005). Despite the indication that prenatal depression may be a significant population health concern for Aboriginal populations, very little research has been done on the topic. Only two studies in Canada, both by the same authors, could be located. While methodological issues such as sample size limited the statistical analyses, the

trends in the data of those studies suggest potentially higher levels of depressive symptoms (Bowen & Muhajarine, 2006a) and potentially higher prevalence of prenatal depression (Bowen et al., 2009) in Aboriginal women relative to non-Aboriginal women, based on scores on the Edinburgh Postnatal Depression Scale (EPDS).

Aboriginal populations experience inequity along virtually all of the determinants of population health (Adelson, 2005; Bennett, 2005; First Nations Centre, 2005; Health Canada, 2014; Mikkonen & Raphael, 2010). The greater socioeconomic disadvantage experienced by Aboriginal communities may help to explain their higher rates of depression and other mental health issues. However, in order to address the socioeconomic disadvantage and consequent health disparities faced by Aboriginal populations, it is critical to understand the broader context that is driving both social inequities and health inequities. In citing Aboriginal peoples among other groups in Canadian society, Galabuzi and Labonte (2002) discuss the concept of social exclusion, which "refers to the inability of certain groups or individuals to participate fully in Canadian life due to structural inequalities in access to social, economic, political and cultural resources". These inequalities are rooted in "oppression related to race, class, gender, disability, sexual orientation, immigrant status and religion" (p 1). Social exclusion can lead to poor health outcomes through pathways including disadvantage along the determinants of health, barriers to healthcare access and healthy living, unhealthy coping behaviours, and chronic stress pathophysiology (Galabuzi and Labonte, 2002; Cudd, 2006; Elo, 2009). Thus, it can be argued that social exclusion may underlie much of both the socioeconomic disadvantage and the chronic psychosocial stress that are recognized as major risk factors for depression. Social exclusion is central to the

concept of 'structural violence', which brings together intersecting traumas of race, gender, class, and other "social locations", showing the "multidimensionality of oppression" (Dominguez & Menjivar, 2014, p.185; Williams, 2015). Structural violence encompasses the trauma imposed by "physical, economic, political, and cultural arrangements (public sector and private institutions) and legacies" that are power structures (Williams, 2015, p.5). Structural violence is multifaceted and often invisible or unrecognized when the focus is experiences of individuals. It is a critical aspect of the societal context of Aboriginal women's lives, and thus will be a guiding concept in the framework proposed in this paper.

The societal context of Aboriginal populations in Canada cannot be properly understood without attention to colonization. The atrocities committed against Aboriginal peoples over the course of colonization have resulted in "massive losses of lives, land, and culture" (Brave Heart & Debruyn, 1998, p.60), and its legacy continues to impact the health and wellbeing of Aboriginal peoples. The concept of intergenerational trauma (IGT), also known as historical trauma, explains how historical oppression continues to affect future generations. IGT theory explains why populations subjected to long-term, mass trauma (e.g., epidemics, genocide, slavery, war) show a higher prevalence of disease even several generations after the original events (Sotero, 2006; Brave Heart & DeBruyn, 1998). The symptoms of IGT are maladaptive social and behavioural patterns passed from generation to generation (Sotero, 2006). There is elevation of psychological problems and destructive behaviour associated with maladaptive coping, such as addictions, suicide, and interpersonal violence (Sotero, 2006; Brave Heart & DeBruyn, 1998). Impaired capacity to parent is a pathway of IGT transmission. The legacy of residential schools and assimilatory child welfare policies are particularly pertinent to understanding IGT among Aboriginal populations. The resultant trauma increased rates of substance abuse, criminal activity, self-harm, and interpersonal violence among survivors. Children of survivors thus experienced disrupted lives. As a result, survivors' children were more likely to engage in similar behaviours. In this way, an intergenerational cycle of maladaptive behaviour was created, and continues to be reinforced by ongoing oppression (ANAC et al., 2002; Chansonneuve, 2005; NWAC, 2007; Kirmayer, Tait, Simpson, 2009; TRC, 2015).

IGT is critical to understanding mental health in Aboriginal populations, both generally, and specifically among pregnant Aboriginal women (Kirmayer, Tait, Simpson, 2009; Roy, 2014). In IGT, historical grief intersects with grief and anger from presentday traumatic experiences, such as loss of family members and friends to addictions, suicide, or violence; personal experiences of violence; poverty and other social disparities; and personal experiences of oppression (including racism and sexism) (Niezen, 2009; Sotero, 2006). Affected by intersecting racism and sexism, Aboriginal women's mental health is impacted both by historical and present-day trauma. As Huhndorf and Suzack (2010) state: "For Indigenous women, colonization has involved their removal from positions of power, the replacement of traditional gender roles with Western patriarchal practices, and exertion of colonial control over Indigenous communities through management of women's bodies, and sexual violence" (p. 1). The normalization of violence and abuse in residential schools, along with internalized racism and sexism, have led to disproportionately high rates of gender-based violence against women within Aboriginal communities (LaRocque, 1994). Aboriginal women are 3.5

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times more likely to experience violence compared to non-Aboriginal women (Halseth, 2013). Domestic violence, in turn, has led to the much higher proportion of lone-parent, female-headed households among Aboriginal populations; such families are more likely to face poverty (LaRocque, 1994), which further intersects with present-day and historical trauma in women's lives.

### 4.1.1.3 Objectives of the Voices and PHACES study

The sole two Canadian epidemiological studies cited earlier (Bowen & Muhajarine, 2006a; Bowen et al, 2009) only examined sociodemographic factors and risk behaviours. The disparities faced by Aboriginal populations in this regard are well-documented. What is lacking in the literature is a theoretical framework of how the unique historical and present-day societal context of Aboriginal peoples influences these factors, and how it may impact depression through other pathways. Insight in this regard may help in the design of more effective interventions that take into account the broader, upstream issues faced by Aboriginal women. Moreover, in light of the identified lack of theoretical frameworks concerning prenatal healthcare utilization identified in a recent systematic review (Feijen-de Jong et al., 2011), this study's results may additionally contribute to a broader understanding of pregnancy experiences.

#### 4.2 Methods

#### 4.2.1 Study design

We conducted a qualitative constructivist grounded theory study called *Voices* and PHACES (Prenatal Health for Aboriginal Communities and EnvironmentS) as a first step to informing research and service provision around depression in pregnant Aboriginal women. Grounded theory methodology is suited to questions about process, changes over time, or a topic that lacks theoretical development (Charmaz, 2009; Charmaz, 2014). The theory emerges from data derived from multiple sources (Charmaz, 2014; Stern, 2009). A rich description of the characteristics of the phenomenon is sought, which permits drawing together the characteristics into an integrated theory (Morse & Richards, 2002). Initially described by Glaser and Strauss (1967), grounded theory methodology has evolved into different branches. In constructivist grounded theory, the researcher seeks the standpoints of the participants, as well as the historical circumstances and social experiences that shape their opinions. A constructivist approach recognizes the existence of multiple interpretations of a situation according to societal context (Charmaz, 2009). A large proportion of the health and social services professionals with whom pregnant Aboriginal women interact come from a different societal context than them. As such, to better understand the construction of prenatal depression, we felt it crucial to interview both Aboriginal pregnant women and the service-providing professionals who work with them.

Data from multiple sources contributed to the development of a theoretical framework on determinants of prenatal depression in Aboriginal women in this research.

Interviews with pregnant Aboriginal women and health and social services professionals, involving open-ended questions, were the primary sources of data. To enrich our understanding, however, we also collected closed-ended sociodemographic data from participants; administered the Edinburgh Postnatal Depression Scale (EPDS) to the pregnant women who participated; engaged with community partners; held a community gathering with stakeholders; examined quantitative epidemiological data from another project (Roy et al., 2017a [Chapter 3]); and, engaged with relevant published literature throughout analysis and writing (Charmaz, 2014).

#### 4.2.2 Academic-community partnerships

A community-based approach was used in the study, involving academiccommunity partnerships between researchers, community organizations (social services agencies and health clinics), and members of local Aboriginal communities. Such an approach was taken to help ensure that the research would be valid, ethical, meaningful for knowledge translation, and respectful of the principles of Ownership, Control, Access and Possession (OCAP<sup>TM</sup>) in Aboriginal research (First Nations, 2007).

Five community organizations served as core partners in the research: Inn from the Cold, Calgary Urban Projects Society (CUPS), Awo Taan Healing Lodge, Elbow River Healing Lodge of Alberta Health Services, and the Adult Aboriginal Mental Health program of Alberta Health Services. In addition to assisting with recruitment of participants, representatives from these organizations served as co-researchers on the study's Research Team. Twelve other organizations chose to act only as recruitment sites. The study also had an Oversight Committee involving four Aboriginal community members (two of whom were traditional Elders), and a representative from Alberta's Ministry of Human Services (a key policy group). A project governance structure, involving regular meetings and consultations, was implemented throughout all stages of the study and is discussed in detail elsewhere (Roy et al., 2014). Conversations, minutes, memos, reports and notes from meetings were sources of data for this constructivist grounded theory.

#### 4.2.3 Interviews with pregnant women and health professionals

Participants were recruited with the help of partner community organizations. Pregnant women were eligible to participate if they were 18 years of age or older, in the second or third trimester of pregnancy, self-identified as Aboriginal, and resided in the Calgary area. Professionals were eligible to participate if they worked with pregnant women in the Calgary area. Theoretical sampling was initially based on characteristics identified from the literature, and later based on potential gaps in the emerging theory (Glasser & Strauss, 1967; Glaser, 1978; Strauss & Corbin, 1990; Stern, 2009; Charmaz, 2009; Charmaz, 2014).

Trained interviewers (four in total) used semi-structured interview guides to conduct face-to-face, one-to-one interviews with participants. Interviews were conducted in mutually convenient locations where participants felt comfortable; in many cases, the organizations from which participants were recruited were able to offer space. Consent to participate was first sought, and interviews were audio-recorded with participants' permission. A \$25 subject fee was given to participants to thank them for their time and to cover any expenses they may have incurred. At the end of the initial interview, participants were asked for permission to recontact them for a member-checking interview. Interviews averaged an hour in length.

Interviews with the women began with a series of open-ended questions concerning sense of wellbeing during the current pregnancy, factors they felt contributed in this regard, their experiences with existing programs, and whether and how their societal context impacted their prenatal mental health. The open-ended questions were followed by administration of the EPDS. The EPDS is a 10-item scale assessing depressive symptoms in pregnant and postpartum women (Cox, Holden, & Sagovsky, 1987). The EPDS has been found to provide valid and reliable results in a wide range of populations, including in Aboriginal women in Canada (Bowen & Muhajarine, 2006a; Cox, Holden, & Sagovsky, 1987). The interviews ended with closed-ended sociodemographic questions.

The interviews of professionals began with brief questions about their job and experience with pregnant Aboriginal women, and then proceeded with open-ended questions concerning their experiences working with the women, factors impacting the mental health of pregnant Aboriginal women, how issues of societal context impacted pregnant Aboriginal women's health, the adequacy and appropriateness of existing programs, and what needed to be changed or improved.

As a step towards ensuring rigour and trustworthiness, the preliminary results derived from the analysis of the interviews were shared with the original participants who were interested and available for a second interview. These member-checking interviews (Charmaz, 2014) involved seeking confirmation that the analysis made sense in light of the participants' experiences and perspectives, and any additional reflections. Member-

checking interviews were also audio-recorded with participants' permission, and transcribed. Participants were again given \$25 for their expenses.

## 4.2.4 Community gathering

Following completion of member-checking interviews and drafting of an interim report, a community gathering was held. Invitees to the event included study participants, other Aboriginal community members, and staff and management of clinical and social service agencies in the Calgary area. The interim report was presented at the event, followed by a presentation by one of the women who had participated in the study, who shared her personal pregnancy story. The presentations were followed by focus-groupstyle discussions to seek audience reactions and reflections on the study results, and on possible recommendations for policies and programs. Research assistants facilitated the discussions, which were audiotaped with permission of attendees. Transcripts and research assistants' notes from the event were analyzed as data.

## 4.2.5 Analysis

Data gathering and analysis were conducted iteratively, until no new information concerning categories within the data were being generated (Charmaz, 2014). Interview transcripts were analyzed using the software NVivo 9 (QSR International, 2010). Preliminary open coding was followed by axial coding to cluster codes into categories, and selective coding to develop themes and concepts (Charmaz, 2014; Strauss & Corbin, 1990). Memos were written on emerging themes and concepts, the relationships between them, points stemming from comparison between groups, and insight from other sources. As encouraged in Charmaz's (2009; 2014) approach to constructivist grounded theory, the existing literature was referenced during analysis, to stimulate insight, and contrast data with existing accounts and perspectives. The interviews with women and those with professionals were analyzed separately, to account for the fact that the knowledge of professionals would be socially constructed in a different manner than that of the women themselves (Charmaz, 2009; Charmaz, 2014). In accordance with the collaborative nature of the study, group analysis was conducted, involving academic and community partner representatives on the Research Team and community members on the Oversight Committee. Two group meetings were devoted to analysis, where results from the coding process were presented to the group by the lead researcher (A.R.) and interpretations sought from group members.

### 4.3 Results

Personal interviews were conducted with 13 pregnant women and 12 professionals between March 2012 and August 2013. Of these 25 participants, seven subsequently participated in member-checking interviews (three women and four professionals). Eleven individuals attended the community gathering for stakeholders held in March 2014.

#### 4.3.1.1 Pregnant women

Eleven of the 13 pregnant women identified as First Nations with status<sup>3</sup>, one identified as First Nations without status, and one identified as Métis; none were presently living on a First Nations reserve. Most were in their 20s, but ranged in age from 22 to 45 years. Seven women had at least one other child, and their age at birth of their first child ranged from 15 to 21 years. Of these seven women, three had none of their kids living with them due to removal by child welfare authorities.

One woman was legally married, three were living common-law, and nine were single (never married). Three were employed full-time, one was employed part-time, two were students, and seven were not employed. Six had not completed high school, four had earned their high school diploma, two had a trade certificate or completed apprenticeship training, and one had completed a university degree. Three had household incomes at or over \$40,000, and 10 had less than \$40,000; of those 10, seven had incomes less than \$15,000.

Eight women self-reported experiencing symptoms consistent with the clinical definition of depression at some point in their lives, of whom two indicated it was during a previous pregnancy or postpartum period. Five had been formally diagnosed with depression, of whom four had received treatment. Six women scored 10 points or higher on the EPDS (indicating probable clinical depression). Of them, two scored higher than

<sup>&</sup>lt;sup>3</sup> In Canada, a First Nations person who is registered under the Indian Act is recognized by the Canadian government to have "status" (Government of Canada, 2015).

13 points, indicating a high probability of clinical depression; only one of them had been told by a health professional that she was depressed.

When asked whether they had family members who had experienced depression, six women indicated yes, four indicated no, and three indicated that they did not know. Of the six who said yes, four indicated that the family members in question had been formally diagnosed by a health professional. Of the 13 women, six had family members who had ended their lives by suicide.

#### 4.3.1.2 Service-providing professionals

Most service-providing professionals were female (11 of 12) and non-Aboriginal (11 of 12). They ranged in age from about 25 to about 55 years. Professions were as follows: two family support workers, a dietician, a family counsellor, a residential counsellor, three nurses, three family physicians, and one obstetrician-gynaecologist. The length of time of participants' current employment position ranged from six months to 20 years. Number of pregnant Aboriginal women seen in a typical month ranged from zero to 60.

#### 4.3.2 Pathways to depression

The breadth and depth of responses corroborate the complexity of mental health issues like depression. A large number, and diverse range, of influencing factors were discussed by participants. The pathways through which possible determinants interrelate to yield depression are summarized in a framework reflected in Figure 4.1.

### 4.3.2.1 Depression

When asked what 'depression' meant to them (either in reflection of their own experiences or that of others they knew), women used phrases like "hitting rock bottom", and described experiences like feeling helpless, hopeless, worthless, empty, lonely, tearful. They described symptoms like being unable to get out of bed, having trouble sleeping, and losing interest in things. One woman described depression as "when you're not yourself [because] a spirit that shouldn't be there ... takes over your body and your mind and lets you think all these awful things and makes you do awful things". Two of the women reported experiencing depression during or after a previous pregnancy. As one of these women described:

I isolated myself. I didn't eat. I couldn't sleep. I was getting anxiety attacks. ... My mom kept coming over trying to get me to leave my house but I wouldn't leave. I didn't sleep in my room. I moved to my living room. ... I just lost interest in everything. ... I was like that for a whole month and I was always crying.

Nearly all of the professionals described interacting with Aboriginal patients or clients with confirmed or suspected mental health issues, with clinical depression being particularly common. Other mental health issues encountered included anxiety, posttraumatic stress disorder, eating disorders, chronic pain, and substance abuse; multiple professionals noted that the latter was a correlate and indicator of poor mental health. Some professionals reported encountering prenatal and postpartum depression among their Aboriginal patients or clients.

#### 4.3.2.2 Chronic stress and trauma

Chronic stress – the state of feeling constantly worried or overwhelmed due to negative life circumstances – was linked by all the women to negative emotions and poor mental health. Trauma - extreme stress following a serious negative event – also came up in the interviews as linked to depression. One woman, whose daughter was removed from her care due to concerns about her mental health, described how it took her some time to recognize the point where life stress led to depression:

I think the hardest [thing] was my daughter being apprehended from me. I was going through depression because I had just gotten out of a recent abusive relationship from my daughter's biological father. I [had] just got out of the [women's] shelter, got my own place. ... I was on my own, just me and [my daughter] in an apartment, dealing with bills, dealing with her [illness], dealing with the threats from ... [her] biological father, and it just became too much for me. I didn't realize that I was depressed. ... I just thought, okay, I'm just stressed, just stressed. I didn't understand the signs of depression. I didn't realize that I was isolating myself. I didn't realize that I was affecting my daughter's health, as well. ... Social Services [took my daughter because] they just want me to be stable and understand signs of depression.

Both women and professionals cited various life circumstances that contribute to depression via the stress and trauma they cause. These factors are categorized and described below. It was apparent from the women's interviews, in particular, that these factors interact with each other in complex ways; moreover, the factors are not discrete, but rather are inherently overlapping. To indicate this complexity, the groupings are shown in Figure 4.1 as overlapping circles. While depression is the endpoint of interest for the purposes of this study, the interview data also pointed to the vicious cycle that can be set off between negative life circumstances, stress and trauma, and depression. To depict this cycle, arrows leading from depression back to boxes earlier in the pathways are included on Figure 4.1.

4.3.2.3 Underlying societal and institutional context

The data pointed to the overwhelming structural violence faced by Aboriginal women, which is enhanced by pregnancy. As defined earlier and as depicted in Figure 4.1, these structures are part of the underlying societal and institutional context that shapes their lives Taken together, these underlying contextual factors appear to drive the pathways leading to poor mental health. They are accordingly positioned on the very left of Figure 4.1.

Past acts of colonization, including (but not limited to) residential schools and the "Sixties Scoop" (1960s-1980s) era of assimilatory child welfare policies, left a legacy of trauma that has been cyclically transmitted as intergenerational trauma (IGT). The intergenerational impact of residential schools, for example, was linked by respondents to interpersonal violence (IPV), parental neglect, family breakdown, addictions, and community dysfunction:

[My spouse is mean]. He's always angry and mad and he takes it out on me. He doesn't know how to deal with himself, he doesn't know how to deal with addictions or his anger, so he turns to drugs and alcohol. ... I think it's because his dad was really mean too and his dad was raised in residential [school]. ... They were raised really strict and they were really abused with, like, sticks - you know, still getting raised in the residential [school] way. They never broke out of that and it just stuck with them until this day, it's still like that. It's passed on ... generation [to] generation.

My mom [was never around] for me and my siblings. ... [Her mom], my Grandma, was in residential school and she said what she got out of it was she didn't know how to love, ... how to show affection. ... She wasn't there for none of her kids. All my uncles [are] in and out of jail through their whole lives. ... My aunties drink a lot and my mom smokes weed. ... I was [also] following in that pattern of drinking and not caring.

I just think that [the residential school system] really interrupted our traditional way of living. [It] had an extremely detrimental effect on us as an individuals and also how we function as a community. We're very dysfunctional [because of it].

In describing dynamics in health and social services, women spoke of experiences with negative, judgmental service-providing professionals, and also of feeling that they could not trust professionals to care about their needs. Professionals acknowledged the existence of racism, stigma, stereotyping, and judgment against Aboriginal peoples in service systems, and shared examples of such behaviour by colleagues. Lack of trust in healthcare led women to avoid accessing health services, which carried repercussion for their physical and mental health. Mistrust of social services, particularly child protective services, was also a strong theme in the data. Like many jurisdictions, Alberta legally mandates the reporting of suspected child abuse or neglect to child protection authorities, including in cases where the child is suspected to have witnessed family violence. While well-intentioned, this law leads some Aboriginal women to simply avoid accessing services. In addition to citing a historical basis for the mistrust of child welfare authorities (namely, the mass displacement of Aboriginal children during the residential school and Sixties Scoop eras), there was concern expressed that current child welfare practices are not working in the best interest of children, families, and communities. Professionals expressed similar concerns about the child welfare system not doing enough to support parents who are struggling to care properly for their children. A separate analysis of data pertaining to women's and professionals' experiences in health and social service systems has been reported elsewhere (Roy, et al., 2017b [Chapter 5]).

Women in the study also reported structural violence in education- and employment-related institutions. For example, one woman described how stringent Employment Insurance guidelines around maternity benefits were leaving her with no option than to pursue social assistance to support herself during her maternity leave. Her story also reflected the stigma attached to Aboriginal women:

I don't want to be that stereotype, another Native pregnant woman who's just going to collect more welfare for her and the kids. I'm actually trying to get out of that whole welfare system. But right now I have to go back to welfare 'cause I didn't collect enough hours to collect EI from work, 'cause I just started there. So I have to go back to social assistance, which doesn't pay much.

Another woman explained that experiences of intense racism in high school led her to drop out, thus limiting her employment options: "I was just having troubles in high school 'cause some of my peers were giving me a hard time. A lot of it had to do with racism, and I couldn't handle it. It just was so stressful being in that environment, [so] I quit high school." Many of the women shared memories of unfair treatment in childhood by peers and teachers at school, as well as present-day unfair treatment by neighbours, strangers, employers, colleagues, and professionals in both social and health service sectors.

Most women and professionals recognized overt and implicit racism and spoke at length of Aboriginal women's experiences with both throughout their lives. One woman reflected on the messaging that young children receive about race in society, and the impact it has on racialized minority children's self-image:

I remember when I was like seven [or] eight years old. [I used to think that] if I my skin was white and if I had blonde lighter hair, I'd be like really pretty. I thought, (chuckle) if I could just be white things would be so different. [I think about] what happened from the time I was born till I was eight years old that made [me think like] that. Adults treat kids like they're not there and [as if] they don't listen and [as if] they're not hearing things like the things that I remember hearing when I was little, [which] was just so much racism. [They] must have thought that I wasn't listening but I was listening.

Several women participants described personal experiences of IPV at the hands of male relatives and male intimate partners, spanning physical, psychological, emotional, financial and sexual forms of abuse. In multiple instances of IPV, the perpetrator's family members also participated in the violence. The women made a clear connection between these experiences and their mental health: "I drank and I drank and I drank ... That's what happens when you're depressed [from this situation]". Several women paralleled their personal experiences with IPV with those of their mothers, suggesting a level of normalization across generations. Women and professionals noted the role of residential school trauma in explaining the high rates of IPV in Aboriginal communities.

Some of the women in this study gave examples of unfair treatment due to being a woman, including sexism in education or workplace settings where they reported feeling underestimated or undervalued as women. One woman exclaimed: "This is really a man's world". While some examples of discrimination shared in the interviews were clearly related primarily to gender, other examples portrayed how race and gender intersect in Aboriginal women's lives. Some women noted the convergence of racism and sexism in the discrimination they faced. As one woman summarized: "[As] both [a woman and an Aboriginal woman], I feel second class. [I] don't get as much respect." Women in this study reported receiving overt racial slurs originating in colonial days, such as, "Savage", "Wagon Burner", "Dirty Indian", and "Squaw". The latter is highly gendered; the

difficulty in untangling sexism and racism was also highlighted in other experiences

shared:

In high school a lot of boys wouldn't want to date me because I was Native. People didn't really want to be my friend because they thought that I was just an alcoholic or that I was abused every day and that my house was filled with, like, alcohol and drugs, and was dirty.

I've dealt with a lot of crap from guys growing up. ... Whenever I was with my friends or out, ... married guys would ask me out or they'd ... be drunk ... and ask me out [and] that just really ticked me off. I'm so tired of being asked that way. [It] made me feel like I am [worthless].

Women and professionals commented that the racialized sexism faced was

exacerbated with pregnancy, since pregnant Aboriginal women are often stereotyped as

bad mothers who party, abuse substances and are promiscuous. As two women explained:

[We] are constantly being asked by anyone and everyone if we're using drugs, alcohol or smoking during pregnancy. They're assuming that we are. And also the assumption that each of our children have different fathers. ... I don't see [women from] other cultures being asked 'Oh, do your kids have the same dad?' or 'Who's that [one's dad], who's your first child's dad, who's your second child's dad?' But I'm constantly asked 'Oh, do your kids have the same dad.' ... It's doctors, social workers, people I meet on the street [asking these questions].

I guess people may be looking at me as an Aboriginal woman that's pregnant. They're judging me, I guess, like 'Oh, she's probably drinking or smoking'. I'm learning not to care what people think, but then it kind of takes a little overwhelming toll on me [because] I do care, I'm human.

Many women spoke of their frustrations with misperceptions about Aboriginal

peoples, including the inaccurate idea that "the government gives [Aboriginal peoples]

free stuff". They spoke of stereotypes of lazy and uneducated people, which left them

feeling angry and misunderstood: "If you're Aboriginal, they do not expect you to make

it so big and have a career". Another described a conversation with a prison staff member

while she was incarcerated: "She said, 'This is going to be a revolving door for you.' I

didn't understand at first. ... I was like, 'This is my first time, what are you talking

about?' Then she said, 'Oh you'll be back.' I'm like, 'How do you know?' and she's just

like, 'I know'."

Women spoke of the need to counter negative stereotypes, and of the chronic strain

of trying to positively represent Aboriginal peoples:

I feel like ... I have to be extra polite because I can see people [look at me differently]. ... I feel like that's one of my coping mechanisms [against racism]. [I figure if I] seem polite [then] maybe I can make the path a little more gentle for the next Aboriginal girl. Maybe somebody will be nicer to her next time. [It's a weight to carry]. But if you get angry ... [and] you're just carrying that around, you're just giving them more fuel to not like you, and to stereotype Natives.

[Throughout my] life [I have] gone through ... discrimination. At first when I found out that I was pregnant, [I thought] 'God, I'm just going to fall under one of those statistics of Aboriginal women becoming pregnant', [and it was] going to stress me out. But you know, as an Aboriginal woman you just gotta be strong. We can get through anything.

Other women were more reluctant to endorse a connection between racism, sexism and the negative circumstances facing their own families or Aboriginal communities generally. One woman chose not to answer any interview questions concerning residential schools, asking to "pass" on those questions. Another spoke negatively about residential school survivors, suggesting that the focus on the legacy of residential schools was "all about money" (financial compensation). Some women insisted that they had no experiences with racism. While almost all of the women reported some experience of male-on-female violence or abuse, very few characterized the experience as genderbased. One woman, in indicating that she had never experienced racism, suggested that those on the receiving end of racial slurs are generally those who "are not well dressed, not well taken care of, especially the girls". Another woman spoke critically of other Aboriginal women "[choosing] not to better themselves":

It kind of makes me sad when mothers find themselves in situations, and they don't try to better themselves. They just keep going in the same circle. You know, I've heard some people just make livings off having kids. ... I know a lot of women that have put themselves in situations where their children [are] taken away and they don't try anything to get them back or they just give up. They give up so, so easily. It makes me sad.

Cudd (2006) has characterized such statements as 'internalized oppression': one of the psychosocial consequences of membership in an oppressed group, wherein members begin to judge themselves and other members of their group based on the negative stereotypes and prejudices held by the dominant (oppressor) group(s) (Cudd, 2006). Internalized oppression was also cited by one of the professionals interviewed, who is Aboriginal herself: "Internalized oppression, like, you know, hating their Indian selves and in turn not liking other Aboriginal people". In addition to perpetuating oppression (Cudd, 2006), internalized oppression may contribute to the negative relationships and unhealthy social environments in Aboriginal communities that were noted repeatedly in interviews, and that are described below.

### 4.3.2.4 Risk factors for prenatal depression

Structural violence creates a set of risk factors that we grouped into socioeconomic, negative relationships, and negative life events and circumstances. As depicted in Figure 4.1, these factors serve as sources of chronic stress that can lead to depression.

### 4.3.2.4.1 Socioeconomic factors

Socioeconomic factors contributing to poor mental wellbeing include low income, low education and unemployment, and the corresponding problems of food insecurity, housing insecurity and financial insecurity. One woman described the impacts on her mental health of spending an extended period of time staying at a crowded homeless shelter during her pregnancy, followed by a period living temporarily with her partner's emotionally abusive family. For some women, financial insecurity was an ongoing issue in their lives; for others, it was brought on by pregnancy and the prospect of 'another mouth to feed'. One woman's morning sickness led to reduced work hours: "[My] stressors [include] financial [stressors]. After I slowed down at work I wasn't making enough to pay my bills and I was getting last notices for rent and utilities and stuff." She was forced to depend on her mother's help to pay her bills, and reported feeling guilty for having to impose on her mother. Women who were employed reported job stress. Women also described how pregnancy and parenting was (or would soon be) interfering with school or career progress.

### 4.3.2.4.2 Negative relationships

Almost all of the women spoke at length of negative relationships with past or present intimate partners. IPV was discussed earlier; other difficult relationship dynamics included infidelity, strained communication, and immature or irresponsible behaviour on the part of the partner. Many of the women were no longer in a relationship with their baby's biological father; his absence was generally deemed as positive by these women, in light of the negative nature of their relationship. However, the women still expressed regret at the lack of partner support in their lives: "A lot of the time I wish my baby's dad was part of it...I'm basically doing this on my own. ... [I feel lonely] when she's kicking, like at night time...I see all these couples, with the dad being there and feeling the kicks and, you know, worrying and stuff like that."

A family counsellor speculated that the men were abandoning their pregnant partners out of fear of being a father, due to themselves hailing from homes where fathers were not present:

Usually [the male partners] are not there. They're just scared and they're gone or maybe they just didn't want to be there because, you know, there's going to be a baby coming and they're not ready to go there: 'I don't know how to be a dad. No I didn't want to be a dad. Now I gotta be a dad. Oh, I'm outta here. I don't know how to do that.' ... Maybe they're just not prepared [because] ... they probably had similar family backgrounds.

Friendships that were built around unhealthy activities like partying, drinking or drug use were categorized by women and professionals as 'negative', and contributed to poor mental health. Many women described having to cut off negative friendships once they found out they were pregnant, since they could no longer do things like party or drink; such a decision left them lonely and isolated, without support or camaraderie of any kind.

Negative relationships with family members, a prominent manifestation of IGT, also came up repeatedly. Negative interactions with neighbours, community members, strangers, as well as colleagues at school or work, were mentioned in interviews, as were racist comments. Finally, negative relationships with health and social services providers were described as having a particularly severe impact on wellbeing. Women described instances of experiencing stigma, judgment, or having otherwise unhelpful interactions when seeking services. Professionals described witnessing or overhearing their colleagues speak or behave in ways that were clearly judgmental; they expressed concern about the impact on the wellbeing of the patient or client. As one participant (a physician) stated: "Patients aren't stupid. They can recognize when someone's judging them for the circumstances they are in. ... The [patient-provider] interaction is, in my opinion, key to an effective therapeutic relationship. So [when I] see these kind of underlying ... prejudiced ideas, I think [they] have an impact on patient care."

### 4.3.2.4.3 Negative life events and circumstances – self, family, community

The women were asked to reflect on their personal wellbeing in physical, emotional, mental and spiritual terms, and discuss factors that were impacting their wellbeing. Exhaustion came up frequently in the women's interviews. While some attributed it to the physical effects of pregnancy, most noted the various chronic and overlapping stressors in their lives (discussed above and below); these led to them feeling overwhelmed and worn out.

Physically, pregnancy-related discomforts were cited as sources of frustration; these included morning sickness, hemorrhoids, abdominal discomforts, aches and pains, fatigue, sleep problems, and other symptoms common in pregnancy. Some women mentioned feeling anxious about gaining weight during pregnancy, citing ongoing concerns about body image. Health concerns such as gestational diabetes and gall stones were also mentioned; in addition to feeling unwell due to their physical symptoms, these health concerns caused stress on account of the challenges of managing them. One woman described the challenges of her newly-diagnosed gestational diabetes: "I ...[have to take] insulin and [watch] my diet and everything. It's real hard because my eating habits were always like junk food ... since I was little. Now that I have to watch every little thing that I eat, it's a little complicated."

Several stressors related to concerns about the baby. Some women worried that their financial insecurity, with the corresponding housing insecurity and food insecurity, would lead to negative effects on their unborn baby's physical development. One woman, for example, described how she was dependent on food banks to feed herself and her family, and was concerned about getting adequate nutrition during her pregnancy. Others were fearful that their drinking prior to finding out that they were pregnant may have harmed their unborn baby; they expressed feelings of guilt and apprehension. Most of the women we interviewed were going through unplanned pregnancies, which was stressful. On the other hand, two of the women described problems with fertility, including one woman who ultimately conceived with the use of in-vitro fertilization. These two women spoke of the considerable distress their fertility difficulties had caused them.

Concerns about a first pregnancy included uncertainty about pregnancy, the birth process, and becoming mothers. Women who already had children described the stress from parenting them while pregnant. In regards to the latter, multiple professionals raised the prevalence of larger-than-average family size among Aboriginal communities, and the resulting stressors from managing a family with several children. Multiple professionals also cited the younger-than-average age at first pregnancy among Aboriginal women, and the negative impact the above would have on socioeconomic stability (and thus on mental health). In regards to these trends, a few professionals wondered during the interviews about awareness of, access to, and cultural acceptability of birth control measures. In contrast to the professionals interviewed, none of the women raised the issues of birth control or family planning in their interviews.

Child welfare systems play a large role in Aboriginal women's mental health concerns. Many women had experience of being in foster care themselves and/or had a child taken away. One woman described her fear around her current pregnancy: "I don't really want to bring another baby into this world just for the baby to get apprehended again." Professionals recognized that fear of child apprehension is a major issue mental health issue for Aboriginal patients and clients: "Scared to actually have the baby that they have inside of them, scared to give birth because welfare might take the baby. And disconnecting from the baby, too, like not wanting to feel the baby moving and stuff like that, 'cause they [don't] want to get close to it."

Structural violence leads to multiple and extreme sources of loss in Aboriginal women's lives. Several of the women in this study described individuals close to them dying in suicide, gang or other violence, and drug overdoses. For some of these participants, the death of someone close to them, occurring often in tandem with other difficult life events and circumstances, pushed them into extreme depression. After the violent death of her alcoholic brother, one participant dropped out of college, quit her competitive athletics, began drinking, and entered an abusive intimate relationship. Reflecting on that period of her life, she described her dysfunctional actions in terms evocative of survivor's guilt: "I felt so bad about my brother, like, 'Why did he go through that, and why didn't I go through that?' So I just, I don't know, I almost felt like it was self-inflicted in a way, like I felt like I need to experience bad stuff." Some of the

deaths discussed had occurred long before the women became pregnant; however, the memories and ramifications of the deaths were still present. Other deaths were experienced during the pregnancy, including one participant whose grandmother passed away due to a chronic illness, and another whose best friend committed suicide. The latter stated: "It was really hard to focus on my pregnancy [after that]".

In addition to deaths, health problems of family members or friends were also cited as stressors, both due to the worry they caused, and also due to stress from practical caregiving responsibilities. Beyond family and friends, problems in the community were cited as impacting the wellbeing of Aboriginal women. These included negative community dynamics such as gossip, corruption among community leaders, crime (including gang violence) and, in off-reserve settings, racism. Living in communities with a high prevalence of negative issues such as addictions, suicide and poverty were also noted to have an impact on women, regardless of whether there was personal experience of the issues, due to the poisoned social environment. Problems were noted both in reserve communities and in urban communities where Aboriginal women lived. Thus, both the women's and professionals' interviews highlighted the role of family-level and community-level stressors in the mental health of pregnant Aboriginal women. Multiple women and professionals noted the link between detrimental family and community dynamics and IGT, pointing to the structural source of these issues.

#### 4.3.2.5 Coping with structural violence

As reflected in Figure 4.1, negative coping mechanisms exacerbate pathways leading to depression. In contrast, protective factors buffer against movement along the

pathways, and include healthy relationships; maintenance of a healthy mind, body and spirit; healthy physical and social environments; and culturally safe and accessible services.

While dealing with the impacts of structural violence in their lives, pregnant women find ways to cope – or, perhaps as Kleinman (2014) would put it, to "endure a state of hopelessness with the realization that they have no alternative" (p. 120). Kleinman (2014) wants to replace "the currently fashionable and superficially optimistic idea of 'resilience'" (p. 119) with the concept of 'endurance'. Substance abuse and addictions came up repeatedly in the women's and professionals' interviews as negative mechanisms used to cope with stress. Professionals characterized substance use as "an easy escape for the time being". Women recognized that alcohol and other substance abuse often worsened their problems: "I was drinking [when I] was in a bad depression, and it just kept leading me to binge drink, and then that led to more depression." However, in the absence of more positive approaches, it was all they had available to cope. One woman explained how she was able to break free of her addictions when she learned healthier ways of coping: "Before, ...when I was mad or angry, I would turn [right away] to alcohol or drugs. ... Now, when I'm mad or stressed out, I talk about it [with family or friends]." Thus, the presence of protective factors is required if women are to resist structural violence in positive ways.

Pregnancy and children become a reason to endure for many women. One woman explained: "Mentally ... you're on a whole different level. Before I was pregnant I was only thinking about myself. Then this little person comes into your life and it's different. It makes you see the world differently. I think about death a lot. I don't want to leave my son behind." Multiple women and professionals spoke of how pregnancy can be a powerful motivator for positive life changes, including improving diet, getting more exercise, and giving up alcohol and drugs for the sake of the baby. Women also reported that their pregnancy helped change their attitudes and perspectives, improving their mental wellbeing and helping them to seek more positive stress-control strategies. Moreover, because pregnancy leads to more interaction with services, there can be increased opportunities for meaningful interventions. However, as cited by both women and professionals, pregnancy may discourage some Aboriginal women from accessing services, due to fear of being judged for their lifestyle (e.g., addictions), or fear that contact with services will lead to their baby being taken from them. Thus, health and social services systems need to address the above fears in order to facilitate access and benefit.

Positive coping strategies included "keeping busy" through activities like housework, schoolwork or employment as a way to "keep [one's] mind off things." Accomplishing tasks, even small tasks like housework, was cited as a way to feel emotionally better, even temporarily. Other strategies mentioned included making time to relax; getting enough sleep; activities such as walking, running, yoga and other forms of exercise; and a healthy diet. Other activities cited by the women included reading, sewing, and culturally-related beading and crafts.

Women described learning cognitive coping skills through mental health and/or addictions counselling, and from traditional Elders or church leaders, highlighting the role of programs and services in facilitating positive coping skills. Women spoke of coping with stress by keeping a positive outlook and remaining optimistic, calmly

rationalizing through difficult situations ("take a step back"), and learning to "calmly walk away and let it be" when dealing with difficult individuals. "Laughter is sometimes the best medicine" was also quoted. One woman explained: "Like the Elders always say, when you put your mind on good things, then good things will come. [The] Creator has a way of, the Universe has a way of, working it out. You gotta know where you're going, who you're going with and where you come from."

Women and professionals noted that spirituality (not necessarily grounded in organized religion) helps some women maintain a positive outlook. Some programs have spiritual components that are non-denominational; others offer traditional Aboriginal practices such as smudging, sweat lodges and other ceremonies. One woman, who overcame significant traumatic life events in her past, described how she found peace in the spiritual significance of the White Buffalo prophesy. Thus, her spirituality and connection to traditional Aboriginal healing approaches were helping her to find peace with the difficult circumstances of the past, and remain optimistic for a healthier future both for herself and for her First Nations people. Finally, multiple women spoke about how they drew confidence from their identities as Aboriginal women, citing the "rich cultural heritage" and "the connection with the Creator". One woman stated: "I feel proud to be Aboriginal because there's no one like us [and] the culture is beautiful. I'm pretty proud and I wouldn't want to be anything else, even though we go through so much as people."

Emotional and practical support from others was cited as key mechanisms for coping positively with negative life events. In the context of pregnancy, relationships with older women who have experienced pregnancy and parenting, and/or peers who are

going through such experiences concurrently, were acknowledged as particularly important. One professional described how she saw herself as a replacement "mother and grandmother" to her patients, in addition to being their nurse, in light of the difficult relationships between many of her patients and their own mothers and grandmothers due to IGT. Professionals involved in group-based prenatal education programs noted the camaraderie that often develops among program participants, who bond over their shared experiences and reach out for mutual support.

Positive physical and social environments – places where women live, study or work, seek programs or services, or otherwise spend time – can help buffer the impact of negative life events. Positive physical environments were described as those that allowed women to feel safe and comfortable, and that permitted easy access to resources (e.g., close proximity to transit, groceries, health and social services). Positive social environments were described as involving positive interactions with others, and positive attributes that permitted women's psychosocial wellbeing. These included positive interactions wherein women felt respected, supported and appreciated. Women used words like "tight-knit" and described moments like "having tea together, just talking" to describe positive social connectedness in their neighbourhoods and home communities. Some women spoke of traditional language and culture binding community members together; they expressed a desire for their children to learn the language and culture, to be a part of that connection.

Barrier-free, effective, and culturally safe services are crucial to positively support pregnant Aboriginal women who are dealing with the outcomes of chronic stress, poverty, and negative coping. Attributes of positive services that were cited in the

interviews included being stigma-free and culturally safe, accessible, culturally appropriate (including incorporating traditional healing practices with mainstream medicine), and taking a holistic approach that addresses underlying issues. Professionals expressed a desire for more support, training and resources to better meet the needs of pregnant Aboriginal women.

## 4.4 Discussion

This study examined prenatal depression in pregnant Aboriginal women, and yielded a framework about its determinants that can inform policy and practice. With the growing interest in person-centered care in both clinical and social services (Brown, 2004; Morgan & Yoder, 2012; Stewart, 2001), we hope this framework can help educate professionals and inform changes in service systems, to better incorporate an understanding of patient or client context. We also hope that this framework can guide intervention development and evaluation, across the spectrum of downstream and upstream determinants. While the study sample was in one locale, we posit that the framework will resonate with the experiences of Aboriginal women in other parts of Canada, the United States, Australia, and New Zealand.

Grounded in an understanding of Aboriginal peoples' lived reality, our framework moves from an individual-based assessment of prenatal depression to one that explicates the structures that support or undermine mental health. Population health promotion interventions are warranted that address these structural and community-level factors. The health promotion function of public health calls for a multi-pronged, multi-sectoral approach in order to "enable people [and populations] to increase control over, and to improve, their health" (WHO, 1986, p 1). Through strategies of building healthy public policy, creating supportive environments, strengthening community action, developing personal skills, and reorienting health services (WHO, 1986), a health promotion approach focuses on action on the broader determinants of health beyond simply behavioural and biological factors. Community participation and capacity have been shown to be particularly powerful protective factors against suicide and mental health concerns among Aboriginal communities (Chandler & Lalonde, 1998; Kirmayer et al., 2000), further highlighting the value of a health promotion approach.

Taking a population health promotion approach does not mean glossing over the continued need to effectively address acute individual circumstances, which constitute most presentations faced by service-providing professionals in clinical and social service settings. Rather, it highlights the multi-pronged, multi-sectoral approach required to work along the three levels of prevention (primary, secondary, tertiary), and across the spectrum of upstream and downstream determinants. It means not overlooking the need for programs, services and policies to address the social determinants of health, racism, sexism, domestic violence, the personal trauma that often underlies addictions and mental health concerns, and the intergenerational effects of residential school trauma. However, clinical and social service professionals still have key roles in health promotion. In addition to creating culturally safe and welcoming service environments for pregnant Aboriginal women (DiLallo, 2014; Ireland et al., 2011; Kruske, Kildea & Barclay, 2006), this approach calls upon professionals to also engage in the larger political work that changing social structures will entail. Such work is also consistent with the 'advocate'

role for physicians outlined in the the CanMEDS Framework of Essential Physician Competencies (The Royal College of Physician and Surgeons of Canada, 2005).

Stigma against Aboriginal patients or clients arose as a significant theme in this study and others (Dietsch et al., 2009; Thurston, Soo, Turner, 2013; Thurston, et al., 2014). That such behaviour exists among helping professionals speaks to its structural location and acceptance. Such a dynamic in service provision may reflect limited understanding among professionals about the societal context of Aboriginal health notably the legacy of residential schools and the existence of intergenerational trauma. The Society of Obstetricians and Gynaecologists of Canada recommends better training of professionals in this regard. Additionally, it recommends acceptance of a holistic view of health and wellbeing, as embraced in traditional Aboriginal worldviews; support for community-directed programs and services; and incorporation of a focus on health promotion and prevention (Smylie, 2000). Smith and colleagues (2006) offer similar recommendations in their study of pregnant and parenting Aboriginal individuals' views on appropriate and effective health services. Such steps would require more engagement with Aboriginal communities by service systems, and thus would require institutionallevel reorientation in approach that goes beyond merely educating individual professionals. Cultural safety has become an important concept in writing about Aboriginal health. Cultural safety moves beyond 'cultural sensitivity' by focussing on power differentials in relationships. These power differentials arise due to structural inequities stemming from various sociocultural factors. In the context of serviceprovision, the nature of the relationship between service-providing professionals and patients or clients is crucial to examine. Professionals must be self-reflexive in order to

provide a culturally safe service environment; however, other issues must also be addressed, like the location, physical environment, admission policies and procedures, artwork displayed, and roles of other staff. In light of colonial practices and occurrences that have defined Aboriginal peoples' historical relationship with health and social services, lack of trust is a major concern. Accordingly, moves towards reconciliation are needed (NAHO, 2008; ANAC, 2009).

The results of this study corroborate other research that has shown the significance of social support as a protective factor against depression. Social support from the intimate partner, peers (other pregnant and parenting Aboriginal women), and mothers and grandmothers was a positive protective factor against depression. Accordingly, interventions that facilitate social support from these sources are warranted. Programs targeted to Aboriginal fathers-to-be, for instance, may help facilitate their role in positively supporting their pregnant partner, and in playing a positive role in parenting after the birth. Such programs could serve to counter the damage that colonization, assimilation and intergenerational trauma have inflicted vis-à-vis the role of Aboriginal men in families (Manahan, 2007). Additionally, Aboriginal-specific group-based prenatal and parenting programs may help Aboriginal women to meet and draw mutual peer support in healthy environments, addressing the striking lack of positive friendships reported in the interviews.

An intriguing difference noted between the women's interviews and the professionals' interviews is around the topic of birth control. Both professionals and women spoke of the challenges associated with having children at a young age (multiple women interviewed reported having their first child in their teens), of the stresses of parenting multiple children, and of the stresses associated with unplanned pregnancies. Yet, while professionals speculated about awareness of, access to, and cultural acceptability of birth control, such discussions were completely absent from the women's interviews – even though many stated that their current pregnancy was unplanned. A couple of the professionals interviewed wondered whether a cultural propensity towards early parenthood and larger families might discourage women from accessing birth control. While such a dynamic may contribute, it is also arguably important to understand how the residential school legacy has hindered open discussion about sexuality and contraception in Aboriginal communities (First Nations Centre, 2005). Furthermore, research on the topic of teen pregnancy also indicates that simply creating awareness on, and enhancing access to, birth control methods may not be enough to dissuade teen pregnancies. Interventions are warranted that help youth develop self-esteem, practise mutual respect in intimate relationships, and attain healthy views on sexuality; moreover, meaningful educational and career opportunities are also required, such that youth have a tangible reason to delay becoming parents (Young/Single Parent Support Network et al., 2000; Best Start Resource Centre, & SIECCAN, 2007). Without positive, communitybased and culturally safe approaches to addressing family planning in Aboriginal communities, the memory of colonial efforts to prevent community growth may be activated.

Aboriginal women are often stereotyped as 'bad mothers'. By contrast, the impression that emerged from both the women's and professionals' interviews is that pregnancy can often spur women to attempt to curb alcohol consumption and other harmful behaviours. This suggests that awareness and desire for change may already be

present in many affected pregnant Aboriginal women; what is required for such women is meaningful support to be successful in making the required life changes. The link between chronic stress or trauma and substance abuse is well-established; this study corroborates other research documenting the importance of interventions that address underlying negative life issues to enable long-term recovery from addictions (Elliott et al., 2005). At the population level, high rates of substance abuse among Aboriginal communities are a symptom of intergenerational trauma from the legacy of residential schools and other events of colonization; multiple women spoke about the cycle of substance abuse across generations in their families originating from relatives (often great-grandparents or grandparents) who were residential school survivors. Thus, attempts at addressing addictions among Aboriginal individuals and communities require a contextualized and trauma-informed approach in order to be effective (Roy, 2014).

# 4.4.1 Strengths, and limitations and methodological rigour

Like all studies, the *Voices and PHACES* study has limitations. We recruited women who were already patients or clients at health or social services organizations; such an approach adheres to standards of ethical research by ensuring participants had connection to resources in the event of trauma triggered by the sensitive nature of the interview questions. However, the above meant that we were unable to reach women who were not accessing any resources – and we thus potentially missed hearing the lived experiences of women facing particularly heightened marginalization. That said, we were still able to recruit and hear the narratives of a highly socially diverse group of women, achieving saturation in the data.

Because of the need for theoretical sampling, we were faced with recruitment challenges part way through the study, as we attempted to find eligible pregnant Aboriginal women of specific characteristics to address gaps in the emerging analysis. We responded to the challenges by approaching additional organizations to join the study as recruitment sites, in order to access a larger and more diverse pool of prospective participants. While this strategy proved successful, it resulted in the data gathering taking much longer than previously planned. During this extended period, several of the women we had interviewed at the start of the study period had moved or otherwise changed contact details. Similarly, some of the professionals had transferred to other employment positions. As a result, contact information they had provided at the time of their first interview was no longer valid, meaning we could not approach them about doing a member-checking interview. Despite the above, we were still able to conduct memberchecking interviews with seven of the original participants.

As the researchers in a qualitative study are themselves instruments in the inquiry, the high level of experience and diverse expertise among this study group – both the Research Team (consisting of both academic and community members) and the Oversight Committee – is a major strength of this study. The involvement of the full group in the analysis permitted in-depth and nuanced interpretation, investigator triangulation, reduction of the influence of individual bias, and the application of multiple lenses (Thurston, Cove, & Meadows, 2008), as recommended to ensure rigour and trustworthiness in constructivist grounded theory (Charmaz, 2009). The use of member-checking interviews and stakeholder focus groups following the preliminary analysis, as well as thorough attention to the existing research literature, also contributed to the trustworthiness of the analysis.

In addition to addressing obligations to conduct ethical research, research that stems from a partnership with the community is arguably more likely to be utilized. Furthermore, the trust and the practical partnerships that are built with the community during the research phase arguably facilitate the future steps required to address this population health issue, namely, the development and implementation of health promotion interventions that engage and enable the community (Vollman, Anderson & McFarlane, 2007; Minkler & Wallerstein, 2008). Accordingly, the community-based nature of the *Voices and PHACES* study is another significant strength. We hope to maintain the forged partnerships in proposed future research and action on the issue of prenatal mental health among Aboriginal women.

# 4.4.2 Conclusion

The determinants of prenatal depression in Aboriginal women are diverse and complex; like many population health issues, they warrant a multi-pronged, multisectoral approach to adequately and effectively address them at a population level. A framework grounded in the lived experience of Aboriginal women has been developed that shows the role of structural violence in prenatal depression in Aboriginal women. The framework is robust in terms of the published literature. It highlights the importance of addressing sources of chronic stress, and mitigating the effects of stress through protective buffers including positive social support. Moreover, this framework calls for a concerted effort to address the underlying societal and institutional contexts that lead to chronic stress and trauma in Aboriginal women.

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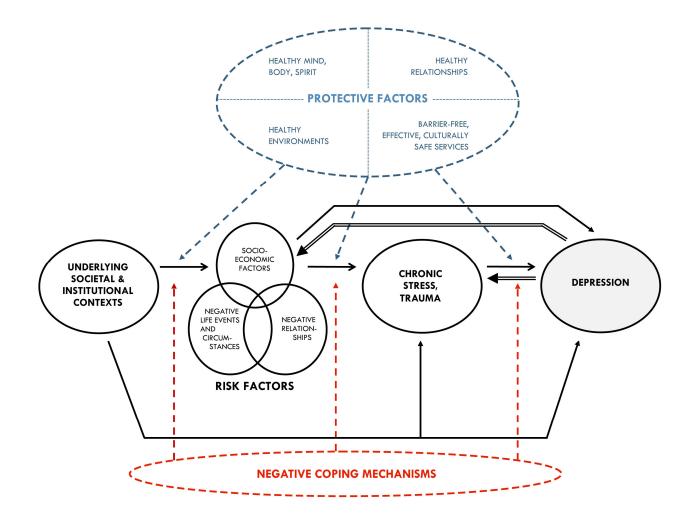


Figure 4.1: A framework for understanding the determinants of prenatal depression in Aboriginal women

# Chapter Five: Towards barrier-free and culturally-safe services for pregnant Aboriginal women: data from the Voices and PHACES study

#### 5.1 Introduction

In Canada, Aboriginal maternal-child health issues have been cited as being of particular concern (Health Council of Canada, 2011; Government of Alberta, 2010; Tough, 2009). As with Indigenous populations in countries such as the United States, Australia and New Zealand, Aboriginal populations in Canada experience enhanced health and social inequities relative to other Canadians. These disparities are linked to the effects of structural violence, social exclusion, and the legacy of colonization (Adelson, 2005; Farmer et al., 2006; Galabuzi & Labonte, 2003), and include higher chronic disease rates, lower life expectancy, and higher child mortality relative to non-Aboriginal populations (Baldwin et al., 2002; Coughlin et al., 2013; Smylie, Anderson, Ratima, Crengle, & Anderson, 2006). Additionally, there is less access to quality health care (Thurston et al., 2014), including prenatal care (Heaman et al., 2007; Johnson, Thiede, & Blewett, 2010; Kildea et al., 2012; Wu et al., 2013). Recruiting Aboriginal women to prenatal programs can be challenging, and high-risk women may not benefit significantly from specialized interventions (Tough, Siever, Johnston, 2007; Tough et al., 2006).

Pregnancy often leads to increased contact with healthcare and social service systems. However, the ability for service systems to effectively meet the needs of pregnant Aboriginal women depends on their accessibility and safety. Using data from a qualitative constructivist grounded theory study (*Voices and PHACES*) conducted in Calgary, Canada between 2012-2014, this paper examines experiences and perspectives on accessibility and safety of health and social service systems used by pregnant Aboriginal women.

#### **5.2 Background and objectives**

Levesque and colleagues (2013) define access as "the opportunity to reach and obtain appropriate health care services in situations of perceived need for care, ... resulting from the interface between the characteristics of persons, households, social and physical environments and the characteristics of health systems, organisations and providers" (p. 4). Accessibility focuses on the *characteristics of services* in this regard: "the nature of services that provide [access]" (p.4). Accessibility of services has five dimensions: 1) Approachability, such that services can be identified and reached by those requiring them; 2) Acceptability, based on social and cultural factors of prospective users; 3) Availability and accommodation, such that users can physically reach services in a timely manner, based on characteristics such as geography and hours of operation; 4) Affordability, reflecting the economic capacity of users to spend the resources (including money and time) to use services; and 5) Appropriateness, referring to the fit between services and the needs of users (Levesque, Harris, Russell, 2013). While the above conceptualization refers to health services, we are applying it to social services as well, in using this conceptualization of accessibility to frame our analysis.

In regards to Aboriginal patients and clients<sup>4</sup> in Canada, various challenges have been identified in accessing health and social services, including geography-related barriers; funding constraints; a lack of services that meet specific needs; multijurisdictional confusion about funding coverage and benefits available; a lack of autonomy and self-determination over services by Aboriginal peoples; a lack of culturally-appropriate services; and racism, stereotyping and a lack of cultural competence and cultural safety (Adelson, 2005; Marrone, 2007; Oelke, 2010; Waldram, Herring & Young, 2006).

In service delivery, there is a need to create a safe, stigma-free environment where patients or clients can feel comfortable and respected, irrespective of sociocultural identity. There is growing recognition that cultural awareness and cultural sensitivity – which focus on recognizing and tolerating differences – are inadequate for achieving such an environment; rather, they are early steps in a continuum of reflective practice (Oelke et al., 2013). Cultural competence refers to the ability of service-providing professionals to work effectively across cross-cultural settings, by incorporating patients' and clients' cultural background, beliefs and values into the care provided (NAHO, 2008; Oelke et al., 2013). Cultural safety builds on cultural competence by focusing on structural inequities stemming from various sociocultural factors, and the resulting power differentials in relationships – particularly that between service providing professionals and patients or clients (ANAC, 2009; NAHO, 2008; Oelke et al., 2013). Cultural safety after the service providing professionals and patients to the need for a critical cultural perspective, wherein culture is defined not as

<sup>&</sup>lt;sup>4</sup> Individuals receiving services in healthcare systems are generally referred to as 'patients', whereas 168

a static set of customs or beliefs, but rather "as a relational process ... influenced by issues of racism, colonialism, historical circumstances, and the current political climate in which we live" (Browne & Varcoe, 2006, p. 164), such that the execution of cultural safety in service systems requires a broader commitment to anti-oppression and decolonization approaches. Cultural competence and cultural safety are particularly important when working with Aboriginal patients and clients, given the lack of trust that stems from the fact that Aboriginal peoples' historical relationship with health and social services is entrenched in colonization (ANAC, 2009; NAHO, 2008; Oelke et al., 2013; Roy, 2014). Despite recognition of the importance of cultural competence and safety, training of service-providing professionals in this regard appears to be limited (Oelke, 2010; Oelke et al., 2013). While some training programs and related interventions have been designed and implemented in countries around the world, reviews of the published literature in this area suggest varying levels of success in effectiveness, and also a need for more rigorous and methodologically-sound evaluation methods that consider a range of meaningful outcomes (Clifford et al., 2015; Horvat et al., 2014; Truong et al., 2014). Moreover, these reviews point to a paucity of intervention literature specific to Canada; the majority of intervention literature appears to be from the United States (Clifford et al., 2015; Horvat et al., 2014; Truong et al., 2014).

Part of the challenge may be the more theoretical nature of the research literature on cultural safety, which can make practical knowledge translation more challenging. In regards to specific recommendations for creating a positive environment in health

individuals receiving services in most social service systems are referred to 'clients'. As this paper engages 169

services for Aboriginal women, the Society of Obstetricians and Gynaecologists of Canada recommends ensuring that professionals recognize the sociocultural, historical and population health context of Aboriginal peoples, including the impact of residential schools; accepting a holistic view of health and wellbeing that is consistent with Aboriginal worldviews; supporting community-directed programs and services; and endorsing health promotion and prevention (Smylie, 2000). Smith and colleagues (2006) offered similar recommendations based on their study of pregnant and parenting Aboriginal women and men.

The *Voices and PHACES* study (with PHACES standing for Prenatal Health for Aboriginal Communities and EnvironmentS) was conducted as a first step to seeking a better understanding of depression in pregnant Aboriginal women. It was initiated after noting a paucity of research specific to this population, and in recognition of the unique social and historical context of this population that would make extrapolating from research on mainstream women inappropriate. We interviewed both pregnant Aboriginal women, and health and social services professionals who work with pregnant Aboriginal women. The study had two objectives: 1) to develop a theoretical framework on determinants of prenatal depression in Aboriginal women, and 2) to examine experiences and perspectives on accessibility and safety of health and social service systems used by pregnant Aboriginal women, with the goal of identifying areas for improvement in meeting their needs. The results of the first objective have been reported elsewhere (Roy et al., 2015 [Appendix I]; Roy et al., 2017 [Chapter 4]).

with both types of service systems, both terms are used in tandem throughout the paper.

# 5.3 Methods

#### 5.3.1 Academic-community partnerships

A community-based approach was used in the study, involving academiccommunity partnerships among University of Calgary researchers, community organizations (social services agencies and health clinics) in the Calgary area, and members of local Aboriginal communities. Such an approach was taken to help ensure that the research would be valid, ethical, meaningful for knowledge translation, and respectful of the principles of Ownership, Control, Access and Possession (OCAP) in Aboriginal research (First Nations, 2007). The methods used in this regard have been discussed in detail elsewhere (Roy et al., 2014; Roy et al., 2015; Roy et al., 2017).

# 5.3.2 Study design

Grounded theory methodology seeks to develop a theory regarding a phenomenon, based on data gathered (Glaser & Strauss, 1967). The researcher seeks a rich description of the characteristics of the phenomenon and draws together the characteristics into an integrated theory (Morse & Richards, 2002). In constructivist grounded theory, the researcher seeks the standpoints of the participants, as well as the historical circumstances and social experiences that shape their opinions. A constructivist approach recognizes the existence of multiple interpretations of a situation according to social context (Charmaz, 2009; Charmaz, 2014). It was recognized that Aboriginal patients and clients have a unique social and historical context relative to non-Aboriginal patients or clients, and relative to the health and social service providing professionals who work with them. As such, we interviewed both pregnant Aboriginal pregnant women and professionals, to compare and contrast their perspectives and experiences.

#### 5.3.3 Data gathering and analysis

Pregnant women and professionals were recruited from partner community organizations. Pregnant women were eligible if they were 18 years of age or older, in the second or third trimester of pregnancy, self-identified as Aboriginal, and lived in the Calgary area. Professionals were eligible if they worked in health or social service positions in the Calgary area. Purposeful and theoretical sampling guided recruitment (Charmaz, 2009; Charmaz, 2014; Glasser & Strauss, 1967; Glaser, 1978; Strauss & Corbin, 1990; Stern, 2009). Data gathering and analysis were conducted iteratively, until saturation was reached (Crabtree & Miller, 1999; Creswell, 1998; Glasser & Strauss, 1967).

Trained interviewers conducted personal, face-to-face interviews in mutually convenient locations, averaging about an hour in length, with participants based on semistructured interview guides. Consent to participate was first sought, which could be indicated either by signing the form, or by stating verbal consent on audio-tape. Interviews were audio-recorded with participants' permission. A \$25 subject fee was given to thank participants for their time and to cover any expenses they may have incurred to participate (e.g., parking, childcare, time away from work, etc.).

After initial analysis, participants who consented to be recontacted were approached for member-checking interviews, a step in maintaining rigor in qualitative research. During these interviews, preliminary results were shared with the original participants who were interested and available for a second interview. The objective of these interviews was to seek confirmation that the analysis made sense in light of the participants' experiences and perspectives, and seek any additional reflections that participants may offer. Member-checking interviews were also audio-recorded with participants' permission, and transcribed. Participants were again given a \$25 subject fee for their time.

Following completion of member-checking interviews, a community gathering was held. Invitees included study participants, other Aboriginal community members, staff and management of clinical and social service agencies in the Calgary area, and other stakeholders. After a presentation sharing the preliminary results of the study, focus-group-style discussions were held to seek audience reactions and reflections on the results, and on possible recommendations for policies and programs.

## 5.3.4 Analysis

The software NVivo 9 (QSR International, 2010) was used for analysis of transcripts. Open, axial and selective coding were used to develop themes and concepts (Strauss & Corbin, 1990). Memoing and references to the existing literature were used to stimulate analysis (Charmaz, 2009; Charmaz, 2014). The themes emerging from the women's interviews and the professionals' interviews were analyzed separately, to account for distinct social construction between the two groups (Charmaz, 2009; Charmaz, 2014), and then compared to explore similarities and differences.

Group analysis was also conducted, involving academic and community study team members. Two group meetings were devoted to analysis, where the lead researcher (A.R.) presented results from the coding process and group members offered their interpretations.

# 5.4 Results

As the objective of this paper is to present broad insight from the experiences of pregnant Aboriginal women and professionals in service systems, specific agencies or clinics have not been named in the results. Instead, overarching themes are presented below, and have been summarized visually in Figure 5.1. As shown in this figure, the key themes can be subdivided into issues at the level of service-providing professionals, and issues in the functioning and environment of service systems themselves. These two categories intersect, as shown in Figure 5.1 by the overlapping circles; the knowledge and skills of service-providing professionals cannot be conceptualized independently of the service systems in which they work. Moreover, as also depicted in Figure 5.1, both service-providing professionals and service systems are situated within the broader societal context of Aboriginal health. Reflection on the application of these themes through specific recommendations has also been offered throughout the Results and in the Discussion.

Thirteen pregnant Aboriginal women participated in the personal interviews. As discussed elsewhere (Roy et al., 2015; Roy et al., 2017), the sample was highly diverse along characteristics including Aboriginal identity and status, age, number of children,

involvement with child welfare authorities, marital status, employment status, education, household income, and personal and family history of mental health issues. The number and type of services accessed by the pregnant women interviewed varied depending on each woman's individual circumstances. Services referenced in interviews included primary health care (family physician or general practitioner for general health issues), prenatal health care (for care specific to the pregnancy), prenatal education programs, parenting programs, women's shelters and domestic violence support programs, homeless shelters and housing support programs, programs that offered assistance to low-income families, counselling services, programs for managing addictions, and education and employment support programs. As would be expected given the recruitment method used (namely, recruitment from clinics and agencies), most women interviewed were connected with more than one service; all women interviewed were connected with prenatal health care, and most attended a prenatal education program.

Twelve service-providing professionals (11 female, one male) participated in personal interviews. Most (11 of 12) were non-Aboriginal. Participants ranged in age from about 25 years old to about 55 years old. Professions were as follows: two family support workers, a dietician, a family counsellor, a residential counsellor, three nurses, three family physicians, and one obstetrician-gynaecologist. The length of time of participants in the current employment position ranged from six months to 20 years. Number of pregnant Aboriginal women seen in a typical month ranged from zero to 60.

Eleven stakeholders attended the community gathering. Two were First Nations Elders, and one was an Aboriginal woman who had participated in the study as an interviewee during her pregnancy. The remaining attendees were either frontline professionals, or managers or administrators, from various health clinics and social service agencies in Calgary.

### 5.4.1 Approachability and appropriateness: Information, resources and support

Referral to one service by another (e.g., referral to a prenatal education program by a primary care clinic, or referral to counselling services by the criminal justice system) was one of the most common ways women connected with services. Other means of connection were self-referral (women seeking out services for themselves), word of mouth, or recommendations from friends or family members.

Some services were described as effective and meaningful in giving pregnant Aboriginal women the information, tools, resources or care they need. Women described positive interactions with health and social services workers wherein they received the practical support they sought. As one woman summarized: "The support from the workers. Just by giving me advice or giving me resources, [or referrals to other] resources that would benefit me". Other women cited counselling and addictions programs that gave them life-changing skills in coping and self-esteem, as well as programs that offered day-to-day necessities like food hampers, transit tickets and milk coupons.

Prenatal programs that offered practical information on pregnancy, childbirth, breastfeeding and parenting were cited as particularly valuable, especially when the environment was one where women felt comfortable to ask questions. One woman explained how receiving salient information helped to prepare her, and also helped reduce her anxiety as a first-time mother: Well I learned a lot ... about being pregnant, you know [you] want [to know what] you're going through, what phases you're going through, just going through topics and ... stuff that you didn't know. 'Cause I didn't know [as] a first-time mom, ... all the stuff I was experiencing was all new to me. ... [So the program] helped me understand my pregnancy, [allowed me to] ask questions. ... When you're going through all these weird phases and you don't know what's happening, you [can] think there's something wrong with your body or ... something bad is happening, but really it's just something good. (Chuckle)

In regards to group-based prenatal education programs, multiple women cited the value of networking with other pregnant women: "I got to meet other pregnant women, to hear their pregnant stories and get some advice from those who are farther along." This camaraderie was particularly significant for many of the women interviewed. As discussed elsewhere (Roy et al., 2015; Roy et al., 2017), many women lacked supportive friendships, and also had complex and challenging relationships with their own mothers and grandmothers, many of whom were residential school survivors.

# 5.4.2 Acceptability: Traditional Aboriginal culture and service provision

A few Aboriginal-specific services (both health clinics and social services agencies) are available in the Calgary area, and both women and professionals cited their existence as positive for meeting the needs of Aboriginal patients and clients. One professional interviewed, who worked at such an Aboriginal-specific service and who was Aboriginal herself, commented on how it made a difference for patients and clients:

I got a great compliment last week from a client saying that, 'I can only tell you about smudging, and ...going to a sweat lodge and ...what I was told in ceremony, [because] you would understand. Whereas if I brought this to ... a non-Aboriginal mental health therapist, they [would not understand]'. I thought that was a great compliment, you know, that, I could understand. ...

Having lived that [as an Aboriginal person myself], I know that's part of who I am.

More Aboriginal-specific services were requested by women, particularly as a way to meet other Aboriginal women with shared experiences. As one woman articulated:

I can't really think of any other Aboriginal programs that I could attend, like you know just for Aboriginals to come and be together and you know just talk and bring your babies like, there's none of that.

Other Aboriginal-specific services suggested by both women and professionals

included more Elder support, more designated spaces in clinics and hospitals for cultural

healing practices such as smudging, and more support for incorporating traditional

Aboriginal perspectives on healing into services.

It was also noted by some professionals that individual patients may have varying

levels of engagement with Aboriginal cultural practices. In offering to connect Aboriginal

patients with Aboriginal-specific resources, care must be taken not to impose

preconceived notions. As reflected by one service-providing professional at the

stakeholder gathering:

[As a service-providing professional], if [you don't have] firsthand experience in the culture and the community, you don't know how to foster it appropriately and [not] oppressively. ... One of the barriers [for us] is [not] knowing ... the [right] and wrong way to approach it. ... Better ... [training] and education on how do we do this [is important]. When we have Aboriginal clients that come to us, I always try to connect them with smudges ... and [Elders] because I think that they can [benefit] from Aboriginal spirituality. ... But [some] haven't grown up in that. ... We've had some situations where we try to connect them and then they take offence at that by saying, 'Well, just because I'm Aboriginal you think I want to go to a smudge'. ... It's still an imposition, it's still me assuming that they would benefit from that ... because they're Native. ... [It is] still like ... an oppression, like 'I'm telling you this would be good for you'. So, how do you ... make these connections and honor the culture without ... stereotyping?

Thus, while the importance of culturally-appropriate services was recognized, there was a call for better training and resources for appropriately incorporating Aboriginal cultural traditions into services, in a respectful manner that addressed diversity and individual preference.

Some of the professionals speculated about the role of traditional Aboriginal culture and worldviews in influencing compliance or adherence among Aboriginal women to mainstream treatment or therapies (e.g., antidepressant medications), and to health-related practices such as birth control and family planning. The professionals wondered if a perceived incongruence between mainstream (Western) medicine and Aboriginal conceptualizations of healing might be the reason behind trends of lower compliance or adherence among Aboriginal patients and clients. They correspondingly expressed a desire to learn how to navigate that incongruence to assist their patients and clients. Interestingly, none of the women interviewed raised the issue of birth control or family planning. Similarly, none of the women offered paradigmatic critiques of Western medicine. By contrast, multiple women shared stories of negative interactions with service-providing professionals and cited barriers to access and compliance, as discussed below.

### 5.4.3 Availability and accommodation: Barriers to accessing services

Barriers to access of services identified in interviews, by women and

professionals in both personal and stakeholder interviews, included issues not specific to

Aboriginal peoples, such as hours of operation, childcare and transportation constraints.

Women who were pursuing education or employment noted the difficulty of finding the

time to participate in programs or access resources:

Yeah, I've heard of all these [services] ... and it's good to have these but you know just having to ... find the time [is hard]. Like for me at least, going to school and working at the same time, working late at night, [it] is pretty hard. It's good to know that ... there's these resources for pregnant women but [finding time is hard].

Attending appointments scheduled during business hours was cited as a specific

example. As one woman explained:

I [go for the] latest appointment just so I don't have to take too much time off work. ... I'm sure not going to miss work [because] I'm still on probation [at work].

The constraint of childcare availability may be enhanced among women with low

social support and a lack of reliable friends or family who can help – which was the case

for several of the Aboriginal women interviewed. One woman cited how her ability to

comply with her court-ordered addictions treatment was complicated by lack of childcare.

The devastating consequence was the apprehension of her son by child welfare

authorities:

[My son] got apprehended 'cause I was supposed to do treatment and I was having complications with childcare. ... The people that were willing to watch my son weren't eligible, they weren't approved to watch my son. Then the people that were approved at the last minute, I couldn't get a hold of

them, like I was just having difficulties with childcare so I couldn't attend. I kept putting it off and putting it off, then finally it got to the point where they didn't [believe] I was taking it too seriously. [But] I was trying and I really wanted to go, but it was just that I couldn't get childcare, somebody to stay with my son while I was gone for a couple of weeks. Then it got to the point where he got apprehended.

At the time of her interview, the above woman had completed her treatment program and was awaiting a parental assessment, with the hope of getting her son back. Multiple professionals also recognized childcare availability as a barrier to seeking services and to attending medical appointments. One professional attending the stakeholder gathering suggested that widespread availability of childcare at all services (social and clinical) for families was warranted, but that funding was required:

As an organization, if we had specific, dedicated funding for childcare, I think that would be helpful. Like we have some programs where we can do that, but I think every program that serves ... mothers as clients should or could have childcare ... provided.

The need for services to be easily accessible by transit was highlighted by multiple women, who cited impediments to travel such as Calgary's cold winters, being accompanied by small children, and the physical discomforts of pregnancy: "especially being big and pregnant and tired, ... you just want to be able to get there and go back". Similarly, a need was cited for services to be available throughout the city, so that women could access resources within their local areas. As stated by one woman:

You know a lot of resources right now are way [in the other] side of town which is so difficult to get there (chuckle). ... I think there should be more places where you could go ask for help. I haven't found anything yet right now [in my area].

Professionals whose patients or clients included women from reserves outside Calgary also commented about transportation constraints for First Nations women living on reserves, which impacted ability to attend city-based specialist appointments, have bloodwork or other medical tests done, or participate in programs or services. It was suggested that transportation services that are in place are hard to access, require considerable paperwork on the part of patients or clients, and have several restrictions for eligibility.

Both women and professionals also suggested that service systems in general could be confusing and difficult to navigate for patients and clients. One woman expressed:

You have to call this number and then when I called that number, they're like oh, oh you have to call to this number and it's just like (frustrated) ah, what do I do, like why can't there just be one simple number?

Professionals at the stakeholder gathering also commented during focus groups about the complex processes and paperwork involved in order to pursue certain resources or opportunities – steps which can be daunting to those with low literacy, and/or those coping with health issues or other life challenges. They suggested that assistance in this regard might help Aboriginal women connect to existing resources and take advantage of opportunities already being offered.

Professionals also expressed an interest in knowing how to make services more accessible, and how to help patients or clients make it to appointments or programs. The issue of missed appointments came up multiple times in the interviews. A few suggested that drop-in rather than appointment-based services might facilitate attendance by Aboriginal patients and clients – particularly pregnant and parenting women.

Additionally, outreach programs were also suggested as a possible option:

[There should be] more outreach programs. Outreach programs are so good, you know, taking the resources to the communities that need it. ... It sets it up for success better. People want to stay in their communities.

## 5.4.4 Interactions with service-providing professionals

Over and above obtaining meaningful resources, information or therapies, women

cited positive interactions with service-providing professionals as critical to their

wellbeing. One woman explained:

#### Participant:

Just like support, when you're feeling like, like you have nobody. That kind of thing. Just mainly someone to talk to I think helps. 'Cause that's what I found helpful is just talking, talking about how I felt, and after talking I felt a lot better.

Interviewer: Like talking to your doctor or talking to [someone else]?

Participant:

Yeah to the doctor and to your nurse or to the ladies in a group if you're comfortable. ... Someone to just be there [to listen].

While some women described having such positive interactions in service

systems, others spoke of experiences with negative, judgmental service-providing

professionals, and also of feeling like they could not always trust professionals to

genuinely care about their needs. One woman gave an example of a time she declined

accessing services because of this distrust:

When I was fifteen I was physically and sexually abused. I suffer from severe depression from that. I wasn't diagnosed, though, because I refused to go see

a doctor. ... I didn't want to talk to a stranger, because I've had it in my head that they were only doing it for the money. They didn't really care about how I actually felt. They didn't really care that I was actually hurt.

Professionals also acknowledged the existence of racism, stigma and judgement

in service systems. They shared examples of such behaviour among their colleagues,

occurring notably behind the backs of patients or clients. One health professional gave

the following example:

There was a patient who was a young Aboriginal woman with a toddler that was crying quite a lot, it turned out to have an ear infection, and so she's sort of pacing around, it's quite a large waiting room, with the toddler. And [my colleague] comes to me, [speaking sternly], and says, "I've got my eye on that patient, they're sneaky you know" and then I realized she meant because she was Aboriginal. And she's [speaking sternly and] says "All of a sudden you'll probably see her drinking the hand sanitizer" or something like that.

Both professionals and women reflected that pregnancy enhanced the stigma

faced by Aboriginal women, who are often stereotyped as irresponsible mothers. As one

physician explained:

Sometimes ... healthcare providers ... put patients ... up to a high standard in terms of how they behave during pregnancy because of ... [the] ramifications for the [baby]. ... I think ... sometimes health care providers demonize patients [for unhealthy behaviours for which] mental health issues are a huge component. ... I think Aboriginal patients or other patients who may be in this situation are going to feel more scrutinized because they're pregnant as opposed to if they're not pregnant. ... Pregnancy is a time when [for Aboriginal women] I think potentially racism [is] more likely to take place.

A woman described her experiences in this regard:

[We] are constantly being asked ... if we're using drugs, alcohol or smoking during pregnancy. They're assuming that we are. And also the assumption that each of our children have different fathers. ... I don't see [women from]

other cultures being asked [these things] by doctors, social workers, people on the street.

Multiple healthcare workers (nurses, physicians) shared anecdotes that reflected increased scrutiny placed on Aboriginal women during the prenatal and postpartum periods, including examples of Aboriginal women being dissuaded by clinicians from breastfeeding because of an automatic suspicion of substance abuse. Participants expressed concern about the impact on the wellbeing of the patient or client of such attitudes. As one participant (a physician) stated:

Patients aren't stupid. They can recognize when someone's judging them for the circumstances they are in. ... The interaction [between service-providing professional and patient or client] is, in my opinion, key to an effective therapeutic relationship. So [when I] see these kind of underlying ... prejudiced ideas [among service-providing professionals], I think [they] have an impact on patient care.

## 5.4.5 Facilitators in the creation of positive service environments

Among service-providing professionals who were participants in the study, there appeared to be a wide variation in level of knowledge regarding upstream determinants of Aboriginal health such as colonization, residential schools, and racism. The level of knowledge reflected in interview responses did not appear to correlate with type of profession. Rather, it seemed that personal background and experience, personal interest in engaging with the issues at hand, as well as the number of Aboriginal women seen as part of current and past jobs, were more associated with the level of familiarity of a participant vis-à-vis the broader social and historical context of Aboriginal women's health. Many of the participants remarked that a better understanding of the broader social and historical context would help service-providing professionals in their field provide better care, and cited a lack of education in this regard during their formal professional training. In both the personal interviews and in the focus group discussions at the community gathering, it was emphasized that many professionals have little understanding of colonization and intergenerational trauma (or, for that matter, personal trauma). One professional, who was herself Aboriginal, exclaimed:

Colleagues that I work with ... do not know their history, don't know about the Treaties, don't know about residential school, don't know about the Sixties Scoop. Don't know about the whiskey traders. ... Alcohol use ... wasn't a part of our culture, ... it's such a big thing now because it's a learned behavior.

The manner of appropriate application of the above knowledge in serviceprovision was not always clear to professionals interviewed, however. Multiple professionals expressed difficulty in conceptualizing the notion of determinants of depression for Aboriginal women as distinct from determinants of depression for all women. This tension played out in their answers in various ways. Some participants pointed out that the main risk factors for prenatal depression (such as housing insecurity, low income, negative life events, negative relationships) and the main protective factors (such as social support) are not unique to Aboriginal women. Such factors are also seen among non-Aboriginal women who are experiencing prenatal depression. Other participants clearly recognized the unique historical and present-day social context for Aboriginal women's health at the upstream, population level, but expressed considerable discomfort in extrapolating from that knowledge when speaking of their individual patients or clients. They expressed concern around such conceptualizations being the fodder for racist stereotypes that paint all Aboriginal individuals with one brush, and that create environments tinged with stigma. They also stressed the importance of accounting for individual needs in service provision. As asserted by one physician:

Several [Aboriginal patients] actually have told me that they try not to be identified as Aboriginal when they enter the system, especially ... the hospital. ... 'Aboriginal' is always [seen as] a risk factor [in service systems]. If you checked it off, all of a sudden you're almost guaranteed a social work consult just because you're Aboriginal. ... I don't like [conceptualizing] Aboriginal [ethnicity] as a risk factor. ... It just further marginalizes. I mean, there are factors that potentially are ... more highly correlated with [Aboriginal populations, but] being Aboriginal [as such] is not the problem. ... I just think it [adds] to the stigma.

Thus, simply conveying knowledge in service-provider training about the context of Aboriginal health is inadequate, and can actually perpetuate racism and stigma in service provision. As one professional summarized: "There needs to be an action piece of it. The awareness is only one piece." To this end, professionals, both in the personal interviews and in the stakeholder focus-groups, expressed a need for better, practical, action-oriented training and resources in order to create a safe, stigma-free environment. Characteristics of such an environment cited by participants include one where patients or clients can feel comfortable and cared for:

I think it's important to establish rapport. [You want to] make sure they feel really comfortable, and ... [that] they get the impression that ... you care about them in this pregnancy.

Multiple professionals noted that, in light of historical and present-day negative experiences of Aboriginal peoples in service systems, earning the trust of Aboriginal patients or clients can be time-consuming. Putting in the time can be challenging in

systems focused on "instant results" and short-term outcomes:

Going back to [the] relationship issue, I think sometimes there's a lot of trust issues in opening that door. I think trust becomes a huge issue for [patients or clients] if they've been hurt or they've been through programs before that have not allowed them to get what they wanted out of it and they're less likely to continue to access it. ... [Also], I think everybody in today's society wants instant results and if they aren't going to see that, it's not the worth the effort for the long term gain. I think a lot of times it's a long process and people aren't willing to stick around for the long process.

The need to understand the other aspects of a patient's or client's life was also

cited as critical to tailoring an effective approach:

Understanding their whole situation [is important]. As a dietician I could make all of these fantastic suggestions ... [about their diet]. But it's definitely not as simple as [that, you need to] understand the constraints that you have to work with. ... I see a lot of women who ... have lots of other issues going on, so they're maybe just not at the point of being ready to ... work on their diet. They might have other things that they need to deal with, like for instance getting stable housing under control. ... So I might be able to just listen to them, let them talk to me, refer them to the social worker that I work with [to] get all of that under control [first].

Additionally, understanding of the broader context of an individual's life was also

cited as a helpful step for maintaining empathy and support in cases of non-compliance or

non-adherence. A consequence of failing to do so is that patients or clients may simply

cease utilizing services where they do not feel supported:

Giving them the healthiest choice but at the same time understanding that it's not the easiest choice for them, I think that's where [clients] kind of get lost and where they ... run away [because] they feel like they're being scolded. ... I'd say it's hard [for service-providing professionals], because it's ... acceptance without promoting any bad behaviors. [But] being a continual support [is important]. Especially if they're working with [the child welfare system], they need a lot of positive support because it's scary.

Understanding one's own privilege was cited as integral to professionals to understand the context of patients or clients, particularly those facing heightened difficulties. As one healthcare provider explained:

I think it's pretty easy [for service-providing professionals] to not see the whole story. [For example], you see an Aboriginal woman who doesn't show up for her regular appointments, and goes home to a partner who's abusing alcohol, and she's got chronic pain and so she takes narcotics. It's pretty easy to just say, 'Wow, what a wreck!' But she's not a wreck. ... She's doing the best she can in this much bigger picture of social and historical abuse and oppression. ... I mean, certainly people in my generation ... didn't [create] the residential schools. But I think we still need to acknowledge that if you're not Aboriginal, you have privilege in your society. You need to do the right thing and learn about the culture and learn how to be supportive, learn how to talk to people about their mental health.

Professionals also emphasized the need to not generalize or stereotype. As one

professional advised:

[Aboriginal women have] the whole spectrum experiences [so] I would say don't have any prejudged notions when you go in. Just assess everyone individually and see what their issues are and, and help them out.

To this end, there was a need identified to be aware of one's own preconceived

notions and prejudices. As stated by one professional:

Personal prejudices is a huge thing and [you need to be] aware of them. ... Not all Aboriginal women fit into any particular box. ... Some of the keys [to serving Aboriginal women include] being aware of your prejudices [and] being aware of how they affect other people.

It was suggested that Aboriginal patients and clients may feel stereotyped in the

face of screening questions for issues such as depression, domestic violence, substance

abuse or low social support. To overcome this perception and the associated stigma, it

was suggested by some professionals that screening should be implemented universally (i.e., not just Aboriginal patients or clients), with the universal nature of the screening made explicit in the preamble to questions. It was emphasized, however, that screening is only meaningful (and ethical) if the professional has the capacity to appropriately address disclosures. One healthcare professional paraphrased the fears that professionals can experience:

I'm afraid that, if I [ask a patient] 'Are you depressed?', she's going to say 'yes'. Then what the hell am I going to do [given my limited time and resources to address it]? ... It would be very daunting to open that up.

Thus, professionals require training and resources for screening to be useful including time, and connections to make meaningful referrals that meet the needs of patients and clients.

Other points raised in regards to creating a safe and stigma-free service environment included the need for training on cultural safety and related skills to extend to all staff at clinics and agencies, including those who may not directly deliver care but who nonetheless interact with patients or clients (such as receptionists or aids). Additionally, some professionals speculated that fee remuneration structures may influence the ability of professionals to have meaningful interactions with patients or clients, with the fee-for-service model for physician payment being particularly criticized. Finally, it was suggested that supporting more Aboriginal individuals to pursue careers in health and social services would also help to make service environments more welcoming for Aboriginal patients and clients.

# 5.4.6 Child welfare services

Discussion of child welfare services and policies was overwhelmingly negative. Women felt that child welfare policies were not working in the best interest of children and families. One woman described her frustrations with a system she feared was misinformed by stereotypes and focused on punishment:

I get really frustrated sometimes with the system. [Child welfare authorities are] judging me over what is written [about my past behaviour]. That's not right - they should actually get more involved with the parent and talk to them face-to-face, one-on-one, to understand what they've been through and what they're going through and why they did the things that they did in life. ... It's our kids suffering for it, for being stereotyped. ... There's nothing we can do to change [the past] but it's good to know [about it] so it can help the parents change in the future.

While recognizing the importance of protecting children from abuse or neglect,

professionals expressed similar concerns about the child welfare system not doing

enough to support parents who are struggling to care properly for their children. One

professional, a nurse, exclaimed:

It drives me nuts [that] they're willing to put a baby in foster care and pay for the foster parent to have a baby ... [but] they're not willing to give [the birth mother] a dime to help her, or to provide a safe place for mom and baby to learn and [get support]. The supports are just bad.

Both women and professionals expressed frustration at the lack of focus on

supporting families and helping to address underlying issues. Professionals, in particular,

noted how child apprehension without appropriate support simply aggravates the trauma

and mental health concerns underlying women's addictions or dysfunctional behavior,

creating a vicious cycle. One professional explained:

[These] women [need support in dealing] with the emotional aspect of losing a baby, [and support] ... to make their life better for another baby. A lot of women who have children taken away... [have more] babies to fill a void in their life. So if that baby keeps getting taken away, they're constantly trying to fill a void that's never going to be filled unless they emotionally have that void filled - whether that's [through] alcohol, drugs, other relationships, or [through] positive ways where it's filled [with positive] support [or] spiritual help. So, I think certainly [child welfare involvement] links back to depression, to [women's] social situation, and to future pregnancies.

Another professional spoke of the long-term impacts on family dynamics:

It's a learned fear if you were the person who had your children taken from you. And then you have more children, and then you're teaching them that fear. ... Instead of taking the children away, [we should] teach the parents how to parent, because you're just creating more trauma by taking these kids away, and then having the parent run through a gazillion hoops, and then get their children back. Then their children are not trusting mom anymore or dad, and then you got a whole lot of other behaviors and all this acting out and stuff, and that takes a while to settle down. ... I know in certain circumstances [child removal] has to be done, [but in other cases] ... something else has to be put in place instead of taking these children away for a year or two years.

Thus, while the need to protect children was recognized, participants felt that more needs

to be done to address the broader issues at play in families.

There was a perception among both women and professionals that Aboriginal

families may be more heavily scrutinized:

I know the majority of [my clients feel that] because they're Aboriginal women, they're targeted [by] people [who] call child services on them. (Social services professional)

I just have a perception ... [that] being Aboriginal ... may trigger people ... to lower their threshold for calling child and family services or, being concerned for child welfare. (Health professional)

I just feel like there's a lot of stereotyping going on within the foster care system or Child and Family Services. I noticed there's a higher percentage of Aboriginal kids in care than other races. That's really sad to see, because I just feel that they're judging Natives because of history. They don't really see how we are as people. ... They stereotype us just because of other people's mistakes. ... If it wasn't for [European colonizers] bringing alcohol and drugs into our society with our people back in the day, we wouldn't even know what that was. From what I was told from my granny ... is that back in the day ... we wouldn't even have to worry about our kids because our aunties, our sisters, our brothers, our cousins, our relatives, we all looked after everyone's kids. I feel kind of stereotyped against by social workers and pretty much authority figures. (Woman)

A consequence of this perception, cited by both women and professionals, was the avoidance of contact with services by pregnant and parenting Aboriginal women, for fear of child apprehension. One woman explained: "You know that's not right for them to [do], for families to go there [for help] and end up getting their kids apprehended, [but that's what happens]."

Professionals described struggling with the above dynamic in their work, but

shared examples of how they attempted to earn the trust of patients and clients. The

primary approach cited was to encourage patients and clients to work collaboratively with

professionals to address their needs, with the assurance that professionals would be

personal advocates for them should the child welfare system need to become involved.

I try to talk about depression and treatment of depression, so: 'If you're feeling isolated and you're not attending appointments and you're not taking care of yourself, that doesn't look good [in the eyes of] Child and Family Services. ... If they see how you're not taking care of yourself or your baby, not getting out of bed, feeling tired, not getting out of the house, not going to your appointments, then that's not going to look good for you. ... So talking about things early when everybody is up front and you can put those supportive things in place, it's healthier for you, it's healthier for your baby and Child and Family Services is less likely to be involved. If we talk about things openly, then I could advocate as a professional ... for you.' ... That advocacy piece is the most important. ... That, hopefully ... leaves them

more comfortable in opening up, and being up front about the kinds of things that are worrisome, ... [and] that lead to apprehensions more, more easily.

Thus, professionals attempt to reframe the fear of the child welfare system into motivation for patients and clients to reach out and seek help, and as a point around which to build relationships of trust.

# 5.4.7 Integration across systems and services (networking, referrals)

Professionals, both in personal interviews and at the stakeholder gathering, were almost unanimous that better networking is needed between services, to ensure continuity of care and to ensure that no one "falls through the cracks". Suggestions raised included having a centralized point of access for all services, and the use of electronic records that span across service systems. In the context of pregnancy programs and services, it was cited by multiple professionals that follow-up of women often ceases after the perinatal period, leaving women potentially vulnerable.

Some professionals who work at non-profit agencies raised the issue of having to compete for funding as a major barrier to cooperation with other agencies. Securing funding was also cited as a challenge given that capacity is not always present within agencies to conduct the rigorous data collection and evaluation required to be competitive in funding competitions.

Multiple professionals raised the issue that much of service delivery is oriented towards managing acute, emergency situations, such that the underlying issues in the women's lives do not generally get addressed:

A lot of times when an Aboriginal woman seeks help, it's for an acute situation, but [the help she gets] doesn't change the past history. ... There's

only time to address that acute issue. ... When you've got a 20 minute appointment ... and you're not likely to come back on a regular basis because of other [barriers], are you really going to delve into all those [underlying] issues and deal with another problem, or are you just going to address the acute issue that's happening on that day that you actually took the step to show up for that appointment?

Multiple professionals (notably physicians) spoke about how they wished they could do more in this regard, but were limited by the very specific job they had the training, capacity and limited time to do. They felt that better networking and a stronger system of referrals between services would help professionals to connect the patients or clients with appropriate help for such other issues. Additionally, it was suggested that "an overhaul of the health care system" was required, in order to focus on prevention and on the underlying issues that determine health.

# **5.5 Discussion**

Although this study was rooted in service systems in the Calgary area, the broad themes that emerged were consistent with literature concerning experiences of Indigenous peoples in other settings in Canada, the United States, Australia and New Zealand (Marrone, 2007; Oelke, 2010; Smith et al., 2006; Thurston et al., 2014; Waldram, Herring & Young, 2006). This consistency suggests transferability of the results of this analysis to contexts other than the specific agencies and clinics cited by participants in the interviews.

Structural violence is a product of "social structures—economic, political, legal, religious, and cultural—that stop individuals, groups, and societies from reaching their

full potential". Often normalized and thus "invisible", these structures yield "disparate access to resources, political power, education, health care, and legal standing [as] just a few examples" (Farmer et al., 2006, p.1686). The research on inequities in access to prenatal care consistently demonstrate that women who have historically suffered systemic and structural violence, including social exclusion or racial discrimination, also experience poor health and social outcomes. These effects include low education levels, poverty and the resultant housing and food insecurity, interpersonal violence, chronic stress, and poorer maternal and neonatal health. The above has been demonstrated in research across countries and populations, including the Roma in Central Europe (Balazs et al., 2012); non-European women in metropolitan Brussels (Beeckman, Louckx & Putman, 2010) and Italy (Chiavarin, Lanari & Salmasi, 2014); African women in Brazil (Nyarko, Lopez-Camelo, Castilla & Wenby, 2013); immigrants to the Netherlands (Choté et al., 2011); Hispanic and Black women in the United States (Cox, Zhang, Zotti & Graham, 2011; Doherty & Johnston, 2015; Gavin, Nurius & Logan-Greene, 2012; Lee, Phillips & Ohsfeldt, 2015; Roman et al., 2010); ethnic minorities in China (Lou, Gao, & Yan, 2014); and, Indigenous women in Australia (Bar-Zeev et al., 2013; Carter et al., 2002; Reibel & Walker, 2010), New Zealand (Wu et al., 2013), the United States (Johnson, Thiede & Blewett, 2010), and Canada (Heaman et al., 2007; Sheppard & Hetherington, 2012; Sutherns & Bourgeault, 2008). The social and health disparities facing Aboriginal peoples in Canada (and Indigenous peoples elsewhere) are outcomes of structural violence; results from this study in regards to the role of structural violence on depression during pregnancy have been reported elsewhere (Roy et al., 2017). As we found from these interviews, accessible and culturally safe services can buffer the

impacts of structural violence on wellbeing during pregnancy (Roy et al., 2017). However, it is also clear that a lack of accessibility and cultural safety in services are themselves acts of structural violence that carry real consequences for health and wellbeing. Similarly, the lack of adequate funding and resources to develop and implement meaningful services – cited repeatedly in the interviews - is also arguably an act of structural violence, given that patients and clients from marginalized groups such as Aboriginal peoples are disproportionately harmed from the lack of effective supports. As argued by Levesque and colleagues (2013), "defining access as an attribute of services emphasises the fact that health services should respond to the population's characteristics to ensure the people's capacity to use the services when facing need for care" (p.7). Thus, commitment, investment and action are required to revamp services to meet needs.

Mental health issues, addictions and a history of trauma are often correlated (Elliott et al., 2005). Pregnancy may galvanize positive life changes and present new opportunities for intervention around these issues. A positive, loving, accepting environment in which a pregnant woman's strengths are recognized and complimented, and in which her pregnancy is celebrated, can go a long way in promoting good mental health during pregnancy. Taking a positive, culturally safe and strengths-based approach in service-provision is thus recommended. Aboriginal women may be at increased risk for mental health concerns (Bowen et al., 2014). A number of studies regarding prenatal mental health in the general pregnant population have called for the implementation of routine screening of *all* pregnant women for symptoms of depression and anxiety (Milgrom, & Gemmill, 2014; Stuart-Parrigon & Stuart, 2014). While the current

guidelines of the Canadian Task Force on Preventive Health Care do not support universal screening, they acknowledge that their conclusion is based on weak evidence (Canadian Task Force on Preventive Health Care et al., 2013). As raised in the interview data, universal screening could decrease concerns around stereotyping Aboriginal women. Similarly, implementing screening practices for *all* women about domestic violence, social support, substance use, etc. – and explaining to patients or clients at the time of screening that these are routinely asked of all women – would also increase the comfort level of both practitioners and patients or clients around these sensitive topics. Screening must, however, be accompanied by the availability of appropriate, culturally safe services to address disclosures (Milgrom, & Gemmill, 2014).

In terms of treating clinical depression in pregnant Aboriginal women, psychotherapeutic approaches should be applied in ways that reflect an understanding of context. Recognition of what is culturally appropriate, recognition of intergenerational trauma and the legacy of colonization, and recognition of multiple sources of personal trauma, for example, are all important in order for counselling to be successful (Kirmayer et al., 2000; Roy, 2014).

As described in the results, Aboriginal-specific group-based prenatal and parenting programs may help Aboriginal women to meet and draw mutual peer support in healthy environments, addressing the striking lack of positive friendships reported in the interviews. Multiple women and professionals suggested doing an Aboriginal version of Best Beginnings, a prenatal education program offered by Alberta Health Services (2015). One professional mentioned a program called Centering Pregnancy that she had run with immigrant women, and suggested that a version adapted for Aboriginal women might work well. Centering Pregnancy is a group-based model of prenatal care; women are placed in groups for prenatal assessments and prenatal education, and the program is inherently relationship-focussed. The latter enhances social support for pregnant women who meet as a group; it also counters the hierarchical nature of traditional prenatal care, involving only the individual patient and the healthcare provider, thereby promoting empowerment (Massey et al., 2006). Prenatal programs modelled around Centering Pregnancy have been implemented in Calgary since 2008, with favourable reactions from both pregnant women and healthcare providers, as well as positive outcomes (McNeil et al., 2012). A 2011 Health Council of Canada report on promising practices for Aboriginal maternal-child health cited Centering Pregnancy as a promising practise (Health Council of Canada, 2011); modifying the program with an Aboriginal focus may thus hold potential.

It was noted by some professionals that individual patients or clients may have varying levels of engagement with Aboriginal cultural practices. Indeed, many Aboriginal individuals, whether urban-situated or from reserves, have lost their traditions due to assimilationist policies (Adelson, 2009; Long & Curry, 1998). For many, however, healing "connotes a recuperation of Aboriginal awareness, which is becoming increasingly synonymous with Native spirituality" (Adelson, 2009, p. 276). This interest has increased since the work of the national Truth and Reconciliation Commission (TRC) which toured Canada from 2008 to 2015 gathering stories from survivors of residential schools (TRC, 2015). When non-Aboriginal providers offer to connect Aboriginal patients with "cultural" resources, however, it may be received as stereotyping, as discussed earlier. In Aboriginal-specific services, however, the conversation about what

fits an individual's needs can take place within a shared history, the specifics of which can be negotiated on safe ground. DiLallo (2014) describes one such service where "consistent and coordinated" care is provided by professionals with extensive cultural competency training so that "women often come to the see the prenatal nurse because they trust her, feel more comfortable with a woman doing physical examinations and believe in her genuine care and concern for their well-being because of an ongoing relationship with the team" (p.43). The importance of Aboriginal-specific services in urban settings was reflected in this study's data, and is also exemplified by friendship centres, of which a network of 118 exists in Canada (NAFC, 2015). In a study in British Columbia, women in one urban setting described the local friendship centres, as safe places run by Aboriginal people, where service-providing professionals could be trusted (Kurtz et al., 2008). In Australia, Dietsch et al. (2011) identified incorporation of peer and kinship support as ways of not only increasing the safety and efficacy of services for pregnant Aboriginal women, but also building community governance and support. The latter is a recommendation echoed by several authors (Burbank, 2012; DiLallo, 2014; Kurtz et al., 2008; Long & Curry, 1998; O'Neil et al., 1998).

Several availability- and accommodation-related barriers to accessing services were raised in this study's data. Specific solutions require further research, and also a contextualized approach tailored to individual agencies or clinics. Given the concerns expressed around hours of operation (from women's interviews) and high rates of missed appointments (from professionals' interviews), options that may be considered include having longer hours of operation (including evenings and weekends), and having services that are drop-in rather than appointment-based. Moreover, additional targeted research is also warranted to more closely examine the underlying reasons for missed appointments among Aboriginal patients and clients, with the goal of developing concrete actions to address those issues.

Better transportation arrangements may assist patients or clients to access services, particularly for women living on reserve who need to access services in the city. Childcare considerations are also important for pregnant and parenting populations seeking services. Programs where the service-providers go to women's homes and/or communities might be considered.

Given concerns expressed around patients or clients 'falling through the cracks' between referrals, consideration is warranted of procedures to follow up women and ensure continuity of care across referrals. Suggestions offered in the professionals' interviews included ideas like having a single point of entry (i.e., centralized access to services) to enable follow up, and the use of electronic records that 'travel' with the patient or client. Further research to examine possible solutions is required. The need for better networking between services, within and across the various health and social service sectors, came up repeatedly in interviews. Many of the professionals expressed frustration about the current systems that remain fairly fragmented in practice. Better networking, coupled with a stronger system of referrals, may allow women to receive more holistic support. Other institutional barriers and reasons for 'falling through the cracks' also need to be identified and addressed.

While the term 'patient compliance' has been widely critiqued for its negative, stigma-laden and paternalistic connotations, it remains in common use both within clinical contexts and in the research literature (Vermeire et al., 2001); accordingly, we have used 'compliance' in tandem with the more favourable term 'adherence' in this paper. Factors influencing adherence are multiple, diverse and complex (Vermeire et al., 2001). While many of the themes hailing from the women's interviews matched the themes hailing from the professionals' interviews and focus-group discussions, a key area of difference, as cited earlier, was the attribution by multiple professionals of cultural norms and traditional worldviews as a key explanatory variable for non-adherence by Aboriginal patients and clients. By contrast, none of the women interviewed made that attribution, nor offered explicit paradigmatic critique of Western medicine. There are various possible reasons for the absence of this theme in the women's interviews. Firstly, as all of the women were urban-based, immersion in traditional culture may not have been as strong as had they been reserve-based. The second possibility is that women may have been hesitant to raise such reflections with our interviewers, some of whom were non-Aboriginal. The third possibility is that congruence with traditional culture may be perceived as relatively less significant among explanatory variables in the eyes of patients and clients, when considered in the context of service systems where racism, racialized sexism, stigma, judgement, and barriers to access remain grave concerns. Undoubtedly, culturally-appropriate services are critical, and the above hypothesis should not be interpreted as contrary to the well-established need to offer culturally-appropriate services for Aboriginal patients and clients. Services that are congruent with Aboriginal worldviews are more likely to be effective in promoting healing. Moreover, given that part of the assault of colonization was the attempted destruction of Aboriginal traditions and cultural identity, the provision of such services is a powerful step in decolonizing service systems and in promoting reconciliation (Kirmayer et al., 2000; Roy, 2014).

However, the risk of tokenism is high when 'cultural differences' are made the exclusive focus of efforts to reframe service systems. Furthermore, focussing on patient-level factors (such as cultural beliefs) to explain poor outcomes instead of system-level factors (such as safe and supportive service environments) can enhance stigma against patients or clients (Thurston et al., 2014). The concept of 'culture' is complex and dynamic, and involves the intersections of historical, economic, social and political aspects and experiences of a group; it is arguably simplistic and stereotypical to reduce 'culture' to a static phenomenon revolving around traditional customs and norms (Smye & Browne, 2002; Browne & Varcoe, 2006). Such a narrow definition is also problematic when it is used to explain the poor health and social outcomes of ethnic minority groups, by pointing to 'cultural' conflict with mainstream approaches to health and wellbeing. Such an approach racializes problems, pathologizes ethnic groups, and enables evasion of difficult conversations about oppressive dynamics in service systems and in society more broadly (Smye & Browne, 2002; Truong et al., 2014). Indeed, the above is at the heart of the distinction between 'cultural sensitivity', which exoticizes and patronizes 'the other', and 'cultural safety', which acknowledges the power hierarchies in place within service systems which can impede recovery and healing of patients and clients (ANAC, 2009; NAHO, 2008; Oelke et al., 2013). Indeed, Metz and Hansen (2014) argue that training of service-providing professionals should move beyond cultural competence to develop "structural competence" - that is, how to bring an understanding to the care of the patient or client of the "economic and political conditions that produce and racialize inequalities in health" (p.127) through structural violence, such that "culture' and 'structure' are mutually co-implicated in producing stigma and inequality" (p.128).

The fact that many healthcare and social services professionals have limited knowledge or understanding of the history of colonization, of residential schools and its intergenerational impacts, and of issues such as racism and sexism, were discussed in both the professionals' personal interviews and in the community gathering focus-group interviews. In this regard, a theme that emerged from the analysis of the interviews was that of a tension between individual-level service provision and population-level understanding of Aboriginal health. Better training on how practitioners should apply the latter to the former may help. A population-level understanding of Aboriginal health allows a comprehension of context for the higher rates of health and social problems in Aboriginal communities. It should not be used to judge or stereotype individual patients or clients, though it may offer context on some of the problems that individual patients or clients may be facing.

As cited here and as discussed in further detail elsewhere (Roy et al., 2015; Roy et al., 2017), this study documented underlying trauma (both personal trauma, and intergenerational trauma) in the lives of Aboriginal women accessing service systems. As discussed above, various professionals spoke of the need to acknowledge and address this trauma, but struggled with how to properly do so. The approach of trauma-informed care seeks to ensure that "service delivery is influenced by an understanding of the impact of interpersonal violence and victimization on an individual's life and development" (Elliot et al., 2005, p 462). Trauma-*specific* care is focussed on addressing the trauma itself; the timing of such interventions in patient or client treatment plans often must be balanced with considerations of acute stabilization of physical health, mental health or self-harming behaviour. By contrast, the goal of trauma-informed care is that "every

interaction [in the service system] is consistent with the recovery process and reduces the possibility of retraumatization" (p 462); trauma-informed care is thus a system-level characteristic. Trauma-informed care, cultural (and structural) competence and cultural safety are all intersecting approaches that seek to incorporate an understanding of life context into the care of patients and clients. In this regard, these approaches intersect with person-centred care (also conceptualized as patient-centered or client-centred care, depending on the field) – an approach to service delivery which seeks to take a holistic and contextualized approach to patient or client needs, in collaboration with the patient or client, and on the basis of an enhanced relationship with the patient or client (Brown, 2004; Morgan & Yoder, 2012; Stewart, 2001). Such an approach has been recognized as integral to service provision by major professional bodies in medicine, nursing and social work (Canadian Association of Social Workers, 2008; Canadian Medical Association, 2007; Canadian Nurses Association, 2010; Institute of Medicine, 2001; Royal College of Physician and Surgeons of Canada, 2005).

While cultural and structural competence, cultural safety and trauma-informed care should be applied in all service systems, their need in the child welfare system is particularly critical, as highlighted by the highly negative perceptions of the system in this study's interview data and in other research (Bennet et al., 2005; Mandell et al., 2007; Trocmé et al., 2004). The history of seizure of Aboriginal children for residential schools and during the "Sixties Scoop" era of child welfare, and the continued overrepresentation of Aboriginal children in child welfare services, contribute to deep distrust among Aboriginal communities of the child welfare system (Bennet et al., 2005; Mandell et al., 2007; Trocmé et al., 2004). Both provincially and nationally, a

disproportionate number of children in child welfare systems are Aboriginal. The reasons for this overrepresentation are many (Trocmé et al., 2004), and rooted in legacies of colonization (Bennett et al., 2005; Mandell et al., 2007). In Alberta, Aboriginal persons account for about 3% of the province's population; yet, First Nations children make up 64% of the children in care (Alberta Child Intervention Review Panel, 2010). Bennett and colleagues (2005) eloquently paint a picture of loss: "from the Missionaries and residential school policies, to the implementation of ill-fitting mainstream child welfare programs and the Sixties Scoop, Aboriginal peoples lost generations of their children to the colonial systems" (p. 26). Systemic change is required to overcome this distrust and ensure that the needs of Aboriginal families are meaningfully met – including by addressing the underlying issues that lead to child apprehension. The finding is alarming that pregnant Aboriginal women are hesitant to access services – including prenatal care - due to fear of child welfare involvement. Alberta is one of many jurisdictions with mandatory reporting laws for suspected child abuse or neglect, the definition of which includes a home where intimate partner violence may be witnessed (Alberta Human Services, 2015). It is acknowledged that this legislation is in place with the critical goal of protecting children in danger; however, consideration is clearly required of ways to mitigate the unintended consequence of deterring marginalized women from utilizing support services. Further research and action are warranted. Participatory Action Research (PAR) may be a particularly meaningful way to examine this issue, given PAR's focus on finding and executing solutions grounded in local context, and the simultaneous focus on individual and community empowerment through the research approach (Baum, MacDougal & Smith, 2006).

Much of the literature on cultural safety places the onus on frontline professionals - such as physicians, nurses and social workers - to create culturally safe service environments (NAHO, 2008; Smye & Browne, 2002). This focus is not inappropriate given the centrality of the relationship between the professional and the patient or client to cultural safety. However, as reflected in Figure 5.1 and as argued by others (Oelke et al., 2013; Truong et al., 2014), professionals are embedded in both the societal context and the context in service environments; these contexts influence the capacity of professionals to succeed in this regard. The need for practical, application-based training of professionals was emphasized in this study's data, as was the need for changes to the broader service environments to make them more supportive of such an approach with patients or clients. It is the experience of multiple members of the research team, who work at the frontlines of healthcare or social service systems, that training of serviceproviding professionals needs to include concrete steps that can be followed in the context of the work that they do (e.g., training on how to communicate better and how to frame questions in an appropriate way, specific ways or opportunities to incorporate the patient's or client's context into care plans, etc.). If simple, concrete, actionable steps are not offered as part of education on these issues, service-providing professionals may be left feeling uncomfortable, ill-equipped or defensive. Training should address their specific concerns around how to pragmatically execute culturally and structurally competent, trauma-informed and culturally safe care. For example, there may be a fear among professionals of coming across as discriminatory if questions to patients or clients appear to correlate with stereotypes. Thus, training on communication is essential, particular on how to broach sensitive topics. Additionally, as discussed in the results,

there may a hesitance on the part of professionals to ask about life issues, because they are not necessarily trained or prepared to address disclosures if/when they occur. Thus, better training on the response to disclosures, and better networking between resources (for referrals), are warranted. Stronger referral networks is an example of a system-level change that is required, in order to support professionals in having culturally safe, trauma-informed and person-centered interactions with their patients or clients. Systemlevel changes in service delivery that would allow increased interaction time between professionals and patients or clients (e.g. by allowing longer appointments), would also enhance the capacity of professionals to implement cultural safety in practice. Limited time as a barrier to person-centered care was a strong theme in this study's data, and consistent with other research on professionals' experiences (Weissman et al., 2005).

Finally, multiple professionals spoke about how much of service-delivery is oriented towards managing acute, emergency situations, such that the underlying issues in the women's lives are not always addressed. Given the key role of the social determinants of health, interventions that address the underlying sources of chronic stress in women's lives are warranted. Moreover, the underlying societal context that drives such issues is also important to address – including domestic violence, racism and sexism, and intergenerational trauma. Ultimately, meaningful and enduring primary prevention necessitates targeting these upstream structural and systemic factors through population-level programs and policies.

#### 5.5.1 Strengths, limitations and methodological rigour

We were able to recruit, and hear the narratives of, a highly diverse group of pregnant Aboriginal women, service-providing professionals and other stakeholders. To adhere to standards of ethical research wherein participants must be assured connection to resources in the event of trauma triggered by sensitive interview questions, we recruited women who were already patients or clients at health or social services organizations. The above meant that we were unable to reach women who were not accessing any resources, which may have limited our ability to capture the most severe of barriers to access facing some Aboriginal women. On the other hand, the exposure of the women in the sample to multiple agencies and clinics allowed us to hear highly informed perspectives on the question of barriers and facilitators to service access and utilization.

The incorporation of professionals' perspectives is also a strength of this study, by permitting greater understanding of barriers and facilitators faced by professionals in delivering services that are accessible and safe. Much of the existing research literature on cultural safety, for example, focusses on patient or client experiences, and on theoretical development. Research geared towards knowledge translation requires engaging with the perspectives of those on the frontlines, and also incorporating a pragmatic lens to offset the abstract nature of the theoretical literature on this topic. The points reflected in Figure 5.1 offer concrete areas to target in further research and action, aimed at knowledge translation. These points are also a contribution to the broader effort of shifting discourse around cultural safety to more concrete, practical recommendations.

Qualitative research is inherently inductive in nature, which carries with it limitations on declaring generalizability, even when steps towards methodological rigour have been taken. Future research to address these limitations might involve using quantitative hypothesis-testing methods to assess the generalizability of points in Figure 5.1 to specific service settings, service types, professionals and patient or client populations.

In regards to methodological rigour, a major strength of this study is the high level of experience and expertise among the diverse members of the study team – critical particularly for qualitative research, wherein researchers are themselves instruments in the inquiry. As recommended for trustworthiness in constructivist grounded theory (Charmaz, 2009; Charmaz, 2014), the involvement of the full team in the analysis permitted the application of multiple lenses to facilitate investigator triangulation, depth and nuance in the interpretation, and reduction of individual bias (Thurston, Cove, & Meadows, 2008). The trustworthiness of the analysis was also enhanced through the use of existing research literature, member-checking interviews and stakeholder focus groups following the preliminary analysis.

The community-based nature of the *Voices and PHACES* study is another significant strength. In addition to addressing obligations to conduct ethical research, research that stems from a partnership with the community is arguably more likely to be utilized. Furthermore, the trust and the practical partnerships that are built with the community during the research phase arguably facilitate the future steps required to translate the key findings of the research into meaningful action.

# 5.5.2 Conclusion

Pregnancy is meaningful point for intervention on a range of health and social issues. In addition to yielding increased contact with health services, pregnancy can also be a potent motivator for positive life changes, as found in this study (Roy et al., 2015; Roy et al., 2017) and in other research (Smith et al., 2006). However, this study's results also suggest that stigma, judgement and fear of child welfare authorities can dissuade pregnant Aboriginal women from accessing services. Thus, in order to capitalize on the opportunities for intervention offered by pregnancy, health and social services systems need to address the above fears, as well as other access barriers highlighted, in order to successfully facilitate access and benefit.

This study supports other research indicating the critical need for cultural safety in service systems. By drawing attention to the complex social, economic, historical and political contexts of Aboriginal peoples, a cultural safety approach to Aboriginal health is inherently ecological in nature. The results of this study, as depicted visually in Figure 5.1, suggest that an ecological perspective is also warranted for understanding service systems themselves. Notably, this study highlights the complexities of implementing cultural safety in practice, particularly for frontline professionals who must work within the constraints of their training and of the broader system and societal environments. Further research and action is thus required to support professionals in creating barrier-free and culturally safe services that meet the needs of Aboriginal peoples.

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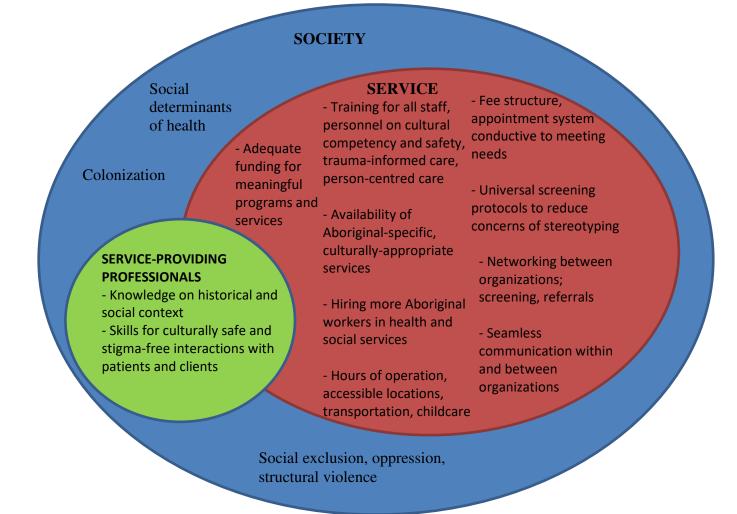
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**Figure 5.1**: Addressing barriers to access and a lack of cultural safety in health and social service systems for pregnant Aboriginal women.

#### **Chapter Six: Discussion**

Using data from two studies, and through results presented in three academic manuscripts, this multi-method dissertation had two objectives: 1) To understand the risk factors, the protective factors and the social context of prenatal depression in Aboriginal populations, with a particular focus on the underlying societal and institutional context of Aboriginal women's health and wellbeing; and 2) To conceptualize barriers to accessibility and safety in service-provision for pregnant Aboriginal women. Each of the three results manuscripts presented detailed discussions and conclusions that situated results within existing knowledge, and also reflected on strengths and limitations of the study designs and analyses. While key points in this regard are summarized again below, this concluding chapter will additionally offer reflections integrating across the three manuscripts and two studies, and will discuss key findings and conclusions of the multimethod dissertation as a whole.

# 6.1 Summary of contributions

Overall, this dissertation offers a number of contributions to expand the existing research literature and enhance our understanding of Aboriginal women's mental health during pregnancy, and of Aboriginal women's experiences and needs in healthcare and social service settings. In addition to detailed discussion of results offered in each of the results manuscript chapters (Chapters 3, 4, 5), key contributions are reiterated below:

As noted in the Introduction (Chapter 1), very little research has been previously done on the topic of prenatal depression in pregnant Aboriginal women, and a comprehensive framework on determinants was found to be lacking. This dissertation offers such a framework, as the product of its first objective; this framework may be used by researchers, practitioners, and decision-makers. Additionally, this dissertation addressed two of the four recommendations identified by Bowen and colleagues (2014) to expand research on the topic of Indigenous women's perinatal mental health: Firstly, it offers insight into the lived experiences of Aboriginal women in regards to their perinatal mental health. Secondly, the analyses contribute to building the evidence base required for the development of meaningful practices for researchers and practitioners working with pregnant and parenting Aboriginal women, through research conducted collaboratively with Aboriginal peoples through academic-community partnerships.

As also noted earlier, the limited previous research on prenatal depression in Aboriginal women and in other ethnic minority women in Canada has focussed largely on downstream, individual-level factors such as low income or education- and, in the case of ethnic minority women, migration status. By explicating upstream societal drivers such as racism, racialized sexism, social exclusion and structural violence, this dissertation offers insight on population health promotion intervention points that can facilitate primary prevention. Moreover, a better understanding of societal context can allow for the development of programs, services and policies that meet the unique needs of Aboriginal and other racialized minority women.

In regards to the second objective of the dissertation pertaining to accessibility and safety of services, this dissertation enhances understanding of pregnant Aboriginal

women's experiences in service systems; it also conceptualizes both barriers and potential solutions at the level of service systems vis-à-vis their ability to meet Aboriginal women's needs. Moreover, this dissertation incorporates insight from service-providing professionals' lived experiences in frontline service delivery, and focusses on the delineation of practical intervention points to enhance accessibility and safety of services. In so doing, this dissertation contributes a knowledge-translation focussed perspective, to an area where much of the existing literature is focussed on patient and client perspectives and on theoretical considerations.

# **6.2 Additional reflections**

To fulfill both objectives, this dissertation engaged with factors spanning the full spectrum between societal (structural) and individual, and between distal (upstream) and proximal (downstream). In so doing, the goal of the dissertation was to integrate pertinent factors together into frameworks or conceptualizations that both reflected the complex interrelations between factors *and* identified possible opportunities for intervention. Both the theoretical framework produced in Chapter 4 from the qualitative *Voices and PHACES* data, and the conceptual model hypothesized for the analysis of the quantitative *All Our Babies* data in Chapter 3, show the factors organized in pathways leading to the outcome of interest (namely, depression). Some may wonder why such a linearized visual presentation was chosen for determinants that collectively are clearly ecological in nature. Such a form was chosen because it facilitates the identification of points of possible intervention along pathways for primary, secondary and tertiary prevention; the

intent in choosing such a form was thus to increase the practical utility of the framework for stakeholders involved in knowledge translation.

The sheer richness of the interview data collected through the *Voices and PHACES* study allowed its data to be used to address both objectives of this dissertation. While the two objectives intersect insofar as they flow from the lived experiences of pregnant Aboriginal women, the objectives are distinct enough to warrant presentation of study results as two separate manuscripts. While accessibility and safety of services is represented on the theoretical framework of determinants produced as part of the first objective, doing a separate analysis as a stand-alone manuscript allowed more in-depth examination of service systems with a focus on identifying areas for improvement in meeting needs.

The determinants of prenatal depression in Aboriginal women are diverse and complex; like many population health issues, they warrant a multi-pronged, multi-sectoral approach to adequately and effectively address them at a population level. As can be seen in the theoretical framework produced from the Voices and PHACES study data (Figure 4.1 in Chapter 4), the points along the pathways at which the negative coping mechanisms can exacerbate development of depression, are also the points at which protective factors can act to buffer the development of depression. Thus, despite the complex aetiology, scope for intervention and prevention does exist. As already well-established in the depression literature (Roy & Campbell, 2013; Roy & Roy, 2017; Swaab, Bao, & Lucassen, 2005), chronic psychosocial stress is a key determinant. The role of stress was apparent in analyses of both the qualitative *Voices and PHACES* data and the epidemiological *All Our Babies* data. Reduction of sources of life stress as well as

positive means of coping with stress, are particularly potent strategies for the treatment and prevention of depression. In regards to reduction of sources of life stress, programs and policies that address the social determinants of health may help address socioeconomic stressors and negative life events or circumstances. In regards to positive means of coping with stress, social support featured prominently as a moderator (protective buffer) in the results of both studies, supporting existing literature on depression (Southwick, Vythilingam, & Charney, 2005; Santini et al., 2015) and representing a relatively modifiable factor to target in programs and services.

As discussed in Chapter 5, a few professionals commented during the Voices and *PHACES* interviews that risk factors such as low education, unemployment or underemployment, financial insecurity, food insecurity, housing insecurity, and issues such as domestic violence, are not unique to Aboriginal women; their existence in any pregnant woman's life would put her at risk for prenatal mental health concerns. However, moving from an individual-level lens to a population-health lens directs attention to the higher prevalence of such risk factors among Aboriginal populations relative to other groups in Canada, and to the underlying societal context that drives such disparities. Ultimately, socioeconomic factors such as the ones listed above, and the corresponding psychosocial stress generated by them, are mediators of the effects of structural violence - as found in the results of both studies in this dissertation. Moreover, members of marginalized populations face unique sources of stress related to social exclusion, that go above and beyond stress from socioeconomic disadvantage; these include constant exposure to discrimination, disrespect, unfair treatment, and other barriers that impede full economic, social and political participation (Galabuzi &

Labonte, 2003; Sue, 2010). These issues were identified in the results of the *Voices and PHACES* study, and are a plausible explanation for the robust association between race and depressive symptoms that persisted in the analysis of the *All Our Babies* epidemiological data even after adjustment for socioeconomic and psychosocial stress variables. Aboriginal women are at the intersections of multiple axes of oppression, including race (reflected in both the *All Our Babies* data and the *Voices and PHACES* data), gender (reflected in the *Voices and PHACES* data) and Indigeneity (reflected in the *Voices and PHACES* data). Meaningful and enduring primary prevention necessitates targeting these upstream structural and systemic factors through population-level programs and policies.

Moreover, an understanding of societal context is also critical to effectively addressing downstream, proximal factors, as well – both at the population and individual levels. The latter would involve tailoring clinical and social services for pregnant Aboriginal women to be culturally appropriate, culturally safe, and trauma-informed, and to explicitly reflect an understanding of the dynamics of intergenerational trauma, racism and sexism in the lives of Aboriginal women. The *Voices and PHACES* results pertaining to service systems, presented in Chapter 5, presents compelling indication for the need for cultural competence, structural competence, cultural safety, trauma-informed care and person-centered care in health and social services. The data further highlight that incorporating the above into service systems involves more than merely enlightening individual professionals; rather, it necessitates a multi-pronged approach that combines practical, application-based training of professionals with changes to service systems themselves.

The role of cultural identity and cultural practices as protective buffers was clear in the Voices and PHACES study results, and supports other research (Aboriginal Healing Foundation, 2006; Kirmayer et al., 2000; Roy et al., 2015) that show their value in interventions aimed at health and wellbeing of Aboriginal individuals and communities. Health and social services that are congruent with Aboriginal worldviews are more likely to be effective in promoting healing. Moreover, given that part of the assault of colonization was the attempted destruction of Aboriginal traditions and cultural identity, the provision of such services is a powerful step in decolonizing service systems and in promoting reconciliation (Kirmayer et al., 2000; Roy, 2014a). However, provision of services congruent with traditional Aboriginal cultures is only one component of creating service systems that meet the needs of Aboriginal patients and clients. Indeed, the risk of tokenism is high when 'cultural differences' are made the exclusive focus of efforts to reframe service systems. Furthermore, focussing on cultural beliefs (a patient-level factor) to explain poor outcomes instead of system-level factors (such as safe and supportive service environments) can enhance stigma against patients or clients (Thurston et al., 2014). As highlighted in Chapters 4 and 5, such explanations were speculated by some professional in the Voices and PHACES interviews, to account for low engagement with birth control and family planning practices and for poor adherence to treatments and therapies among Aboriginal patients and clients. Pointing to 'cultural' conflict with mainstream approaches to health and wellbeing to explain the poor health and social outcomes of ethnic minority groups is problematic; such an approach racializes problems, pathologizes ethnic groups, and enables evasion of difficult conversations about oppressive dynamics in service systems and in society more broadly (Smye & Browne,

2002; Truong et al., 2014). As argued by Richardson and Stanbrook (2015), "a narrative of polarized paradigms ... is unhelpful and misleading" (p. 162). While their argument was presented in the context of the recent case of the two First Nations girls in Ontario who refused chemotherapy for highly treatable leukemia, it holds true for understanding Aboriginal experiences in health and social services more broadly. As they subsequently state (and which can be equally applicable to social services):

To make medical treatment acceptable to our Aboriginal patients, the health care system must earn their trust by delivering respect. We must ensure that our Aboriginal patients, their families and communities feel welcome, are comfortable self-identifying as Aboriginal and do not fear judgment based on stereotypes. (p. 162)

## 6.3 Strengths and limitations

The strengths and limitations of the study designs and analyses of both the *All Our Babies* and the *Voices and PHACES* studies have been presented in the manuscripts of Chapters 3, 4 and 5, and are summarized briefly once again as follows:

Limitations of the *All Our Babies* study include possible selection bias based on recruitment specifically through services and the exclusion of women unable to speak English, possibly leading to the exclusion of more marginalized women. Limitations of the secondary analysis conducted as part of this dissertation include its cross-sectional nature, limiting conclusions about causation; the vague wording of the discrimination item in the survey questionnaire, limiting assessment of discrimination experiences; and the small numbers of women in specific ethnic groups (especially Aboriginal groups), limiting the ability to conduct separate analyses due to concerns of Type II error. Strengths include the large sample size; the adequate variability along key sociodemographic and socioeconomic variables to analyse their effects; and the use of stepwise regression modelling to assess pathways relevant to understand for designing meaningful interventions.

Limitations of the Voices and PHACES study include the inability to access women not attached to services, potentially missing the perspectives of those who may be especially marginalized; the lack of inclusion of women under the age of 18 years, thereby missing first-hand accounts of the experiences of pregnant Aboriginal adolescent women; and, the unanticipated delays in study timelines, leading to loss of contact with multiple women and professionals and thus a more limited number of member-checking interviews completed than planned. Strengths include the diverse samples of both women and professionals recruited through theoretical sampling, enabling thorough saturation in the data; the community-based approach involving academic-community partnerships and a clear project governance structure, to assure validity, address ethical considerations, and enhance applicability of the research to future knowledge translation; the high level of experience and diverse expertise of study team members; and the groupanalysis approach used to interpret the data collected. The involvement of the full study team (academic and community research team members, and Oversight Committee members) in the analysis permitted in-depth and nuanced interpretation, investigator triangulation, reduction of the influence of individual bias, and the application of multiple lenses (Thurston, Cove, & Meadows, 2008); these are all strategies of methodological rigour to ensure trustworthiness in constructivist grounded theory (Charmaz, 2009). The use of member-checking interviews and stakeholder focus groups

following the preliminary analysis, as well as thorough attention to the existing research literature, also contributed to the trustworthiness of the analysis – and thus are also identified as strengths via enhancing methodological rigour.

A few additional reflections are offered below on the strengths of this dissertation as a whole: This research is an example of a multi-method design, wherein data from two separate complete studies – one qualitative, one quantitative – provided insight for reaching overarching conclusions on the key research questions of interest. The inductive approach of qualitative methods allows in-depth understanding of particular situations and contexts, notably for building more abstract ideas, theories or hypotheses; in the case of the Voices and PHACES study, it allowed grounding in the lived experiences of both pregnant Aboriginal women and of service-providing professionals who work with them. The deductive approach of quantitative methods allows testing of theories or hypotheses, and permits answering questions on the generalizability of findings to a target population of interest (Morse & Niehaus, 2009; Sandelowski, 2000). As most population health issues are highly complex, reliance on a single method often does not offer adequate insight. There is accordingly growing interest in mixed-methods and multi-methods designs in fields such as population health, in which research is often geared towards informing ultimate knowledge translation (Kania et al., 2013; Morse & Niehaus, 2009; Roy, 2014b; Sandelowski, 2000). The multi-method design of this dissertation is thus a significant strength.

The importance has been emphasized throughout this dissertation of contextualizing downstream (proximal) determinants of health within broader upstream dynamics such as structural violence. However, in so doing, it is important not to lose sight of the need to generate research products that are pragmatic and amenable to knowledge translation. Basic research in anthropology and sociology offer important theoretical lenses for understanding complex sociocultural phenomena, including structural violence - but often do so in abstract, academic-based terms. When such lenses are applied to research in practice-based disciplines such as public health, health services and clinical medicine, there is arguably a need to balance theoretical considerations with knowledge translation considerations. Ultimately, analyses that engage exclusively with the macro level - by detaching completely from the meso and micro levels - may be theoretically meaningfully, but pragmatically challenging to apply in real-world contexts. Paul Farmer, a physician-anthropologist and a key scholar in the literature on structural violence and health, and colleagues (Farmer et al., 2006) remind us of the need to avoid "false debates":

The debate about whether to focus on proximal versus distal interventions ... is as old as medicine itself. But there is little compelling evidence that we must make such either/or choices: distal and proximal interventions are complementary, not competing. ... Public health is rife with false debates along precisely these lines ... (p.1689)

Thus, when examining structural violence and health, practical intervention points should be identified across the spectrum of upstream drivers and downstream mediators. This dissertation's comprehensive approach to analyzing across this spectrum is thus another significant strength.

Finally, as cited previously, another major strength of this dissertation is the community-based nature of the *Voices and PHACES* study. In addition to addressing obligations to conduct ethical research and facilitating trustworthiness of results, research

that stems from a partnership with the community is arguably more likely to be utilized. Furthermore, the trust and the practical partnerships that are built with the community during the research phase arguably facilitate the future steps required to address this population health issue, namely, the development and implementation of health promotion interventions that engage and enable the community (Vollman, Anderson & McFarlane, 2007; Minkler & Wallerstein, 2008). We hope to maintain the forged partnerships in proposed future research and action on the issue of prenatal mental health among Aboriginal women. Future directions in this regard may include the development and evaluation of some of the possible interventions highlighted earlier (such as Aboriginal-specific prenatal programs for pregnant women; programs for Aboriginal fathers-to-be to enable them to support their pregnant partners; and training initiatives for service-providing professionals on cultural competence, cultural safety and traumainformed practice). Future directions may also include a large-scale epidemiological study to test the theoretical framework proposed in Chapter 4.

### 6.4 Conclusion

Poverty; a paucity of accessible and culturally safe health and social services; a social environment poisoned with collective trauma, racism and sexism; domestic violence; and limited social support – these issues encompass the experiences of Aboriginal women, and contribute to poor physical and mental health during pregnancy, as indicated by this research and other research (Bowen & Muhajarine, 2006a, 2006b; Bennett, 2005). Aboriginal women's mental health concerns may be further aggravated

by the stresses of pregnancy and parenting. As such, pregnancy is arguably a critical time to offer healing-oriented interventions. Given the significant role of parenting in the transmission of intergenerational trauma (Sotero, 2006), pregnancy also offers a meaningful point of intervention for breaking the vicious cycle (Roy, 2014a; Smith et al., 2006). The results of this dissertation research suggest that pregnancy may be a particularly ripe time for health promotion interventions, in light of women's heightened motivation to make healthy changes and the increased contact with services – provided the programs and services offered are safe, supportive, respectful and responsive to needs.

Despite significant forces of oppression and structural violence, Aboriginal individuals and communities – and Aboriginal women in particular – have shown considerable strength and resilience. Drawing on this strength and resilience to facilitate healing is important to addressing prenatal depression and other pressing public health issues affecting Aboriginal populations.

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#### Appendix A: Intergenerational Trauma and Aboriginal Women: Implications for Mental Health during Pregnancy

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An Interdisciplinary Journal Honoring the Voices, Perspectives and Knowledges

of First Peoples through Research, Critical Analyses, Stories, Standpoints and Media Reviews

# Intergenerational Trauma and Aboriginal Women: Implications for Mental Health during Pregnancy

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# Abstract

Intergenerational trauma (IGT) explains why populations subjected to long-term, mass trauma show a higher prevalence of disease even several generations after the original events. Residential schools and other legacies of colonization continue to impact Aboriginal populations, who have higher rates of mental health concerns. Poor maternal mental health during pregnancy can have serious health consequences for the mother, the baby, and the whole family; these include impacting the cognitive, emotional and behavioural development of children and youth. This paper has the following objectives: 1) To define intergenerational trauma and contextualize it in understanding the mental health of pregnant and parenting Aboriginal women; 2) To summarize individual-level and population-level approaches to promoting mental health, and examine their congruence with the needs of Aboriginal populations; 3) To discuss the importance of targeting IGT in both individual-level and population-level interventions for pregnant Aboriginal women. Various scholars have suggested that healing from IGT is best achieved through a combination of mainstream psychotherapies and culturally-entrenched healing practices, conducted in culturally safe settings. Pregnancy has been argued to be a particularly meaningful intervention point to break the cycle of IGT transmission. Given the importance of pregnant women's mental health to both maternal and child health outcomes, including mental health trajectories for children and youth, it is clear that interventions, programs and services for pregnant Aboriginal women need to be designed to explicitly facilitate healing from IGT. In this regard, further empirical research on IGT and on healing are warranted, to permit an evidence-based approach.

Key words: intergenerational trauma; historical trauma; colonization; Indian Residential Schools; Sixties Scoop; pregnancy; maternal-child health; Aboriginal; women; children and youth; mental health; depression; health promotion.

#### Introduction

The mental health of children and youth is closely linked to parental mental health – particularly maternal mental health. Maternal mental health during pregnancy is particularly pertinent in this regard. Mental health concerns during pregnancy are a serious public health issue. Prenatal depression, for example, is estimated to impact around 10% of pregnant women in Canada (PHAC, 2005); this number is believed to be higher in groups such as Aboriginal women (Bowen & Muhajarine, 2006a), though research is limited.

Prenatal depression and other mental health issues during pregnancy are recognized to have potentially serious maternal, foetal and child health consequences. These include neurological, cognitive and immune impacts on the mother; elevated risk of adverse pregnancy outcomes such as preterm birth and low birthweight; increased risk of postpartum depression and other postpartum mental health problems in the mother, which can negatively impact child behavioural and cognitive development, as well as general family wellbeing; and increased risk of mental health problems in the child later in life (Bowen & Muhajarine, 2006b; Swaab, Bao, & Lucassen, 2005). The latter may be due to various reasons. Firstly, there are possible foetal programming pathways that may physiologically predispose the unborn baby to future mental health concerns (Swaab, Bao & Lucassen, 2005). Moreover, poor maternal mental health can severely impact mother-child interactions, which in turn can greatly impact the mental wellbeing of children (Letourneau et al., 2012).

The symptoms and risk factors for prenatal depression are believed to be similar to those of depression at any other time of life (Bowen & Muhajarine 2006b). Diverse theories have been proposed on the aetiology of depression and other mental health disorders; these inform both individual-level and population-level interventions. Relative to non-Aboriginal populations, Aboriginal populations appear to experience a higher prevalence of various mental health disorders (Kirmayer et al., 2000; First Nations Centre, 2005; Bennett, 2005). Present-day social disparities, such as higher rates of poverty, likely play a role in explaining the above; however, there is increasing recognition that the mental health issues facing Aboriginal populations are rooted in intergenerational trauma from the legacy of colonization. In combining with intersecting racism and sexism, the impact of intergenerational trauma on Aboriginal women is particularly severe.

The objectives of this paper are as follows: 1) To define intergenerational trauma and contextualize it in understanding the mental health of pregnant and parenting Aboriginal women; 2) To summarize individual-level and population-level approaches to promoting mental health, and examine their congruence with the needs of Aboriginal populations; 3) To discuss the importance of targeting intergenerational trauma in both individual-level and population-level approaches to promoting mental health in pregnant Aboriginal women.

# Intergenerational Trauma (IGT)

Various terms have been used in the literature to describe the phenomenon of the intergenerational transmission of historical trauma and unresolved grief. This paper will use "intergenerational trauma", abbreviated as IGT. IGT theory is based on the observation that populations subjected to long-term, mass trauma (i.e., historical occurrences such as colonization, slavery, war, genocide) show a higher prevalence

of disease even several generations after the occurrence of the original events (Sotero, 2006). The symptoms of IGT "as a disease are the maladaptive social and behavioural patterns that were created in response to the trauma experience, absorbed into the culture and transmitted as learned behaviour from generation to generation" (Sotero, 2006, p.96). In particular, psychological problems and destructive behaviour associated with maladaptive coping, such as addictions, suicide and violence, are noted to be elevated (Sotero, 2006; Brave Heart & DeBruyn, 1998).

Post-traumatic stress disorder (PTSD) is recognized by the Diagnostic and Statistical Manual (DSM-5) (APA, 2013) as a psychological disorder. PTSD, however, is at the individual level, and is in reference to traumatic incidents within the individual's own past. By contrast, IGT involves collective historical trauma. IGT theory sprung largely from work studying World War II Holocaust survivors and their children, and has since been applied to other populations subjected to long-term, mass trauma (relevant literature reviewed by Brave Heart & Debruyn, 1998 and Sotero, 2006). The term "American Indian Holocaust" has been used to describe the atrocities committed over the course of colonization against Aboriginal peoples in North America and elsewhere, resulting in "massive losses of lives, land, and culture" (Brave Heart & Debruyn, 1998, p.60). The historical events of colonization include: seizures of land and forced relocation to reserves (termed "reservations" in the United States) and settlements; widespread mortality through colonization-driven disease epidemics, starvation and mass murder; the horrors of residential schools (termed "boarding schools" in the United States); disruption of traditional ways of life; tearing apart of communities and families; and, assimilatory policies that meet the United Nation's definition of cultural genocide (Brave Heart & DeBruyn, 1998; Kirmayer et al., 2000; Sotero, 2006; Menzies, 2008). The experiences of these events put Aboriginal populations in a constant state of grief and despair; however, since traditional Aboriginal customs of mourning were prohibited throughout much of history, the grief could not be properly resolved (Brave Heart & DeBruyn, 1998). Thus, there is the transmission of unresolved historical grief from generation to generation. In IGT, historical grief mingles with grief, anger and trauma from present-day experiences, such as loss of family members and friends to addictions, suicide and violence; personal experiences of violence; poverty and other social disparities; and personal experiences of oppression (including racism and sexism), which reinforce the stories of ancestral oppression (Sotero, 2006).

Social, environmental and even biological methods of transmission are proposed to explain how the psychological and emotional consequences of mass trauma and unresolved grief are passed on from generation to generation (Sotero, 2006). Among the transmission pathways proposed include impaired capacity to parent (Brave Heart & DeBruyn, 1998; Sotero, 2006; Menzies, 2008). In this regard, the legacies of residential schools and the "Sixties Scoop" era of assimilatory child welfare policies offer particularly illustrative examples. The explicit purpose of residential schools was to assimilate Aboriginal children into mainstream Canadian society. Children in residential schools were seized by force from their families and communities, mistreated, overworked, denied basic needs like food, water and appropriate medical care, and both witnessed and personally experienced brutal physical, sexual and psychological abuse at the hands of school staff. Children in residential schools were taught that Aboriginal cultural and spiritual traditions. Students left schools dissociated from their traditional culture yet still not accepted by mainstream society, lacking a sense of identity, lacking basic life skills, and highly traumatized from the chronic mistreatment and abuse they had endured. The experience impaired

survivors' ability to form meaningful interpersonal relationships involving trust or intimacy. Isolation from family and community further resulted in a lack of preparedness for marriage, family life and parenting. The trauma of their experiences led many survivors to substance abuse, criminal activity, self-harm, as well as domestic violence against partners and children. Children of survivors thus faced abuse, neglect and the consequences of their parents' self-destructive behaviour, such as substance abuse. As a result, survivors' children in turn were more likely to become involved in abuse or domestic violence and to engage in substance abuse and other self-destructive behaviour. What has ensued is a vicious intergenerational cycle of violence, addictions, self-harm and trauma (ANAC & Planned Parenthood Federation of Canada, 2002; Chansonneuve, 2005; NWAC, 2007).

Although the last residential school closed in the 1990s, "by the 1960s child welfare agencies successfully replaced residential schools as the preferred system of care for First Nations children" (Bennett et al., 2005, p.18). What ensued over the next two decades is referred to as the infamous "Sixties Scoop" (Johnston, 1983): the mass removal of Aboriginal children, for adoption and foster care in non-Aboriginal homes far away from their communities. Like residential school survivors, these children were dissociated from their traditional culture, yet still faced racism and exclusion by mainstream culture (Bennett et al., 2005; Johnston, 1983; Mandell et al., 2007; Sinclair, 2007). Some were abused by their foster or adoptive parents, including the high-profile cases of Cameron Kerley (a First Nation teenager who killed his adoptive father in 1983 after years of sexual abuse at his hands) and Richard Cardinal (a Métis teenager who committed suicide in 1984 after years of abuse and neglect in foster care) (Mandell et al., 2007). The lack of senses of identity, stability and belonging became especially acute at adolescence, during which time many of these children turned to maladaptive and destructive behavior, such as substance abuse, rebelliousness, aggression and suicide. A disproportionate number of these children ended up in the criminal justice system (Bennett et al., 2005; Johnston, 1983; Mandell et al., 2007; Sinclair, 2007). It has been noted that Aboriginal peoples were underrepresented in the criminal justice system at the turn of the twentieth century, and were represented at about the same proportion as in the population prior to World War II. By the early 1990s, however, the proportion had skyrocketed; in Manitoban jails, for example, nearly 70% of men, 90% of women, 70% of boys and 80% of girls were Aboriginal (Aboriginal Justice Inquiry - Child Welfare Initiative, as cited in Mandell et al., 2007). Various studies show a compelling association between involvement in the criminal justice system and experience in the child welfare system (Mandell et al., 2007; Sinclair, 2007).

Although there now is greater Aboriginal control of child welfare services for Aboriginal children, the consequences of the "Sixties Scoop" continue to play out as the now-grown survivors of the "Sixties Scoop" become parents themselves. The legacy of the "Sixties Scoop" thus converges with the legacy of residential schools, and other events of colonization, via the ongoing transmission of trauma and dysfunction across generations.

#### IGT and Aboriginal women

IGT is gendered; while colonization and the ensuing trauma has impacted all segments of Aboriginal populations, the impact has been especially heavy on Aboriginal women. The explicit patriarchy embedded into Aboriginal societies by missionaries, residential schools, and the Indian Act have yielded inequities and oppression based on gender (LaRocque, 1994). Internalized racism and sexism, in concert

with the normalization of violence and abuse in residential schools, have contributed to disproportionately high rates of gender-based violence against women within Aboriginal communities (LaRocque, 1994). At the intersections of both racism and sexism, Aboriginal women's mental health is shaped both by present-day traumatic experiences as well as by historical trauma. Domestic violence has been suggested to be a key reason for the much higher proportion of lone-parent, female-headed households among Aboriginal populations; such families, in turn, are at greater likelihood of facing poverty (LaRocque, 1994), which further intersects with present-day and historical trauma in women's lives.

#### IGT and mental health during pregnancy

In the context of IGT, the stresses of pregnancy and parenting may further exacerbate Aboriginal women's mental health concerns. As such, pregnancy can be argued to be an especially important time to offer healing-oriented interventions around IGT. Additionally, given the key role that parenting has in transmitting trauma to the next generation (Sotero, 2006), pregnancy also offers a meaningful point of intervention for breaking the vicious cycle of IGT. Accordingly, both clinical and population-level interventions for pregnant Aboriginal women's mental health should address IGT and incorporate appropriate healing processes.

#### Individual-level Approaches to Mental Health

A wide range of theories, spread across biological and psychosocial camps, have been proposed to explain mental illness at the individual level. The biomedical model for mental illness advances biological mechanisms as explanations for mental illness. Biological systems proposed to be involved include the monoaminergic systems of neurotransmission (Elhwuegi, 2004), structures of the brain (notably in the limbic system, which is implicated in emotional and cognitive functioning) (Joca, Ferreira, & Guimaraes, 2007), proinflammatory immune function (Schiepers, Wichers, & Maes, 2005), and the hypothalamicpituitary-adrenal (HPA) axis, which is the body's key stress response system (Swaab, Bao, & Lucassen, 2005). Disruptions in one or more of these systems are believed to be at the root of mental illness (Sadock & Sadock, 2007). Psychosocial theories of mental illness offer explanations based on factors such as emotional and cognitive disposition, nature of relationships with others, and the mental impact of life experiences. Traditional perspectives in psychology include the psychoanalytic perspective, the behavioural perspective, the cognitive perspective, the humanist perspective, and the sociocultural perspective, which each offer various theories to account for the aetiology of mental illness (Sdorow & Rickabaugh, 2002). Contemporary conceptualizations of mental health generally embrace a biopsychosocial approach; such an approach recognizes that the complexity of mental health requires a broader view than can be offered with any single traditional theory (Engel, 1977). A biopsychosocial approach to understanding depression, for example, would explain the aetiology of depressive disorders in terms of the interaction between biopsychological vulnerabilities (stemming from biological, cognitive, emotive, environmental and social factors, which either predispose or protect against distress) and stressors, such as stressful life events (Garcia-Toro & Aguirre, 2007; Roy & Campbell, 2013; Schotte, Van Den, De, Claes & Cosyns, 2006). The biopsychosocial approach to understanding health is similar to Urie Bronfenbrenner's bioecological model for understanding child development; there is a focus on understanding the entire system in which health occurs (Bronfenbrenner, 1994; Engel, 1977).

In mainstream medicine, clinical diagnoses of mental disorders are based on criteria laid out in the Diagnostic and Statistical Manual (DSM-5) (APA, 2013), which are assessed during a clinical interview. Depending on the type and severity of the disorder, treatment may involve pharmaceutical approaches, or psychotherapeutic approaches, or a combination of both (Sadock & Sadock, 2007). Pharmaceutical treatments may bring about prompt relief of symptoms in some (though not all) patients; however, side effects and risks do exist, notably in the context of pregnancy and breastfeeding (Belik, 2008). Furthermore, pharmaceutical approaches do not address the underlying psychosocial roots of distress; therefore symptom relief may be difficult to sustain in the longer term. In this regard, psychotherapeutic strategies can help individuals recognize issues in their lives contributing to poor mental health, and develop coping skills and strategies in the face of those issues (Sadock & Sadock, 2007). However, many mainstream psychotherapists are not familiar with IGT and the colonial context of Aboriginal peoples' health, or with Aboriginal values and worldviews. As discussed by McCormick (2008), mainstream counselling services have had only limited success with Aboriginal clients due to "cultural misconceptions of what is normal; an emphasis on individualism; fragmentation of the mental, physical, emotional, and spiritual dimensions of the person; neglect of Aboriginal history; and neglect of the client's social support system" (p.342). Furthermore, a lack of cultural safety in mainstream mental health services, as discussed later in this paper, can reinforce IGT by subjecting Aboriginal clients to further oppression (NAHO, 2008; ANAC, 2009). Most importantly, both pharmaceutical and psychotherapeutic approaches promote the internalization of solutions (i.e., therapies are aimed at creating biological, cognitive or behavioural changes within the individual); as such, these approaches to do not address the broader social, economic and political factors that determine health at the population level. Given the collective nature of IGT and its colonial and neo-colonial roots, population-level interventions are also required to bring about meaningful transformation of individuals and communities.

# Population-level Approaches to Mental Health

The Government of Canada has defined a population-health approach as one that "uses both short- and long-term strategies to improve the underlying and interrelated conditions in the environment that enable all Canadians to be healthy, and [to] reduce inequities in the underlying conditions that put some Canadians at a disadvantage for attaining and maintaining optimal health" (ACPH, 1999, p.xv). Over the last few decades, there has been considerable discussion and debate as to the best way to execute a population-health approach.

The 1974 Lalonde Report speaks of "populations at risk" - i.e., those people exposed to risk factors of interest. Lalonde suggests that prevention strategies should target these groups of people, notably to help them make better lifestyle "choices" (Health and Welfare Canada, 1974). This approach to prevention is countered by Rose (1985), who suggests that the causes of incidence are not the same as the causes of individual cases of illness; in simpler terms, Rose explains that understanding the reasons why individuals get sick will not necessarily explain differences in rates of illness between populations. Rose suggests that prevention strategies aimed at the entire population, that target environmental and policy factors, may lower disease incidences by shifting the population distribution of the health characteristic of interest in a more favourable direction (Rose, 1985).

Frohlic and Potvin (2008) commend Rose for highlighting the importance of structural factors on health, while pointing out the victim-blaming implications of Lalonde's considerable emphasis on the notion of

individual lifestyle "choices". However, Frohlic and Potvin criticize Rose's population approach on the basis that non-targeted interventions may not have uniform impacts on all segments of the population. They argue that advantaged segments of the population are likely to benefit substantially more from the population approach to prevention; therefore, such an approach runs the risk of increasing population inequities. They speak of "vulnerable populations" (under which they include Aboriginal populations) who are at "higher risk of risks" (p.218) due to various structural barriers, and argue the importance of targeted interventions for such groups (Frohlic & Potvin, 2008). McLaren and colleagues (2010), however, have critiqued the interpretation of Rose offered by Frohlic and Potvin. McLaren and colleagues have argued that whether or not a population approach to prevention is focused on structure or agency. McLaren and colleagues further caution that the concept of "vulnerable populations" (those at greater risk of risks) is open to being conflated with Lalonde's concept of "populations at risk"; such a conflation leads back to an emphasis on risk exposure rather than on the structural factors driving health (McLaren, McIntyre & Kirkpatrick, 2010).

From the above discussions and debates, it is apparent that the conundrum of prevention at the population level lies in adequately addressing both downstream factors surrounding risk exposure, as well as upstream structural issues that impact health and wellbeing through the social determinants of health. Through an exploration of recent population-level interventions aimed at promoting maternal-perinatal health, it is apparent that there has been a greater emphasis on downstream factors than on upstream factors. Risk factors for maternal mental health issues, such as prenatal depression, include factors such as low socioeconomic status, unmarried status, experiences of domestic violence, high psychosocial stress, poor diet and low social support (Bowen & Muhajarine, 2006b). Social support has been targeted as a potentially modifiable factor in a number of recent perinatal health interventions. For example, a randomized-control trial of a prenatal intervention involving in-home nurse visits showed different patterns of success among pregnant women in Calgary, based on whether they were high-risk or low-risk for poor maternal and perinatal health outcomes. Not surprisingly, the needs of high-risk women were not being fully met with a conventional prenatal intervention (Tough et al., 2006). Other interventions have targeted women defined as "high-risk" based on depressive symptoms screening (Dennis, 2010; Jesse et al., 2010; Smith et al., 2011). These interventions have met with little (Smith et al., 2011) to only moderate success (Dennis, 2010; Jesse et al., 2010). The lack of dramatic success is likely because these interventions do essentially nothing to change the broader, structural factors impacting women's mental health. It is clear that more needs to be done to address upstream factors. This is particularly true in the context of Aboriginal women, whose health is impacted by the structural factors driven by the legacy of colonization. Furthermore, given the unique social, cultural and historical context of Aboriginal populations, tailoring prenatal and mental health interventions to meet the needs of pregnant Aboriginal women is also important to ensure both effectiveness and cultural safety.

The health promotion function of public health suggests that a multi-pronged, multi-sectoral approach is required in the process of "enabling people [and populations] to increase control over, and to improve, their health" (WHO, 1986, p.1). Health promotion interventions use strategies of building healthy public policy, creating supportive environments, strengthening community action, developing personal skills, and reorienting health services (WHO, 1986). Health promotion interventions have been suggested to be especially effective in mental health, given the complexity of the determinants involved (Herrman,

Saxena, & Moodie, 2005). Because health promotion "focuses on achieving equity in health" (WHO, 1986, p.1), a health promotion approach to mental health among pregnant Aboriginal women would advocate tailoring interventions for the specific needs of pregnant Aboriginal women. Furthermore, a health promotion approach focuses on action on the broader determinants of health beyond simply behavioural and biological factors - such as political, economic, social, cultural and environmental factors (WHO, 1986).

The Government of Canada's document "Toward a Healthy Future: Second Report on the Health of Canadians" discusses the health disparities facing Aboriginal populations, and links these health disparities to the social disparities faced by Aboriginal populations along social determinants of health such income, education, employment and housing (ACPH, 1999). What is conspicuous by its complete absence in this report, however, is identification of colonization as the broader driver behind present-day social and health inequities. Similarly, colonization and IGT are also not explicitly discussed in the program descriptions for First Nations and Inuit Health Branch (FNIHB) community-based health promotion programs on maternal and child health (Health Canada, 2011). Reference is made in the program descriptions to the social determinants of health, health promotion, community capacitybuilding, and the incorporation of traditional culture (Health Canada, 2011); however, concretely-defined components to explicitly address IGT in the mental health of pregnant Aboriginal women are not mentioned. Of the mental health promotion programs offered by FNIHB, the Indian Residential Schools Resolution Health Support Program description refers explicitly to IGT, in the context of residential school abuses. Otherwise, explicit reference to colonization and IGT are similarly limited in the program descriptions (Health Canada, 2011). In the last few years, largely through the work of the Truth and Reconciliation Commission of Canada, there has been increasing awareness of the traumatic experiences of students who attended residential schools, culminating in a formal apology from the Government of Canada on June 11, 2008 (Truth and Reconciliation Commission of Canada, 2011). However, the impact of the history of residential schools on subsequent generations of Aboriginal peoples has not received as much media or political attention. This may in part be due to the limited empirical research on the issue, as discussed below.

# Addressing IGT in Mental Health Interventions for Pregnant Aboriginal Women

As discussed earlier, historical trauma and unresolved grief are reinforced and augmented with the trauma and despair stemming from present-day circumstances, including experiences of racism and sexism. In the context of health and social services, a lack of cultural safety contributes to oppression of Aboriginal peoples, and therefore to IGT. Cultural safety expands the notion of cultural sensitivity by focusing on structural inequities based on various sociocultural factors, and the resulting power differentials in relationships - notably in the relationship between service providers and patients or clients. In order to provide a culturally safe environment in which patients or clients can feel respected and empowered, service providers must be self-reflexive. This is particularly important in the context of Aboriginal patients and clients; Aboriginal peoples' historical relationship with health and social services is entrenched in colonization, making lack of trust a major concern (NAHO, 2008; ANAC, 2009). The literature has suggested a number of best practices for health and social services for Aboriginal patients and clients, to ensure both safety and responsiveness. The Society of Obstetricians and Gynaecologists of

Canada, for example, offers a list of recommendations for health services in the area of Aboriginal women's health. These include: ensuring that professionals have an adequate understanding of the sociocultural, historical and population health context of Aboriginal peoples, notably the legacy of colonization; embracing a holistic view of health and wellbeing, in line with Aboriginal worldviews; supporting community-directed services, programs and initiatives; and supporting health promotion and prevention (Smylie, 2000). In the context of pregnant and parenting Aboriginal persons, Smith and colleagues (2006) found that participants of their study seek health care that is respectful, strengths-based, client-directed, holistic, that permits healing and trust, that is culturally appropriate, that addresses the "mind, body and soul" (p. E39), and that includes fathers and other family members.

Various scholars have suggested that healing from IGT is best achieved through a combination of mainstream psychotherapies and culturally-entrenched healing practices (Brave Heart & DeBruyn, 1998; Brave Heart, 2003; McCormick, 2008; Menzies, 2008). McCormick (2008) comments that, when facilitated by therapists with "adequate understanding and respect for Aboriginal cultural values [such that] the therapist [does not] mistakenly try to change core cultural values of their Aboriginal clients" (p.342), there are certain mainstream psychotherapeutic approaches that have proven to be helpful for Aboriginal clients. In addition to individual psychotherapies, group and family therapies have proven to work well, given the congruence with the emphasis of family and community in Aboriginal worldviews (McCormick, 2008). However, it is important that mainstream therapies be complemented with traditional healing practices that allow connection with one's Aboriginal identity, and promote healing through balance; interconnectedness; relationships with family, community and nature; spirituality; and the use of Aboriginal rituals and traditions (McCormick, 2008). Traditional Aboriginal healing practices vary between communities, and include smudging, sweat lodges, sun dances, pipe ceremonies, potlachs and healing circles (University of Ottawa, 2009); healing circles, for example, can be incorporated into group therapy (Heilbron & Guttman, 2000). The focus on holism is reflected in traditional approaches such as the Medicine Wheel, and the four sacred medicines of sage, sweet grass, tobacco and cedar (Little Brown Bear, 2012; University of Ottawa, 2009). Drawing on traditional healing practices is especially important in the context of IGT, given that part of the assault of colonization that led to unresolved grief was the banning of traditional cultural practices (Brave Heart & DeBruyn, 1998). Brave Heart, DeBruyn and colleagues at the Takini Network in the United States have developed the Historical Trauma and Unresolved Grief (HTUG) Intervention, which has shown success. This group trauma and psychoeducation intervention combines processes for acknowledging and confronting historical trauma, with traditional Aboriginal rituals for grief resolution and healing. The intervention is congruent with mainstream group psychotherapies done for PTSD, and allows reconnection with Aboriginal identity and cultures as a powerful means of healing (Brave Heart & DeBruyn, 1998; Brave Heart, 2003).

In addition to individual-level interventions, population health promotion interventions are also important, that address structural and community-level factors that influence healing from the legacy of colonization. Chandler and Lalonde (1998) suggest that "cultural continuity" in a community can impact mental health. Their markers for cultural continuity include community involvement in land claims, evidence of self-government, existence of health and social services, and existence of cultural facilities. Although termed "cultural continuity", various scholars (e.g., Kirmayer et al., 2000) point out that these markers speak to broader issues of community participation and capacity, in addition to engagement with traditional culture and Aboriginal identity. Community capacity and local control are powerful counters to

the historical and present-day oppression associated with colonization, and in which IGT is largely rooted. As stated by Kirmayer:

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Community development and local control of health care systems are needed, not only to make services responsive to local needs but also to promote the sense of individual and collective efficacy and pride that contribute to mental health. Ultimately, political efforts to restore Aboriginal rights, settle land claims and redistribute power through various forms of self-government hold the keys to healthy communities. (Kirmayer et al., 2000, p.614).

While various conceptual models have been proposed to explain IGT (Brave Heart & Debruyn, 1998; Sotero, 2006; Menzies, 2008), they are largely rooted in qualitative research and theoretical discussion. The inductive approach of qualitative research allows for considerable depth in insight; given the complexities of IGT, qualitative research is certainly integral to fully understanding the intricate issues at hand. However, qualitative research cannot address questions of generalizability of results to a target population of interest (Morse & Niehaus, 2009; Roy, 2014; Sandelowski, 2000). Accordingly, quantitative and mixed-methods research approaches are also required, to ensure that IGT is considered in evidencebased decision-making around services and policies (Blackstock, 2009; Roy, 2014). There has been some quantitative work done in recent years. Whitbeck and colleagues (2004), for example, have developed historical loss scales. Recent studies have also attempted to assess IGT through indicator variables about life experiences associated with IGT in Aboriginal populations (e.g., sexual abuse, child abuse, family violence, alcoholism, being taken away from birth parents), or by inquiring about family members' attendance at residential schools (Balsam, et al., 2004; Cedar Project Partnership et al., 2008). However, as argued by Sotero (2006), discussion of IGT in the literature is largely theoretical and qualitative in nature. Similarly, although there is considerable discussion of the concept of healing in the context of Aboriginal mental health, "the major part of the literature that examines healing for Aboriginal people tends to be based on opinion and conjecture, not on research. ... [The] literature does not provide empirical evidence [as] support" (McCormick, 2008, p 341). Given the increasing focus on evidence-based decision making in the design of both clinical and population interventions, more empirical studies are needed on both IGT and Aboriginal healing, drawing on both quantitative and qualitative approaches. In particular, further research of these issues in pregnant Aboriginal women can help to provide contextspecific evidence to address the overall lack of explicit consideration of IGT, discussed earlier in this paper, in both individual-level and population-level interventions aimed at Aboriginal maternal mental health.

Given the link between experiences of interpersonal violence and an array of health and social problems, Elliott and colleagues (2005) have suggested that all health and social services for women should be "trauma-informed"; in other words, "service delivery [should be] influenced by an understanding of the impact of interpersonal violence and victimization on an individual's life and development" (p 462). Elliott and colleagues' paper is concerning personal trauma from interpersonal violence; however, extrapolations of their points can be made to the issue of IGT and Aboriginal peoples. Given the link between IGT and social, behavioural and health problems in Aboriginal populations, an argument can be made that health and social services for Aboriginal peoples in general should be influenced by the recognition of the legacy of colonization and the need to heal from this legacy; in other words, they should be IGT-"informed". While the above should apply to services for all Aboriginal peoples, it is particularly pertinent for pregnant Aboriginal women. Qualitative research conducted by Smith and colleagues (2006)

suggests that Aboriginal parents see pregnancy as a time for reflection on the intergenerational legacy of colonization, driven by the strong desire to give their children a better future. As such, pregnancy is "a powerful opportunity to support and facilitate people to choose a healing path" (pp E34-E35), to heal themselves and break the vicious cycle of IGT for the sake of their children. As discussed earlier, IGT has a large role in Aboriginal women's overall mental health. Given the importance of pregnant women's mental health to both maternal and child health outcomes, including mental health trajectories for children and youth, it is clear that interventions, programs and services for pregnant Aboriginal women need to be designed to explicitly facilitate healing from IGT.

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## Appendix B: Research with, not on: Community-based Aboriginal Health Research through the *Voices and PHACES* Study

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CHAPTER 6

# Research *with*, not *on*: Community-based Aboriginal Health Research through the "Voices and PHACES" Study

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#### Introduction

Prenatal depression is a significant issue in Canada, where approximately 10% of pregnant women will experience depression (PHAC, 2005). Prevalence may be much higher in disadvantaged and marginalized groups, such as Aboriginal populations (Bowen & Muhajarine, 2006a); however, there is a paucity of research on prenatal depression in Aboriginal women. To support the development of evidence-based population health interventions, the project team proposed a program of research to examine prenatal depression among Aboriginal women from a population-health perspective. As the first step, we launched a qualitative study named "Voices and PHACES," with PHACES standing for "Prenatal Health in Aboriginal Communities and EnvironmentS."

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In response to the sad history of exploitation of, and harm to, Aboriginal communities through academic research, there is growing recognition of the importance of community-based approaches and academic-community partnerships. While the benefits of community-based research are generally unquestionable, its execution can often be challenging. This chapter describes the process followed in the "Voices and PHACES" study to engage, and work in partnership with, communities and policy-makers. The chapter also discusses challenges we faced and how we addressed them, and offers recommendations for researchers and community members considering this type of research.

#### Research with (not on) Aboriginal Communities

Savan and Sider define community-based research (CBR) as "a range of research approaches that link community members and external researchers in investigations that promote progressive social change as well as deeper understanding of specific issues important to communities" (2003, p. 33). CBR recognizes the value of different sources of knowledge and different methods of knowledge acquisition, and also mandates multiple means of dissemination to facilitate the application of research results for meaningful social change (Scott & MacKean, 2007).

Israel and colleagues situate CBR in public health by highlighting the focus "on social, structural, and physical environmental inequities through active involvement of community members, organizational representatives, and researchers in all aspects of the research process" (1998, p. 173). In public health, CBR goes hand-in-hand with health promotion, which is "the process of enabling people to increase control over, and to improve, their health" (p. 1) through the strategies of building healthy public policy, creating supportive environments, strengthening community action, developing personal skills, and reorienting health services (WHO, 1986). In this regard, Israel and colleagues (1998) point out that CBR is particularly significant for marginalized communities whose members have limited access to power and resources. The impact of the history of colonization on Aboriginal peoples in Canada can be seen in the disproportionate number of health and social problems they face. While the health inequities facing Aboriginal populations

are daunting, Aboriginal individuals and communities also have considerable strength and resilience (Dion Stout & Kipling, 2003; Wesley-Esquimaux & Smolewski, 2004). This community capacity facilitates health promotion as a means to address the health inequities at hand. There is ample evidence that community participation can result in better policies, programs, and other interventions (Lombe & Sherraden, 2008; Thurston, Dutton, & Emery, 2012). Indeed, one of the reasons why certain programs have had limited success in alleviating the health inequities faced by Aboriginal peoples is the failure to take local context, culture, and means of knowledge exchange into consideration in design and evaluation (Smylie et al., 2009). Health research endeavours that have the goal of health promotion in Aboriginal communities must engage with the fact that "contemporary health knowledge and health behavior among Indigenous individuals and communities are influenced by an interplay of pre-colonial systems of health, historic and ongoing processes of colonization, and exposure to non-Indigenous systems of health" (p. 437); this interplay varies across communities, based on local context (Smylie et al., 2009). By facilitating engagement with local context, CBR yields "the potential to design more effective public policies [and] to successfully advocate for policy change" (Ritas, 2003, p. 4).

According to the Royal Commission on Aboriginal Peoples (RCAP) (1996), Aboriginal people have had little chance to challenge misinformation and ethnocentric or racist interpretations of research results. The First Nations Centre (2007) reported that historical research practices were "disrespectful, damaging and stigmatizing" (p. 3). The result is that research had "acquired a bad name," with outcomes that were "as often as not, misguided and harmful" (Castellano, 2004, p. 98). In addition to coping with problematic research practices and outcomes, Aboriginal communities have had little control over the research process (First Nations Centre, 2007). RCAP found that research concerning Aboriginal peoples has usually originated from outside the Aboriginal community and has usually been conducted by non-Aboriginal individuals. The lack of control within the research process and exclusion from determining research in general have been likened to historical colonial policies directed towards Aboriginal populations within Canada (Castellano & Reading, 2010). Furthermore, Durst argued that research, in regards to Aboriginal populations, has historically been used as "an instrument of oppression, imperialism and colonialism" (as cited in First Nations Centre, 2007, p. 3).

In response to the adverse processes and outcomes from historical research practices. Aboriginal communities have begun to demand an ethical basis for research rooted in self-determination. In general, Aboriginal populations require that health research benefits Aboriginal peoples, that Aboriginal peoples be full partners in health research at all stages, and that Aboriginal peoples own, control, access, and possess (OCAP) health research data. OCAP outlines key principles of a critical framework for research (First Nations Centre, 2007; Schnarch, 2004). The First Nations principles of OCAP, as trademarked by the First Nations Information Governance Centre (2010), stem specifically from First Nations groups' historical ways of knowing; other Aboriginal groups may have different approaches. However, research practices that are respectful, participatory, and beneficial to the communities they involve can be applied broadly to all Aboriginal populations. The Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS) also includes a chapter focused on applying the TCPS policy provisions within Aboriginal contexts. The TCPS is intended to provide guidance to researchers to ensure that research "involving Aboriginal peoples is premised on respectful relationships" (CIHR, NSERC, and SSHRC, 2010).

In summary, Aboriginal health research endeavours must ensure that the research process does not replicate the very processes and outcomes of colonization that the research is seeking to address (Martin, 2008; Tuhiwai Smith, 2006; Varcoe et al., 2011). To this end, a decolonizing approach to research is warranted that involves "critical examination and dismantling of individual and systemic assumptions and power relationships, including the suppression of Indigenous systems of knowledge" (Smylie et al., 2009, p. 437). CBR plays a critical role in this regard. We accordingly used CBR in the research project described in this paper to facilitate an ethical approach that was respectful of the OCAP principles.

#### The "Voices and PHACES" Study

Depression carries consequences for health and well-being. The health consequences of prenatal and postpartum maternal depression can also

be found in the baby and other family members, making it a significant maternal-child health concern. The associated continuous elevation of stress-related hormones has serious implications; for example, it can contribute to adverse pregnancy outcomes such as preterm birth and low birth weight (Swaab, Bao, & Lucassen, 2005; Bowen & Muhajarine, 2006b), and can preprogram a fetus to be at increased risk for depression and anxiety later in life (Swaab, Bao, & Lucassen, 2005). Pregnant women who are depressed are also more likely to engage in unhealthy coping behaviours such as smoking, alcohol consumption, and illicit drug use, and less likely to use prenatal health services (Bowen & Muhajarine, 2006b). Women with prenatal depression are more likely to experience postpartum depression (Bowen & Muhajarine, 2006b; Beck, 2006). Maternal depression can impact the mother's interactions with her infant, her partner, and her other children, yielding negative effects on the children's long-term cognitive and behavioural development (Bowen & Muhajarine, 2006b; Beck, 2006). Thus, good maternal mental health is critical for the physical, mental, and psychosocial health of the entire family. In this regard, programs, policies, and services that enhance maternal mental health during pregnancy can serve as a preventive tool for many of the issues identified by the Government of Alberta's Ministry of Children and Youth Services (now part of Alberta Human Services) in its 2010 Business Plan.

The Ministry of Children and Youth Services of Alberta and the Alberta Centre for Child, Family and Community Research (ACCFCR) have both identified Aboriginal maternal-child health issues as being of particular concern (Government of Alberta, 2010; Tough, 2009). Not only do Aboriginal populations in Canada experience greater health and social inequities relative to other Canadians, but many of the risk factors and health consequences associated with prenatal depression are more prevalent among Aboriginal populations (Bennett, 2005), suggesting that prenatal depression should be assessed. However, empirical research on the determinants of depression among pregnant Aboriginal women is limited. Population-level studies to date on all types of depression have found that socio-economic disadvantage and chronic psychosocial stress are major risk factors (Bowen & Muhajarine, 2006b). It is also clear, however, that the causal pathways of depression, both at the clinical and the population levels, are complex. Given the unique historical and

present-day social context of Aboriginal peoples, it would be erroneous to assume that the results of studies in non-Aboriginal populations can be directly applied to Aboriginal populations. Notably, Aboriginal women experience intersecting stressors from race, gender, social exclusion, and intergenerational trauma from the legacy of residential schools and other occurrences of colonization (Bennett, 2005; Sotero, 2006). Research that takes these factors into consideration is therefore crucial for the development of effective and evidence-based policies, programs, and services for this population.

To address the above, we launched the "Voices and PHACES" study as a first step in a proposed program of research on prenatal depression and Aboriginal women. "Voices and PHACES" is a constructivist-grounded theory study involving semi-structured interviews with pregnant Aboriginal women and health-service and social service professionals who work with them in the Calgary area. Through these interviews, the objectives are to gain insight on: (a) the factors that impact maternal mental well-being during pregnancy; (b) the social context in which Aboriginal women live their lives; (c) the appropriateness and adequacy of existing programs and services; and (d) how these programs and services can be improved or expanded to better meet the women's needs.

At the time of submission of this chapter (June 2013), data gathering for "Voices and PHACES" is still in progress. Interviews with twelve pregnant Aboriginal women and twelve professionals have been completed. Preliminary results point to a number of risk factors that are consistent with prenatal depression studies in other populations, including stressful life events, social and economic factors, negative previous pregnancy experiences, and experiences of violence and abuse. However, risk factors related to this population's unique social and historical context are also apparent, including experiences with the child welfare system, family members' residential school experiences, historical (intergenerational) trauma, stigma, racism, and sexism. Negative coping mechanisms for stress identified in the interviews include substance abuse. Positive coping mechanisms include social support and access to Aboriginal traditional practices, which appear protective. While services in Calgary are working well in certain ways, the preliminary results suggest there is a need for more culturally appropriate and safe services, better networking among agencies, and interventions with service providers to reduce stigma. Once all interviews are completed and the data fully analyzed, a theoretical framework will be proposed on the determinants of depression in this population. This framework will be translated into key recommendations for dissemination to stakeholders, and will form the basis for future stages of our proposed program of research.

In the early stages of conceiving this study, University of Calgary researchers decided to engage with community organizations and stakeholders, and pursue academic-community partnerships for a community-based approach to the research. One reason for this decision was ethical concerns about how research should be done with Aboriginal peoples, rather than on them. A community-based approach was pursued to ensure research that was respectful of the principles of OCAP and of the guidelines laid out in the TCPS. Another reason was sensitivity to the complexity of gender issues for Aboriginal communities (Huhndorf & Suzack, 2010; Varcoe et al., 2011) and the historic role of community in advancing change, especially for women. Thirdly, ethical and practical considerations for reaching and recruiting the target samples played a role. Recruitment of both pregnant women and service professionals for the study is being done through clinics and agencies in and around the city of Calgary. Recruitment strategies vary between sites: display of posters and pamphlets in high-traffic areas; distribution of pamphlets by clinic or agency staff to individual patients or clients who may be eligible to participate (the prospective participants then contact research study staff for more information if interested); and, presence of research study staff on-site to speak with prospective participants directly. Fourth, the organizations play an integral role in addressing potential participant distress. In the event of participant distress during the interview process, the interviewers are to contact the "point person" identified in each organization who agreed to facilitate access to counselling and other services for distressed participants. These precautions were considered necessary given the varying levels of vulnerability among our target population, and the sensitivity of some of the questions being asked in the interviews. Finally, apart from success in recruitment, it was also important to the academic researchers that the products of the study be meaningful for eventual knowledge translation into beneficial programs and policies. Thus, the engagement of relevant stakeholders as partners was recognized as important.

#### Community-based Approach and Academic-community Partnerships in "Voices and PHACES"

For the sake of simplicity, we have dichotomized "academic" and "community" parties in our discussions below, with "academic" signalling those who entered the research via their role at the university. This dichotomy should not be interpreted to suggest a hierarchy between parties; indeed, at the heart of CBR is recognition of the equal value of the contributions of all parties. Furthermore, the distinction between "academic" and "community" is not always clear in CBR; in the case of "Voices and PHACES," one of the academic research team members (L. Crowshoe) is also a local First Nations person. He is thus a member of both the university and the community, and brings both perspectives to the research.

Community-based approaches to research vary with the contexts and settings involved. In the case of "Voices and PHACES," the formation of the study's academic-community partnerships was initiated by the academic researchers, rather than by the community parties involved. However, once they were approached, there was immediate interest by the community members in the topic and the proposed preliminary outline for the study. Some proponents of community-based research would insist that it must be initiated strictly by a community to be truly community-based; we, however, do not hold that position, and instead posit that academic researchers can serve as allies to communities who may not always have the resources (including time and training) in place to readily initiate rigorous research. Savan and Sider (2003) also embrace a more inclusive definition of CBR; in their discussion of the range of possible approaches to CBR, they highlight that partnerships between university researchers and community entities are quite common in CBR initiatives. Thus, the defining dynamic of CBR is in the nature of the partnership between academic and community entities, and the values honoured, rather than strictly around the question of which entity initiated the research. Flexibility of methods is one important value (Anderson, Khan, & Reimer-Kirkham, 2011).

Community engagement in "Voices and PHACES" is present in the five community organizations (health clinics and social service agencies) in the city of Calgary that are the core community partner agencies for the study. Secondly, there is the involvement of Aboriginal community

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members and Elders, and the government of Alberta, in advisory capacities. Thirdly, there is an explicit commitment to the dissemination of study results to relevant stakeholders, in forms that are useful for knowledge translation. We have worked to ensure involvement of community members, organizations, and stakeholders from government in the decision-making surrounding the design, implementation, dissemination, and governance of the study.

#### **Community Organizations**

Early in the study's conception, the academic researchers approached various community organizations in the city of Calgary that work with Aboriginal women. Five organizations joined as partners and supplied letters of partnership: Inn from the Cold, Awo Taan Healing Lodge, Calgary Urban Projects Society / CUPS, Elbow River Healing Lodge (of Alberta Health Services), and the Adult Aboriginal Mental Health Program (of Alberta Health Services). One or more of the academic researchers had previous relationships with leaders in these organizations. The letters laid out the terms of reference agreed upon for the partnership, and copies are kept on file by each partner. Formalizing the partnerships was viewed as important (Scott & Thurston, 1997) because the relationship involved much more than a "letter of support." The letters were included in applications for research ethics board approval and for funding. At this time, 13 other organizations have also joined the study as additional recruitment sites. Although not as deeply involved in the study as the five partner organizations, they have expressed enthusiasm for the research and an interest in receiving the report of the final results.

#### **Research Team and Oversight Committee**

The research team includes both academic and non-academic members: academic members are researchers at the University of Calgary (one doctoral student and five faculty members in the Faculty of Medicine); non-academic members are representatives from the five partner community organizations. The research team brings complementary expertise to the table, enabling both rigorous and feasible research, and research that is responsive to community needs and different models of service delivery, relevant for eventual knowledge translation, and therefore useful for practical application by front-line service providers. The project's oversight committee consists of five individuals, four of whom are Aboriginal community members from the Calgary area. The fifth member is a representative from the Ministry of Human Services of the Government of Alberta. The role of the oversight committee is to provide guidance to ensure that the research is ethical, appropriate, and meaningful for Aboriginal communities, that all interactions with individuals and communities are culturally appropriate and culturally safe (congruent with Aboriginal cultural practices, and conducted in a manner in which individuals and communities feel empowered and respected), that the principles of OCAP are observed, and that the research is meaningful from a policy perspective.

Two of the four Aboriginal community members on the oversight committee are Elders, meaning they are respected advisors, helpers, and ceremonial leaders in their communities (Stiegelbauer, 1996). In addition to offering guidance and oversight along with other committee members, the Elders support the research team in conducting the research in a manner that resonates with traditional perspectives of the Elders' communities. They also help support traditional Aboriginal team processes and protocols at study meetings and other study-related events. Because Elders may not belong to an institution or program that pays their salary, it may be appropriate for researchers to give an honorarium for their involvement. We included this honorarium cost as an item in the budget in our application for grant funding, to enable us to do so.

Because the study is focused on urban Aboriginal women who come from many locations in Alberta and possibly other provinces, how best to institute a formal community-based ethical review process was a dilemma. The oversight committee has been advising us in regards to ethical considerations specific to Aboriginal communities, as well as in the interpretation, validation, and dissemination of results. At the time of this study's initiation in 2011, there was no mechanism in place at the University of Calgary for community-based ethical review of studies focused on urban Aboriginal populations. More recently, the Institute of Public Health's Group for Research with Aboriginal Peoples for Health (GRAPH) has established a community advisory board that can offer review of research projects. Additionally, the University of Calgary's Conjoint Health Research Ethics Board (CHREB) now has representatives from the Alberta First Nations Information Governance Centre. One of these is co-chair of the oversight committee of our study, and it was initially through involvement with our project that she met with and came to serve on CHREB. The latter demonstrates the power of relationships in creating an institutional environment where CBR can be strengthened.

#### **Governance and Communications**

The study's governance process includes three general meetings, where the research team and oversight committee attend together, allowing for interactive discussions and exchanges of ideas and viewpoints. To date, the first of the three planned general meetings has occurred. At this first meeting, discussions were focused on the processes for recruitment and data gathering, as well as the wording and content of the interview guides and the consent forms. The second general meeting, which will be held when the interviews are close to completion, will be devoted to group analysis. During this meeting, the lead researchers will present preliminary codes and themes from the interviews, and seek reflection from attendees on relationships among codes, themes, and overall interpretation. The third general meeting will be held towards the end of the study, and the dissemination plan for the research findings to both academic and community audiences will be discussed. In this regard, the non-academic team members and the oversight committee, in particular, will play a valuable role in the translation of research findings into key recommendations for policy and programs, which will be disseminated to community and governmental agencies in the final report. Additional meetings, teleconference calls, and email conversations are conducted as needed outside of these general meetings. In this way, all parties involved have an opportunity to contribute meaningfully to decisions.

#### **Dissemination to Stakeholders**

In order for research findings to make a true difference, they must be disseminated widely, and to the appropriate audiences. Research results will be disseminated in academic venues such as peer-reviewed journals, academic conferences, and presentations. Additionally, the research findings will be disseminated to stakeholders. To this end, a gathering (of managers and service providers from clinical and social service agencies

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in and around Calgary, representatives from Aboriginal organizations, Aboriginal community members, and pregnant Aboriginal women) is planned for the end of the study to share findings and recommendations. The gathering will include an opportunity for attendees to share their thoughts and reflections about the statements and recommendations in the report; the final report will be modified as appropriate, based on feedback received. That report will be submitted to community partners, funders, and the Government of Alberta. Additionally, the report will be made more widely available to those interested, notably gathering attendees and the participants in the study. The contents of the report will also be shared through oral presentations to staff members and patients/clients alike at the partner organizations. Finally, the report will be presented to the educational offices of the Faculty of Medicine at the University of Calgary, and the Faculties of Nursing at each of University of Calgary and Mount Royal University, so that they may consider the findings in their curricula.

We also want to make the study results accessible for Aboriginal women themselves. We expect to deliver oral presentations tailored specifically for Aboriginal patients and clients at clinics and agencies. If it proves feasible to do so, we are also considering the possibility of creating a short video to be uploaded to YouTube, which would convey the results in simple terms and in an engaging manner.

#### **Challenges Encountered in "Voices and PHACES"**

Structures in academia around project funding and ethical approval, and the various policies and procedures of financial and human resources departments at universities, can make CBR more difficult. The structures and policies are intended to protect both academic researchers and community members; however, they can create obstacles vis-à-vis relationships with community partners, who may not always understand the reasons for the complex processes at hand. Most notably, the various procedures that need to be followed have lengthy turnaround times; this can lead to long gaps of time when it may feel to the community partners like "nothing is happening." It is generally expected that partnerships with community agencies be fully and concretely established in advance of submitting both funding applications and applications for research ethics board approval. This can put the community partners "on hold" for lengthy periods of time when success is not guaranteed.

In our case, community members did not have the time to work on writing up the application for project funding, though academic members did keep them informed of its content and its progress. We were very fortunate to secure funding, as funding competitions are highly competitive in Canada, with low success rates. Academic researchers have had to develop "thick skins" to deal with this high rate of rejection; community members, on the other hand, may get discouraged by the often blunt style of criticism of academic peer reviewers, which can risk the burgeoning relationship among partners. Although this did not occur with "Voices and PHACES," it has proven to be a difficulty in other CBR projects in which the authors have been involved.

Research ethics board approval at our institution can take anywhere from six weeks to six months, depending on the specific issues in the research, and also on the workload of the ethics review board at the time of submission. The original ethics application for "Voices and PHACES" took less time than usual (about four weeks from time of formal submission), due to efforts on the part of the board's then-chair to expedite review of graduate students' dissertation projects. However, ethics modification applications submitted more recently (to add new recruitment sites) have taken up to six weeks for approval, despite the new sites being fairly similar to original sites. As turnaround time is due to workload volume of the research ethics board, it is difficult to predict how long the process will take, which can lead to frustration, especially for community partners.

In a process involving so many steps—securing funding through a successful grant application, obtaining ethics approval (funds cannot be accessed before then), having funds released following the appropriate university financial services process, and recruiting and hiring study staff following the appropriate university human resources process—many months pass during this lengthy, rigorous process from application to implementation. Changes in staff, capacity, and enthusiasm may occur at the partner agencies during this long period. These changes can complicate the dynamics of project management. In "Voices and PHACES," there were staff changes at one of our community partner

agencies during the interim period of time, and an individual who had enthusiastically endorsed the partnership was no longer in that managerial position. The new person was not familiar with the research partnership agreement that had been struck many months before, so some confusion and some tension resulted. Changes in space-use needs at one of the partner agencies meant that a concern developed around doing interviews on-site, whereas that was the original plan. In the intervening months, one of the agencies had a negative experience with another (unrelated) research project, and became hesitant to maintain involvement in the "Voices and PHACES" project. We addressed all of these issues with open dialogue and discussion, listening carefully to concerns, and offering clarification and assurances as possible. For example, some of the concerns that surfaced in the above scenarios included concerns around how much time agency staff would have to invest in recruiting for the study (we were able to reach an understanding on the limits in this regard), and concerns around clients feeling uncomfortable at being approached on-site by study staff (for the agency expressing this concern, we agreed that posters and pamphlets would be the principal recruitment strategy). In some cases, we reworked the initial partnership agreement to address new circumstances (e.g., the altered availability of rooms on-site for interviews). As Varcoe and colleagues (2011) report, these "experiences illustrate how trust is never a given, but rather, is created though attention to relationships and reflexivity" (p. 225). The importance of relationship development cannot be overstressed; this is particularly true for CBR involving Aboriginal peoples, for whom relatedness is a major component of traditional ways of knowing (Tuhiwai Smith, 2006).

The need for developing and maintaining a diverse set of human relationships is one reason that CBR is considerably more time-consuming than many other research designs, and involves extra steps for academic researchers above and beyond those otherwise required in the research-intensive environment. Because people in community agencies are busy with other priorities, it can often take multiple contacts across several weeks just to arrange an initial meeting or conversation. In addition, community organizations also have their own formal governance structures, and it can take several weeks as various levels of agency leadership review and approve a proposed partnership. In "Voices and PHACES," this phenomenon of multiple follow-ups being required (and long wait times for responses) has continued throughout the partnership, even though the enthusiastic support is still there among agencies. We strive to demonstrate "respect, relevance, reciprocity, and responsibility" (Varcoe et al., 2011, p. 226) by accommodating the agencies' and community members' needs whenever possible, so as to facilitate their involvement (e.g., issuing friendly follow-ups and reminders, going to agencies for meetings rather than making them come to us, and working around their schedules and availabilities).

CBR is a particularly challenging form of research for doctoral students, who face fairly stringent requirements for degree completion, as well as institutional requirements directed at the educational process. At the helm of "Voices and PHACES" is a doctoral student who has had to revise graduation timelines, and revise plans surrounding the other components of her dissertation, around the progress of "Voices and PHACES." Her supervisory committee members have been flexible, understanding, and supportive. They have permitted her, for example, to amend the other projects in her original dissertation proposal, so as to allow her to still graduate in a reasonable period of time. Some supervisory committee members also have existing relationships with some of the community partner agencies, due to involvement in other (separate) research studies or due to other professional connections; this connectedness has helped in the relationship-building and trust-development processes required in CBR.

Scientific and community perspectives can often conflict. For instance, ethical considerations around research participant confidentiality and autonomy can conflict with the desire of helping professionals at agencies or clinics to access information revealed in interviews, for the sake of incorporating it into treatment or rehabilitation plans. For example, "Voices and PHACES" participants are administered the Edinburgh Postnatal Depression Scale as part of the interview, and multiple partner organizations requested that we share each woman's score with her physician or counsellor. While we understood the good intentions of the clinics and agencies in this regard, we had to decline this request. We engaged in open dialogue to explain the ethical reasons that constrained us and to work with the organizations to find alternatives that respected all perspectives. The alternative we were able to implement instead was to tell research participants their scores on the scale in question, and to suggest to the participants that they could choose whether or not to share the score with their helping professionals.

One of the challenges of CBR is being clear on who makes up the community. Aboriginal communities are diverse, especially in urban settings. Academic communities (departments, disciplines, universities) are also diverse. When large, multidisciplinary groups try to come to consensus, it helps to have a spirit of respect and compromise at the table. One example we experienced was the recommendation from some of our community members that we use the medicine wheel to frame a particular question in the interview guide, to make it culturally appropriate. Other members were concerned that participants who were not immersed in their traditional culture would be confused, and even offended, by this approach. Our compromise was to have the interviewer ask the participant about their familiarity and comfort with the medicine wheel framework, and then proceed to ask the question accordingly. Group dynamics in large, multidisciplinary teams also can be a challenge at meetings. As some team members were more talkative and dominated discussions at the first general meeting, we provided the opportunity to contribute outside of the meeting by following up with individual members afterwards to get additional feedback one-to-one. Multidisciplinary discussions can become challenging due to differing areas of expertise. To assist community members, we prepare lay-language versions of documents initially written in scientific language (e.g., research proposals), so that they are not inhibited by the technical jargon. At the same time, community partners educate the academic partners about Aboriginal culture, jurisdictional issues, and practical concerns around connecting with patients and clients, as well as other matters. When approached with mutual respect, the challenges of multidisciplinary discussions can be overcome, and the benefits reaped for all involved.

#### **Reflections and Recommendations**

Our experiences with the "Voices and PHACES" study resonate with experiences reported by others who have engaged in CBR (Israel et al., 1998; Savan & Sider, 2003). CBR involves many extra steps above and beyond those entailed in more "traditional" research methods; these can lead

academic researchers to shy away from pursuing CBR. As noted earlier, the demands of CBR can raise particular concerns when considering such an approach as part of a graduate student dissertation. Given the complexity, uncertainty, and extra completion time that CBR adds to a dissertation, there may seem to be little incentive for a graduate student to opt for such a project. The doctoral student leading "Voices and PHACES" (A. Roy) has indeed faced unique challenges in her dissertation relative to her classmates who have pursued more traditional dissertation projects. She has, however, also relished the unparalleled opportunity that the experience has provided her, with respect to building skills in project development and management, and in collaborative research. These skills will be critical for success in her future career in academic research and medicine, in which she hopes to continue working in partnership with Aboriginal communities both as a population health researcher and as a physician. We have found that, while difficult, the challenges associated with CBR are surmountable. Based on our experiences, we can offer some recommendations to readers who are contemplating CBR.

- Draft and agree upon formal terms of reference for partnerships, in writing. Having a written account can help ensure clarity, and it can serve as a written record for future reference by all parties involved. The latter is particularly relevant in light of the length of time that can pass between the forging of partnerships and the start of data gathering.
- Approach conflicting ideas or opinions with a spirit of compromise, whenever possible. When it is not possible to compromise, communicate the reason (e.g., university policies, agency policies, budget constraints, etc.) to defuse the potential for misunderstandings and hurt feelings. Furthermore, never be afraid to ask for flexibility at the institutional level; such requests may have positive results, and may also provide education on CBR that may facilitate its acceptance.
- *Maintain clear and open communication, and encourage back-andforth dialogue.* Ensure that everyone has the opportunity to both hear and be heard, and to contribute meaningfully and equitably to decisions. Keeping everyone "on the same page," so to speak, requires active effort. For academic researchers, use of lay

language to communicate scientific ideas to community partners is integral. Attaching deadlines to tasks and issuing friendly reminders in regards to the progress of tasks can also be helpful for keeping everyone on track. "Checking in" in order to offer support to facilitate task completion is appreciated by community members; for many of them, research activities are often volunteer endeavours, above and beyond their normal job duties.

- *Patience and flexibility are important*. CBR can be timeconsuming, complex, and unpredictable. It is advisable to factor possible delays into projected timelines, and to be prepared to "return to the drawing board" should circumstances around the partnerships change. In this regard, fostering a culture of forgiveness and mutual accountability can help.
- *Mutual respect is integral.* CBR unites academic researchers and community members around a common goal: conducting meaningful inquiry to lead ultimately to beneficial outcomes. Every partner has a role to play in the research, and every partner's contribution is of value for the realization of the research objectives.
- A further recommendation we can offer to academic researchers on CBR in Aboriginal contexts is to learn about cultural protocols *specific to the community* (or communities) involved, notably around how to respectfully approach Elders to participate. Firstly, it is advisable to ask multiple sources about how to identify Elders, as there is variation both between and within communities as to recognition of Elder status. Norms and traditions also vary by community regarding how to approach Elders. In many First Nations communities, it is traditional to approach Elders with tobacco or other sacred items (e.g., cloth items specific to the Elder's tribal culture) when making a request for their involvement (Stiegelbauer, 1996). If unsure, ask: in our experience, Aboriginal community members are more than happy to explain their cultural protocols (and to forgive inadvertent transgressions), when approached respectfully by researchers who have a sincere interest and a genuine desire to work in a true partnership.

#### Conclusion

As with any relationship, challenges can occur in academic-community partnerships. These can be addressed through an approach characterized by mutual respect, cooperation, and clear communication. Academiccommunity partnerships facilitate research that is valid, respectful, and meaningful for "real world" usage. Community partners bring to the table critical perspectives on community needs and contexts, and valuable insight on knowledge translation. Academic partners bring to the table the formal skills and tools required for rigorous, valid research. In combining these strengths, CBR can yield tangible benefits for individuals and populations. The question of benefit is particularly pertinent in the context of Aboriginal health research, in light of the troubling historical record that exists around research about these populations. Along with benefits stemming from the knowledge gained from the research results, there are also broader benefits to the community associated with the participation and capacity-building involved in the research process. For non-Aboriginal external researchers, CBR is also an opportunity to learn about reconciliation. In these ways, CBR that follows the principles of OCAP can be a powerful counter to the legacy of colonization.

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## Appendix C: All Our Babies survey questions corresponding to variables used

- Parity (2<sup>nd</sup> trimester questionnaire)
- Negative experiences with a pregnancy (2<sup>nd</sup> trimester questionnaire)

1. Have you ever been pregnant before? [prevpreg]				
1 - O Yes				
2 - O No If no, skip to question 11.				
2. How many times have you been pregnant (not including this pregnancy)? [numpreg]				
We would now like to ask you some questions about your previous pregnancies, including those you may have lost. Please tell us if you have experienced any of the following and the number of times you have experienced them.				
Have you ever experienced				
3. A miscarriage in the first trimester? (ie. when you were less than or equal to 12 weeks pregnant) [miscarl] 2 - O No				
1-O Yes Number of times: [nummiscar1]				
4. A miscarriage in the second trimester? (ie. when you were 13 to 20 weeks pregnant) [miscar2]				
2 - O No 1 - O Yes Number of times: [nummiscar2]				
5. A stillbirth? (e.g. born dead over 20 weeks gestation or with a weight above 500 grams) [still] 2 - <b>O</b> No				
1 - O Yes Number of times: [numstill]				
6. An abortion? [abort] 2 - O No				
1 - O Yes Number of times: [numabort]				
7. Neonatal death? (death in the first 28 days after birth) [death] 2 - O No				
1 - O Yes Number of times: [numdeath]				
8. Live births? [child] 2 - O No				
1 - O Yes Number of times: [numchild]				
How many months between when your last child was born (ie – delivery date) and the start of this pregnancy?				

months [interpreg]

## 9. Were any of your children less than 2500 grams (5 lbs 5 oz) when they were born? [childlbw] 3 - O Don't Know

- 2-**O** No
- 1-O Yes How many children? \_\_\_\_\_ [numlbw]

10. Were any of your children born preterm (before 37 weeks gestation)? [childptb]

- 3 O Don't Know
- 2-Q No
- 1-O Yes How many children? \_\_\_\_\_ [numptb]
- Social support (2nd and 3rd trimester questionnaires) Medical Outcomes Study Social Support Survey

2. People sometimes look to others for companionship, assistance, or other types of support.

How often is each of the following kinds of support		Fill in only one circle for each line				
available to you if you need it?		None	A little	Some	Most	A11
		of the	of the	of the	of the	of the
		Time	Time	Time	Time	Time
		1	2	3	4	5
Someone to help you if you were confined to bed	[ssbed]	0	0	0	0	0
Someone you can count on to listen to you when you need to talk	[sslisten]	0	0	0	0	0
Someone to give you good advice about a crisis	[sscrisis]	0	0	0	0	0
Someone to take you to the doctor if you needed it	[ssdr]	0	0	0	0	0
Someone who shows you love and affection	[sslove]	0	0	0	0	0
Someone to have a good time with	[ssgood]	0	0	0	0	0
Someone to give you information to help you understand a situation	[ssinfo]	0	0	0	0	0
Someone to confide in or talk to about yourself or your problems	[ssconfide]	0	0	0	0	0
Someone who hugs you	[sshug]	0	0	0	0	0
Someone to get together with for relaxation	[ssrelax]	0	0	0	0	0
Someone to prepare your meals if you were unable to do it yourself	[ssmeal]	0	0	0	0	0
Someone whose advice you really want	[ssadvice]	0	0	0	0	0
Someone to do things with to help you get your mind off things	[ssthings]	0	0	0	0	0
Someone to help with daily chores if you were sick	[sschore]	0	0	0	0	0
Someone to share your most private worries and fears with	[ssfear]	0	0	0	0	0
Someone to turn to for suggestions about how to deal with a personal	[ssdeal]	0	0	0	0	0
problem						
Someone to do something enjoyable with	[ssenjoy]	0	0	0	0	0
Someone who understands your problems	[ssprob]	0	0	0	0	0
Someone to love and make you feel wanted	[sswant]	0	0	0	0	0
Someone available to confide in or talk about your pregnancy	sspreg	0	0	0	0	0

- Psychosocial stress (2nd and 3rd trimester questionnaires) Cohen Perceived Stress Scale
- Depressive symptoms (2nd and 3rd trimester questionnaires) Edinburgh Postnatal Depression Scale

We would like to ask you a series of questions about how you have been feeling.									
	Fill in only one circle for each line								
1. In the <u>past month</u> , how often have you		Never	Almost	Sometimes	Fairly	Ofte			
			Never		Often				
		1	2	3	4	5			
Felt upset by something that happened unexpectantly	psil	O	O	O	D	0			
Felt unable to control important things in your life	psi2	0	0	0	0	0			
Felt nervous or stressed	psi3	Q	Q	Q	Q	Q			
Felt confident in your ability to handle your personal problems	psi4	0	0	0	O	0			
Felt that things were going your way	psi5	Q	Q	Q	Q	000			
Felt unable to cope with all the things you had to do	psió	0	0	0	0	0			
Felt able to control irritations in your life	psi7	0	0	0	0	0			
Felt on top of things	psi8	0	0	0	0	0			
Felt angry because of things that happened that you couldn't control	psi9	D	0	0	0	0			
Felt that difficulties were piling up so high that you couldn't overcome them	psi10	D	O	0	O	O			

For the next questions, please check the answer that comes closest to how you have felt in the <u>past 7 days</u>, not just how you felt today.

- 2. In the past 7 days, I have been able to laugh and see the funny side of things edps1
- 1 O As much as I always could
- 2 O Not quite so much now
- 3 O Definitely not so much now
- 4 **O** Not at all

3. In the past 7 days, I have looked forward with enjoyment to things [edps2]

- 1 O As much as I ever did
- 2 O Rather less than I used to
- 3 O Definitely less than I used to
- 4 O Hardly at all

4. In the past 7 days, I have blamed myself unnecessarily when things went wrong [edps3]

- 1 O Yes, most of the time
- 2 O Yes, some of the time
- 3 O Not very often
- 4 O No, never

#### 5. In the past 7 days, I have been anxious or worried for no good reason edps4

- 1 O No, not at all
- 2 O Hardly ever
- 3 O Yes, sometimes
- 4 O Yes, very often

# 

6. In the past 7 days, I have felt scared or panicky for no very good reason [edps5]	
1 - O Yes, quite a lot	
2 - O Yes, sometimes	
3 - Ō No, not much	
4 - O No, not at all	
7 In the next 7 days things have been prefixed as for a first 1. the	
<ul> <li>7. In the past 7 days, things have been getting on top of me [edps6]</li> <li>1 - O Yes, most of the time I haven't been able to cope at all</li> </ul>	
2 - O Yes, sometimes I haven't been coping as well as usual	
3 - O No, most of the time I have coped quite well	
4 - Q No, I have been coping as well as ever	
· · ··································	
8. In the past 7 days, I have been so unhappy that I have had difficulty sleeping [edps7]	
1-O Yes, most of the time	
2 - O Yes, sometimes	
3 - O Not very often	
4 - O No, not at all	
9. In the <u>past 7 days</u> , I have felt sad or miserable [edps8]	
1 - O Yes, most of the time	
2 - O Yes, sometimes	
3 - O Not very often	
4 - O No, not at all	
10. In the past 7 days, I have been so unhappy that I have been crying edps?	
1 - O Yes, most of the time	
2 - O Yes, quite often	
3 - O Only occasionally	
4 - O No, never	
11. In the <u>past 7 days</u> , the thought of harming myself has occurred to me [edps10]	
1 - Ō Yes, quite often	
2 - O Sometimes	
3 - O Hardly ever	

- 4 O Never
- Personal history of depression (2nd trimester questionnaire)

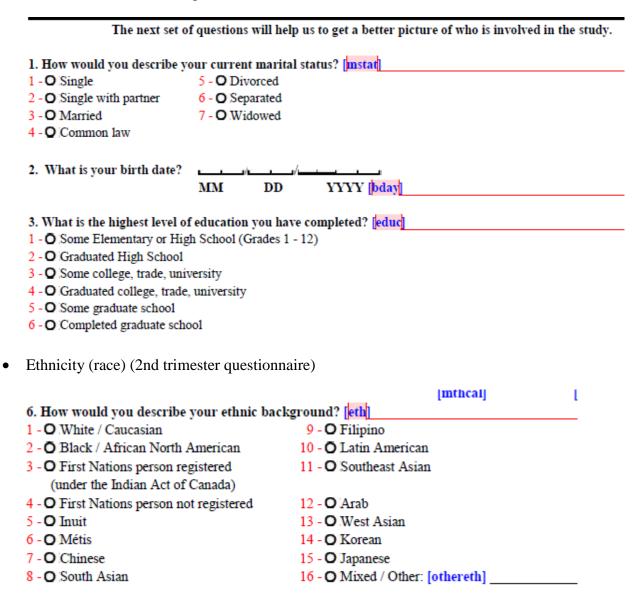
5. Have you ever experienced feeling sad, blue, depressed or down for most of the time for at least 2 weeks? 1 - Q Yes 2 - Q No

• Current physical health (2nd and 3rd trimester questionnaires)

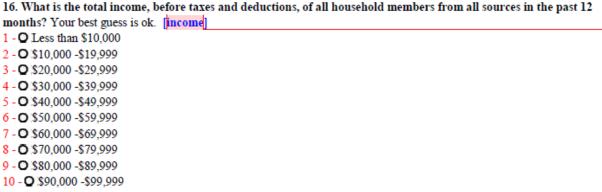
## 13. In general, how would you rate your physical health? [sfl]

- 1 O Excellent 4 O Fair
- 2 O Very good 5 O Poor
- 3 O Good

- Marital status (2nd trimester questionnaire)
- Age (2nd trimester questionnaire)
- Education (2nd trimester questionnaire)



• Income (2nd trimester questionnaire)



- 11 O \$100,000 or more
- Abuse (3rd trimester questionnaire)

We ask all participants if they have experienced any of the following difficult situations. 1. Have you ever you experienced physical abuse? [q2physab] 1 - O Yes 2 - O No

2. Have you ever you experienced emotional abuse (including psychological or verbal? 1- O Yes 2- O No

3. Have you ever you experienced sexual abuse? [q2sexab] 1 - O Yes 2 - O No

4. Have you ever you experienced financial abuse (eg. including withholding or controlling money)? 1- O Yes 2- O No

5. Have you ever you experienced neglect? [q2neglect] 1- O Yes 2- O No

• Discrimination (3rd trimester questionnaire)

7. During this pregnancy, have you experienced discrimination of any kind (age, sex, race, sexual orientation, disability etc.)? [q2discrim]
 1 - Q Yes

2 - Q No

• Employment (3<sup>rd</sup> trimester questionnaire)

1. Which of the following best describes your <u>MAIN</u> activity? Please select only one.

- 1 O Working at a job or business (self-employed, part-time, full-time)
- 2 O A homemaker
- 3 O Looking for a job
- 4 O On maternity leave
- 5 O A student
- 6 O On medical leave
- 7 O Other: [q2othemplstat]
- Diet (2<sup>nd</sup> trimester questionnaire)

## 9. In this pregnancy, on average, how often do you take a prenatal vitamin? [pnvit]

- 1 O Never
- 2 O 1 3 times a week
- 3 0 4 7 times a week

#### Appendix D: Exploratory analyses of All Our Babies ethnicity data

Table D1 shows mean Edinburgh Postnatal Depression Scale (EPDS) scores, as well as proportions scoring above the cut-offs of 10 and 13 (indicating possible clinical depression), across 15 ethnicity categories listed in the All Our Babies questionnaire. A sixteenth category listed in the questionnaire, Inuit, had a sample size of 0, and thus is not listed in the table. The White/Caucasian group had the lowest mean EPDS score estimates of all ethnic groups. The Black/African North American, South Asian, Filipino, Southeast Asian, and Arab groups had higher mean estimates with no overlap in 95% Confidence Intervals (CIs) relative to the White/Caucasian group, suggesting a statistically significant difference. The Chinese, Latin American and Mixed/Other groups also had higher mean estimates relative to the White/Caucasian group, though with some overlap in 95% CIs. First Nations registered, First Nations not registered, Métis, West Asian, Korean and Japanese groups had higher mean estimates relative to White/Caucasian, but had wide CIs that overlapped with the CIs for the White/Caucasian group. The wide CIs of these latter groups are likely due to their very small sample sizes. As with the mean estimates, the proportions facing possible clinical depression, at both 10 and 13 score cut-offs, was notably lower in the White/Caucasian group relative to the other ethnic groups.

As discussed in the main text of the paper (Chapter 3), the 15 ethnicity categories were initially collapsed into three categories: White/Caucasian, Aboriginal (consisting of First Nations registered, First Nations not registered, and Métis groups), and non-Aboriginal racial minority (consisting of the remaining ethnic groups). Tables D2 and D3 each compare the effect of Aboriginal identity with the effect of non-Aboriginal racial minority identity, through the use of

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indicator terms for each with reference to the White/Caucasian group. Table D2 shows the beta coefficients generated using OLS linear regression involving EPDS score as a continuous outcome variable. The beta coefficients in Table D3 represent risk differences generated via binomial regression using generalized linear modelling of the binomial family and identity link, involving EPDS scores dichotomized at the cut-off of 10 to indicate possible clinical depression. In addition to a model with only the two race indicators, models were also run involving adjustment for each of the key risk and protective factors of interest. For the binomial regression modelling of Table D3, adjustments were done only for the variables that remained statistically significant in the final stage of the multivariable OLS linear regression modelling conducted in the main analyses (last column in Table 3.5 in Chapter 3); only these variables were subsequently assessed in the binomial regression modelling documented in Table 3.6, and thus the exploratory analyses in Table D3 were also limited to only those variables.

As can be seen in Table D2, the two race indicators had very similar beta coefficients, indicating similar difference in number of points in mean EPDS score estimates relative to the White/Caucasian group. As one would predict given the very small sample size, the CIs for the Aboriginal indicator were wide for all the beta coefficients, and the corresponding p-values varied with adjustment for different covariates. Tests for interactions between the Aboriginal indicator and each covariate were also run; most were statistically insignificant, with the exception of statistically significant interaction terms with the indicator term for the youngest category of age, and with social support. The beta coefficients and associated CIs and p-values for these interaction terms are documented in Table D2. Conclusions from Table D3 are similar, though the differences in the beta coefficients (risk differences in this case) are slightly more

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pronounced in Table D3 relative to Table D2. However, the CIs in the Aboriginal category are very wide, and include the values of the non-Aboriginal racial minority category.

As stated in the Discussion section of the paper's main text (Chapter 3), further research on the experiences and needs of particular ethnic groups may help in the design of targeted, context-specific interventions. In Table D1, it is apparent that there was diversity in EPDS score between the various ethnicity categories. For example, while all other groups had higher score mean estimates and higher proportions facing possible clinical depression compared to the White/Caucasian group, the Southeast Asian group had values that were strikingly high; these high numbers may suggest unique and/or heightened sources of distress faced by this particular group. Moreover, as discussed in the Introduction and the Discussion of Chapter 3, Aboriginal peoples in Canada face unique sources of distress relative to other groups, due to the ongoing legacy of colonization. Given the small sample size of the Aboriginal category, meaningful interpretation of the results in Tables D2 and D3 is difficult. It is difficult to assess, for example, whether the overall similarity in beta coefficients between the Aboriginal category and the non-Aboriginal racial minority category is genuine, or instead due to a lack of statistical power to detect true differences that may exist. Similarly, it is difficult to interpret the meaningfulness of the interaction effects that were found with young age and with low social support; with only 8 Aboriginal women in the young age category, and only 6 Aboriginal women in the low social support category, generalizability is challenging. Further targeted research is required.

What can, however, be noted from the three tables presented in this appendix is that women from both broad racial minority categories (Aboriginal women and non-Aboriginal racial minority women) experienced markedly higher levels of depressive symptoms relative to White/Caucasian women, and, correspondingly, higher proportions were facing possible clinical

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depression. In this way, the exploratory analyses in this appendix support the overarching

conclusions of the main analyses of the paper, which suggest that falling in the socially dominant

racial category (namely, White/Caucasian) may facilitate better mental health.

ETHNICITY	SAMPLE	MEAN EPDS	PROPORTION	PROPORTION
CATEGORY	SIZE	SCORE [95% CI]	SCORING 10	SCORING 13
			ORABOVE ON	ORABOVE ON
			EPDS	EPDS
White/Caucasian	2481	4.9 [4.7, 5.0]	0.11	0.04
First Nations registered	10	7.8 [4.0, 11.5]	0.40	0.30
First Nations not	5	5.4 [-1.2, 11.8]	0.20	0.20
registered				
Métis	11	5.5 [2.4, 8.7]	0.27	0.09
Black/African	44	6.5 [5.2, 7.8]	0.25	0.11
Chinese	143	5.4 [4.7, 6.1]	0.15	0.06
South Asian	94	6.5 [5.6, 7.3]	0.22	0.13
Filipino	56	7.2 [6.3, 8.2]	0.27	0.05
Latin American	69	5.8 [4.8, 6.7]	0.14	0.04
Southeast Asian	46	8.2 [6.8, 9.7]	0.30	0.22
Arab	39	6.7 [5.2, 8.2]	0.26	0.13
West Asian	11	5.4 [3.1, 7.7]	0.18	0.00
Korean	3	5.5 [-7.1, 18.1]	0.33	0.00
Japanese	10	5.9 [2.4, 9.3]	0.20	0.10
Mixed/Other	105	5.6 [4.8, 6.4]	0.14	0.08

#### Table D1: EPDS scores by 15 ethnicity categories

Table D2: A comparison of the effect of Aboriginal identity and non-Aboriginal racial	
minority identity on continuous EPDS score	

	OLS linear regression Beta coefficient [95% CI] (p-value)		
	Aboriginal category indicator*	Non-Aboriginal racial minority category indicator*	
Race indicators alone	1.4 [-0.04, 2.9] (0.06)	1.3 [0.9, 1.6] (<0.001)	
Adjusted for age	2.7 [0.7, 4.6] (0.007)	1.3 [0.9, 1.6] (<0.001)	
	Interaction term between Aboriginal category indicator and young age indicator: -4.4 [-7.7, -1.0] (0.01)		
Adjusted for parity	1.4 [-0.05, 2.9] (0.06)	1.3 [0.9, 1.6] (<0.001)	

Adjusted for marital status	1.3 [-0.2, 2.8] (0.1)	1.3 [0.9, 1.6] (<0.001)
Adjusted for income	0.9 [-0.6, 2.3] (0.3)	0.9 [0.6, 1.3] (<0.001)
Adjusted for education	1.2 [-0.3, 2.7] (0.1)	1.3 [0.9, 1.6] (<0.001)
Adjusted for employment status	1.2 [-0.3, 2.6] (0.1)	1.2 [0.9, 1.5] (<0.001)
Adjusted for personal depression history	1.3 [-0.2, 2.7] (0.09)	1.5 [1.2, 1.8] (<0.001)
Adjusted for current physical health	1.5 [0.01, 2.9] (0.05)	1.3 [0.9, 1.6] (<0.001)
Adjusted for past negative pregnancy	1.5 [-0.03, 3.0] (0.05)	1.3 [0.9, 1.6] (<0.001)
experiences		
Adjusted for experiences of discrimination	1.4 [-0.1, 2.8] (0.07)	1.2 [0.9, 1.6] (<0.001)
Adjusted for experiences of domestic	1.2 [-0.3, 2.6] (0.1)	1.4 [1.0, 1.7] (<0.001)
violence		
Adjusted for psychosocial stress	0.1 [-1.0, 1.1] (0.9)	0.4 [0.2, 0.7] (<0.001)
Adjusted for social support	-0.6 [-2.6, 1.2] (0.008)	0.6 [0.3, 0.9] (<0.001)
	Interaction term between	
	Aboriginal category indicator	
	and social support:	
	4.7 [1.2, 8.2] (0.008)	
Adjusted for regular vitamin use	1.4 [-0.1, 2.9] (0.06)	1.3 [0.9, 1.6] (<0.001)

\*White/Caucasian group as reference

# Table D3: A comparison of the effect<sup>1</sup> of Aboriginal identity and non-Aboriginal racial minority identity on possible clinical depression (EPDS score 10 or above)

	(generalized linear mode	ial regression I, binomial family, identity link) e [95% CI] (p-value) Non-Aboriginal racial minority category indicator*
Race indicators alone	0.19 [0.01, 0.4] (0.034)	0.08 [0.05, 0.1] (<0.001)
Adjusted for personal depression history	0.14 [-0.04, 0.3] (0.125)	0.09 [0.06, 0.1] (<0.001)
Adjusted for current physical health	0.19 [0.01, 0.4] (0.036)	0.08 [0.05, 0.1] (<0.001)
Adjusted for experiences of domestic	0.18 [0.003, 0.4] (0.046)	0.09 [0.06, 0.1] (<0.001)
violence		
Adjusted for psychosocial stress	-0.02 [-0.03, -0.02] (<0.001)	0.03 [0.009, 0.05] (0.006)
(dichotomized)		
Adjusted for social support	-0.01 [-0.01, 0.1] (0.864)	0.03 [0.009, 0.06] (0.044)
	Interaction term between	
	Aboriginal category indicator	
	and social support:	
	0.47 [0.1, 0.8] (0.006)	

<sup>1</sup>Adjustments presented for variables statistically significant in the OLS multivariable regression modelling \*White/Caucasian group as reference

## Appendix E: List of study team members and community agencies, *Voices and PHACES* study

#### Academic (University of Calgary) research team members:

Amrita Roy Dr. Wilfreda Thurston (Principal Investigator) Dr. Scott Patten Dr. Suzanne Tough Dr. Lynden (Lindsay) Crowshoe Dr. Tanya Beran

#### Community partner research team members:

Alana Heise (CUPS and Awo Taan Healing Lodge) Dayton English (Inn from the Cold, 2011-2013) Linda McLean (Inn from the Cold, starting 2014) J. Gale Getz (Adult Aboriginal Mental Health Program) Nicole Eshkakogan (Elbow River Healing Lodge)

#### Oversight Committee members:

David Turner (community member and Oversight Committee co-chair) Bonnie Healy (community member and Oversight Committee co-chair) Marion Lerat (Elder) Lloyd Ewenin Jr. (Elder) Suzanne Anselmo (Alberta Human Services)

#### Community partner agencies:

Inn from the Cold Calgary Urban Projects Society (CUPS) Awo Taan Healing Lodge Elbow River Healing Lodge of Alberta Health Services Adult Aboriginal Mental Health Program of Alberta Health Services

#### Other recruitment sites:

Northeast Calgary Women's Clinic; Isis Women's Health Clinic; Riley Park Maternity Clinic; Tsuu T'ina Nation – Health and Wellness Centre; Closer to Home and its prenatal program Kiwehtata; Brenda Strafford Centre for the Prevention of Domestic Violence; University of Calgary Native Centre; Mount Royal University Iniskim Centre; Alberta Health Services Calgary and Area Aboriginal Hospital Liaisons program; EFW Radiology's maternal-fetal medicine clinics in Calgary; Alberta Health Services Community Health Centres; Métis Child and Family Services Aboriginal Parent Link Centre

#### Appendix F: *Voices and PHACES* participant recruitment material

Information pamphlet and posters

#### Goals

Based on the interviews, we will develop recommendations, which we will share with our partner organizations as well as other clinical and social service agencies in Calgary. We will also share the recommendations with the Government of Alberta, Aboriginal organizations, Aboriginal communities and Aboriginal women themselves. These recommendations will help guide the design of policies, programs and services, so that they are appropriate and effective for this population. The findings from the interviews will also guide future research.

Alberta Health Services CENTRES Atwo Taan Healing Lodge Society





### For more information on participation, please contact:

Keri Williams (Coordinator)
 Phone: 403-220-5330
 Email: <u>phaces@ucalgary.ca</u>

### For questions on the research, please contact:

 Amrita Roy (MD-PhD Student) Phone: 403-220-5330 Email: <u>amroy@ucalgary.ca</u> OR Dr. Wilfreda Thurston (Professor) Phone: 403-220-6940 Email: <u>thurston@ucalgary.ca</u>

Department of Community Health Sciences, University of Calgary 3rd Floor, TRW Building 3280 Hospital Drive NW Calgary, AB T2N 4Z6





## Voices and PHACES

(Prenatal Health for Aboriginal Communities and EnvironmentS)

'Understanding Depression Among Pregnant Aboriginal Women'

# What

Good mental health during pregnancy is extremely important for the health and wellbeing of mothers and their unborn babies, as well as other family members. While there has been some research on depression during pregnancy (prenatal depression), very little has examined the issue specifically among Aboriginal women. The purpose of this study is to understand the risk factors, protective factors, and social context for mental health in pregnant Aboriginal women. This information will help programs and services to meet the needs of pregnant Aboriginal women and their families.

### Who

We are looking for pregnant women to interview. If you are:

- pregnant (in your second or third trimester)
- Aboriginal
- 18 years of age or older

then we would be delighted if you joined our study. Please contact us for more information. Your participation is completely voluntary, and your answers are confidential. As a thank-you, you will receive a \$25 gift card.

We will also interview health and social services professionals in Calgary who work with pregnant Aboriginal women. If you are interested, please contact us for more information. As a thank-you, an honorarium will be given.

### How

The research team hopes to interview women and healthcare and social services professionals. In order to meet the needs of pregnant Aboriginal women, it is important to understand:

- the experiences of Aboriginal women that impact their feelings during pregnancy
- the effectiveness of existing programs and services, and how they could be improved or expanded upon.

Researchers from the University of Calgary have partnered with five organizations in Calgary:

- Inn from the Cold
- Calgary Urban Project Society (CUPS)



artist: Lisa Brawn

- Awo Taan Healing Lodge
- Elbow River Healing Lodge (Alberta Health Services)
- Adult Aboriginal Mental Health Program (Alberta Health Services)

Aboriginal community members, Elders, and key policy makers are also involved.

The project is funded by The Alberta Centre for Child, Family and Community Research.

# Sharing our stories about

# pregnancy...

#### You are invited to participate in:

## **Voices and PHACES**

### (Prenatal Health for Aboriginal Communities and EnvironmentS)

Researchers from the University of Calgary have partnered with the Adult Aboriginal Mental Health Program, Awo Taan Healing Lodge, Calgary Urban Project Society (CUPS), Elbow River Healing Lodge, and Inn From the Cold to conduct a study on health during pregnancy. The goal is to understand the things that impact the mental wellbeing of Aboriginal mothers-to-be. We would like to interview pregnant Aboriginal women about their experiences.



If you are in your **second or third trimester, Aboriginal, and 18yrs or older,** we would be delighted if you joined our study. As a thank-you, you will receive a \$25 Safeway gift card.

For more information please contact: 1-403-220-5330 OR phaces@ucalgary.ca

This study has been approved by the Conjoint Health Research Ethics Board of the University of Calgary, and is funded by the Alberta Centre for Child, Family and Community Research.

phaces@ucalgary.ca	phaces@ucalgary.ca	phaces@ucalgary.ca	phaces@ucalgary.ca	ہو	phaces@ucalgary.ca	phaces@ucalgary.ca	phaces@ucalgary.ca	phaces@ucalgary.ca	phaces@ucalgary.ca
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Sharing our stories



about

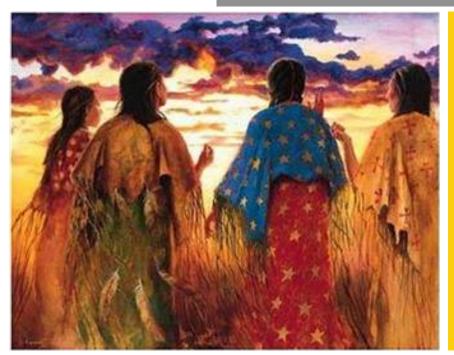
pregnancy...

### You are invited to participate in: **Voices and PHACES** (Prenatal Health for Aboriginal **Communities and EnvironmentS)**

Researchers from the University of Calgary have partnered with the Adult Aboriginal Mental Health Program, Awo Taan Healing Lodge, Calgary Urban Project Society (CUPS), Elbow River Healing Lodge, and Inn From the Cold to conduct a study on health during

The goal is to understand the things that impact the mental wellbeing of Aboriginal mothers-to-be. We would like to interview pregnant Aboriginal women about their experiences.

For more information please contact: 1-403-220-5330 OR phaces@ucalgary.ca



If you are **18yrs or older**, Aboriginal, and in your second or third trimester, we would be delighted if you joined our study. As a thankyou, you will receive a \$25 Safeway gift card.

This study has been approved by the Conjoint Health Research Ethics Board of the University of Calgary, and is funded by the Alberta Centre for Child, Family and Community Research.

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<b>1-403-220-5330</b>	<b>1-403-220-5330</b>	<b>1-4,03-220-5330</b>	<b>1-403-220-5330</b>	<b>1-403-220-5330</b>	<b>1-403-220-5330</b>	<b>1-403-220-5330</b>	<b>1-403-220-5330</b>	<b>1-403-220-5330</b>

#### Appendix G: Voices and PHACES consent forms

For women's interviews, professionals' interviews and community gathering attendees



**<u>TITLE</u>**: Understanding depression among pregnant Aboriginal women: a constructivist grounded theory study in the city of Calgary

**SPONSOR:** University of Calgary

#### **INVESTIGATORS**:

- Dr. Wilfreda E. Thurston, Professor, Department of Community Health Sciences (Faculty of Medicine, University of Calgary) and Department of Ecosystem and Public Health (Faculty of Veterinary Medicine, University of Calgary)
  - Tel: 403-220-6940
  - o E-mail: <u>thurston@ucalgary.ca</u>
- Amrita Roy, MD-PhD Candidate, Department of Community Health Sciences (Faculty of Medicine, University of Calgary)
  - Tel: 403-220-5330
  - E-mail: <u>amroy@ucalgary.ca</u>
- Dr. Scott Patten, Professor, Department of Community Health Sciences and Department of Psychiatry (Faculty of Medicine, University of Calgary)
- Dr. Suzanne Tough, Professor, Department of Community Health Sciences and Department of Pediatrics (Faculty of Medicine, University of Calgary)
- Dr. Lindsay Crowshoe, Assistant Professor, Department of Family Medicine (Faculty of Medicine, University of Calgary)
- Dr. Tanya Beran, Associate Professor, Department of Community Health Sciences (Faculty of Medicine, University of Calgary)

This consent form is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, please ask. Take the time to read this carefully and to understand any accompanying information. You will receive a copy of this form.

#### **BACKGROUND**

The mental wellbeing of pregnant women is important not only for the health of the mother, but also for the health of the child, and the wellbeing of the whole family. Depression is a mental health concern. Depression during pregnancy is known as prenatal depression. A number of factors have been suggested in past studies to be linked to prenatal depression; however, there is still a poor understanding of the risk factors and protective factors involved, and how these factors impact mental health during pregnancy. The understanding is especially limited regarding prenatal depression among pregnant Aboriginal women. Furthermore, while it is generally recognized that issues related to the broader social context of Aboriginal peoples (such as racism, sexism and the history of colonization) affect Aboriginal women's health, very little research has been done to understand their exact impacts.

Ethics ID: 24158 Study Title: Understanding depression among pregnant Aboriginal women PI: Dr. Wilfreda Thurston Version 3 (September 26, 2011) Page 1 of 4 FACULTY OF UNIVERSITY OF MEDICINE CALGARY

#### WHAT IS THE PURPOSE OF THE STUDY?

This study is the first component of a multi-staged research project we are planning to better understand the risk and protective factors of prenatal depression in pregnant Aboriginal women. We will be conducting one-to-one personal interviews with pregnant Aboriginal women, as well as health and social services professionals who work with pregnant Aboriginal women. Through these interviews, we hope to better understand the views of pregnant women and professionals on the factors involved in prenatal depression, as well as on historical and present-day social context as a factor impacting health. We hope that the results of our research will help in the design and implementation of effective programs, services and policies to improve the health and wellbeing of pregnant Aboriginal women.

#### WHAT WOULD I HAVE TO DO?

You have been asked to participate in a face-to-face interview. The interview will take about one hour of time to complete. Interviews will be conducted by a research team member, in a mutually agreed upon place. To provide an accurate record of the interview for our analysis, permission will be requested to audio-tape the interview. You may request that the tape recorder be turned off at anytime during the interview. Notes will also be taken during the interview.

#### WHAT ARE THE RISKS?

There are no direct risks to participation. If any questions we ask you as part of the interview cause you to feel uncomfortable or upset, you are able to refuse to answer and/or to end the interview. We will offer you information and referrals to support services, and will end the interview if it seems to be causing you too much distress.

#### WILL I BENEFIT IF I TAKE PART?

If you agree to participate in this study there may or may not be a direct benefit to you. The information we get from this study may help to provide better programs and services in the future to pregnant Aboriginal women.

#### **DO I HAVE TO PARTICIPATE?**

Your participation is completely voluntary. If you decide participate, you may ask questions, make comments, refuse to answer any questions, or withdraw participation completely, at any point in the study. Should you wish to withdraw from the study, please inform the research team member or contact the individuals listed below.

#### WHAT ELSE DOES MY PARTICIPATION INVOLVE?

Your participation involves only the time required for the interview.

Ethics ID: 24158 Study Title: Understanding depression among pregnant Aboriginal women PI: Dr. Wilfreda Thurston Version 3 (September 26, 2011) Page 2 of 4



At the end of your interview, you will be asked for your permission for us to contact you again in a few months' time, for a second interview. During this follow-up interview, we will share the results of our research, and get your opinion about whether you feel the results are accurate. Participation in this first interview does <u>not</u> obligate you to participate in the second interview, if you do not wish to do so.

#### WILL I BE PAID FOR PARTICIPATING, OR DO I HAVE TO PAY FOR ANYTHING?

To thank you for your time, and to cover any expenses that you may incur due to your participation (such as transportation costs to the interview location, childcare, or other costs), you will receive \$25 in the form of a Safeway gift card.

If you decide to participate in our follow-up interview (see above), you will again receive a \$25 gift card.

#### WILL MY RECORDS BE KEPT PRIVATE?

Yes. Your privacy and confidentiality will be assured. Your identifying information (name and contact information) will be separated from your interview answers, and will never be released in any reports or publications stemming from this research. Your interview answers will be pooled with interview answers from other participants, and analyzed in grouped form. Participant information and interviews will be securely stored in locked cabinets in the Department of Community Health Sciences (Faculty of Medicine, University of Calgary), and electronic files will be password-protected. Except as required by law, access to the list of names of participants is limited to the lead investigators.

Your information and answers will remain confidential. Please note, however, that if you reveal to us that any children under the age of 18 years have been, or may be, in danger of harm or neglect, we are legally obligated to report this to Alberta Child and Youth Services. You will be reminded of this obligation at the start of your interview.

#### AGREEMENT TO PARTICIPATE

#### **Option 1: SIGNATURES**

Your signature on this form indicates that you have understood to your satisfaction the information regarding your participation in the research project and agree to participate as a subject. In no way does this waive your legal rights nor release the investigators or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time without jeopardizing your health care. If you have further questions concerning matters related to this research, please contact:

Dr. Wilfreda (Billie) Thurston : (403) 220-6940 Or

Ethics ID: 24158 Study Title: Understanding depression among pregnant Aboriginal women PI: Dr. Wilfreda Thurston Version 3 (September 26, 2011) Page 3 of 4



Amrita Roy : (403) 220-5330

If you have any questions concerning your rights as a possible participant in this research, please contact The Director, Office of Medical Bioethics, University of Calgary, at 403-220-7990.

Participant's Name	Signature and Date
Investigator/Delegate's Name	Signature and Date
Witness' Name	Signature and Date

The University of Calgary Conjoint Health Research Ethics Board has approved this research study. A signed copy of this consent form has been given to you to keep for your records and reference.

Option 2: VERBAL CONSENT

Your verbal consent indicates that you have understood to your satisfaction the information regarding your participation in the research project and agree to participate as a subject. In no way does this waive your legal rights nor release the investigators or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time without jeopardizing your health care. If you have further questions concerning matters related to this research, please contact:

Dr. Wilfreda (Billie) Thurston : (403) 220-6940 Or Amrita Roy : (403) 220-5330

If you have any questions concerning your rights as a possible participant in this research, please contact The Director, Office of Medical Bioethics, University of Calgary, at 403-220-7990.

The University of Calgary Conjoint Health Research Ethics Board has approved this research study. A copy of this consent form has been given to you to keep for your records and reference.

Ethics ID: 24158 Study Title: Understanding depression among pregnant Aboriginal women PI: Dr. Wilfreda Thurston Version 3 (September 26, 2011) Page 4 of 4



**<u>TITLE</u>**: Understanding depression among pregnant Aboriginal women: a constructivist grounded theory study in the city of Calgary

**SPONSOR:** University of Calgary

#### **INVESTIGATORS**:

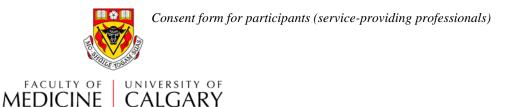
- Dr. Wilfreda E. Thurston, Professor, Department of Community Health Sciences (Faculty of Medicine, University of Calgary) and Department of Ecosystem and Public Health (Faculty of Veterinary Medicine, University of Calgary)
  - Tel: 403-220-6940
  - o E-mail: <u>thurston@ucalgary.ca</u>
- Amrita Roy, MD-PhD Candidate, Department of Community Health Sciences (Faculty of Medicine, University of Calgary)
  - o Tel: 403-220-5330
  - E-mail: <u>amroy@ucalgary.ca</u>
- Dr. Scott Patten, Professor, Department of Community Health Sciences and Department of Psychiatry (Faculty of Medicine, University of Calgary)
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- Dr. Lindsay Crowshoe, Assistant Professor, Department of Family Medicine (Faculty of Medicine, University of Calgary)
- Dr. Tanya Beran, Associate Professor, Department of Community Health Sciences (Faculty of Medicine, University of Calgary)

This consent form is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, please ask. Take the time to read this carefully and to understand any accompanying information. You will receive a copy of this form.

#### **BACKGROUND**

The mental wellbeing of pregnant women is important not only for the health of the mother, but also for the health of the child, and the wellbeing of the whole family. Depression is a mental health disorder. Depression during pregnancy is known as prenatal depression. A number of factors have been suggested in past studies to be linked to prenatal depression; however, there is still a poor understanding of the risk factors and protective factors involved, and how these factors impact mental health during pregnancy. The understanding is especially limited regarding prenatal depression among pregnant Aboriginal women. Furthermore, while it is generally

Ethics ID: 24158 Study Title: Understanding depression among pregnant Aboriginal women PI: Dr. Wilfreda Thurston Version 3 (September 26, 2011) Page 1 of 4



recognized that issues related to the broader social context of Aboriginal peoples (such as racism, sexism and the history of colonization) affect Aboriginal women's health, very little research has been done to understand their exact impacts.

#### WHAT IS THE PURPOSE OF THE STUDY?

This study is the first component of a multi-staged research project we are planning to better understand the risk and protective factors of prenatal depression in pregnant Aboriginal women. We will be conducting one-to-one personal interviews with pregnant Aboriginal women, as well as health and social services professionals who work with pregnant Aboriginal women. Through these interviews, we hope to better understand the views of pregnant women and professionals on the factors involved in prenatal depression, as well as on historical and present-day social context as a factor impacting health. We hope that the results of our research will help in the design and implementation of effective programs, services and policies to improve the health and wellbeing of pregnant Aboriginal women.

#### WHAT WOULD I HAVE TO DO?

You have been asked to participate in a face-to-face interview. The interview will take about one hour of time to complete. Interviews will be conducted by a research team member, in a mutually agreed upon place. To provide an accurate record of the interview for our analysis, permission will be requested to audio-tape the interview. You may request that the tape recorder be turned off at anytime during the interview. Notes will also be taken during the interview.

#### WHAT ARE THE RISKS?

There are no risks to participation.

#### WILL I BENEFIT IF I TAKE PART?

If you agree to participate in this study there may or may not be a direct benefit to you. The information we get from this study may help to provide better programs and services in the future to pregnant Aboriginal women.

#### **DO I HAVE TO PARTICIPATE?**

Your participation is completely voluntary. If you decide participate, you may ask questions, make comments, refuse to answer any questions, or withdraw participation completely, at any point in the study. Should you wish to withdraw from the study, please inform the research team member or contact the individuals listed below.

Ethics ID: 24158 Study Title: Understanding depression among pregnant Aboriginal women PI: Dr. Wilfreda Thurston Version 3 (September 26, 2011) Page 2 of 4



#### WHAT ELSE DOES MY PARTICIPATION INVOLVE?

Your participation involves only the time required for the interview.

At the end of your interview, you will be asked for your permission for us to contact you again in a few months' time, for a second interview. During this follow-up interview, we will share the results of our research, and get your opinion about whether you feel the results are accurate. Participation in this first interview does <u>not</u> obligate you to participate in the second interview, if you do not wish to do so.

#### WILL I BE PAID FOR PARTICIPATING, OR DO I HAVE TO PAY FOR ANYTHING?

To thank you for your time you will be given an honorarium of \$25. If you decide to participate in our follow-up interview (see above), you will again be given \$25.

#### WILL MY RECORDS BE KEPT PRIVATE?

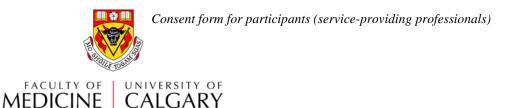
Yes. Your privacy and confidentiality will be assured. Your identifying information (name and contact information) will be separated from your interview answers, and will never be released in any reports or publications stemming from this research. Your interview answers will be pooled with interview answers from other participants, and analyzed in aggregate form. Participant information and interviews will be securely stored in locked cabinets in the Department of Community Health Sciences (Faculty of Medicine, University of Calgary), and electronic files will be password-protected. Except as required by law, access to the list of names of participants is limited to the lead investigators.

#### AGREEMENT TO PARTICIPATE

#### **Option 1: SIGNATURES**

Your signature on this form indicates that you have understood to your satisfaction the information regarding your participation in the research project and agree to participate as a subject. In no way does this waive your legal rights nor release the investigators or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time without jeopardizing your health care. If you have further questions concerning matters related to this research, please contact:

Dr. Wilfreda (Billie) Thurston : (403) 220-6940 Or Amrita Roy : (403) 220-5330



If you have any questions concerning your rights as a possible participant in this research, please contact The Director, Office of Medical Bioethics, University of Calgary, at 403-220-7990.

Participant's Name	Signature and Date
Investigator/Delegate's Name	Signature and Date

The University of Calgary Conjoint Health Research Ethics Board has approved this research study. A signed copy of this consent form has been given to you to keep for your records and reference.

Signature and Date

Option 2: VERBAL CONSENT

Witness' Name

Your verbal consent indicates that you have understood to your satisfaction the information regarding your participation in the research project and agree to participate as a subject. In no way does this waive your legal rights nor release the investigators or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time without jeopardizing your health care. If you have further questions concerning matters related to this research, please contact:

Dr. Wilfreda (Billie) Thurston : (403) 220-6940 Or Amrita Roy : (403) 220-5330

If you have any questions concerning your rights as a possible participant in this research, please contact The Director, Office of Medical Bioethics, University of Calgary, at 403-220-7990.

The University of Calgary Conjoint Health Research Ethics Board has approved this research study. A copy of this consent form has been given to you to keep for your records and reference. Ethics ID: 24158 Study Title: Understanding depression among pregnant Aboriginal women PI: Dr. Wilfreda Thurston Version 3 (September 26, 2011) Page 4 of 4



#### **Consent to Participate in Research**

**<u>TITLE</u>**: Understanding depression among pregnant Aboriginal women: a constructivist grounded theory study in the city of Calgary

**SPONSOR:** University of Calgary

#### **INVESTIGATORS**:

- Amrita Roy, MD-PhD Candidate, Department of Community Health Sciences (Faculty of Medicine, University of Calgary)
  - o Tel: 403-220-5330
  - o E-mail: amroy@ucalgary.ca
- Dr. Wilfreda E. Thurston, Professor, Department of Community Health Sciences (Faculty of Medicine, University of Calgary) and Department of Ecosystem and Public Health (Faculty of Veterinary Medicine, University of Calgary)
  - o Tel: 403-220-6940
  - o E-mail: thurston@ucalgary.ca
- Dr. Scott Patten, Professor, Department of Community Health Sciences and Department of Psychiatry (Faculty of Medicine, University of Calgary)
- Dr. Suzanne Tough, Professor, Department of Community Health Sciences and Department of Pediatrics (Faculty of Medicine, University of Calgary)
- Dr. Lindsay Crowshoe, Assistant Professor, Department of Family Medicine (Faculty of Medicine, University of Calgary)
- Dr. Tanya Beran, Associate Professor, Department of Community Health Sciences (Faculty of Medicine, University of Calgary)

This consent form is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, please ask. Take the time to read this carefully and to understand any accompanying information. You will receive a copy of this form.

#### BACKGROUND

The mental wellbeing of pregnant women is important not only for the health of the mother, but also for the health of the child, and the wellbeing of the whole family. Depression is a mental health concern. Depression during pregnancy is known as prenatal depression. A number of factors have been suggested in past studies to be linked to prenatal depression;

Understanding depression among pregnant Aboriginal women Ethics ID: 24158, PI: Dr. Wilfreda Thurston Version 1 – March 17, 2014 Page 1 of 4 however, there is still a poor understanding of the risk factors and protective factors involved, and how these factors impact mental health during pregnancy. The understanding is especially limited regarding prenatal depression among pregnant Aboriginal women. Furthermore, while it is generally recognized that issues related to the broader social context of Aboriginal peoples (such as racism, sexism and the history of colonization) affect Aboriginal women's health, very little research has been done to understand their exact impacts.

#### WHAT IS THE PURPOSE OF THE STUDY?

This study is a component of a multi-staged research project to better understand the risk and protective factors of prenatal depression in pregnant Aboriginal women. As part of this study we conducted one-to-one personal interviews with pregnant Aboriginal women, as well as health and social services professionals who work with pregnant Aboriginal women. The information gathered in this study will help us to better understand the views of pregnant women and professionals on the factors involved in prenatal depression, as well as on historical and present-day social context as a factor impacting health. We hope that the results of our research will help in the design and implementation of effective programs, services and policies to improve the health and wellbeing of pregnant Aboriginal women.

#### WHAT WOULD I HAVE TO DO?

You are asked to participate in a workshop. We want to find out what you think about the results of our study and, based on these results, what recommendations you would suggest. During the workshop you will attend a presentation on research results and be asked to share your thoughts and opinions.

The researchers are interested in your feedback. You will be asked to provide feedback in a group format using written and/or verbal methods. The time commitment for you is approximately four hours.

#### WHAT ARE THE RISKS?

There are no risks to you from being in this study. You do not have to answer all the questions, and you can quit at any time.

#### WILL I BENEFIT IF I TAKE PART?

You will not likely benefit directly from taking part in this study however we hope this study will provide valuable information that can be used to address the issue of prenatal depression among pregnant Aboriginal women.

#### DO I HAVE TO PARTICIPATE?

You do not have to take part in this study. You can also stop at any time. Your participation is entirely voluntary and you can refuse to participate without losing your rights. You do not have to answer every question asked of you. Remember that all information provided will be held confidential and will not be released except as provided in this letter.

If at any time you want to withdraw from the study altogether, just contact the research team.

#### WHAT ELSE DOES MY PARTICIPATION INVOLVE?

We will need to collect your name, the name of your organization and contact information for workshop registration purposes.

#### WILL I BE PAID FOR PARTICIPATING, OR DO I HAVE TO PAY FOR ANYTHING?

You will not be paid. You will not have to pay for anything related to the workshop. You will be provided lunch to thank you for your participation.

#### WILL MY RECORDS BE KEPT PRIVATE?

If you sign this consent form, you are agreeing to take part in this study. Audio recordings will be made of group discussions during the workshop. Notes will be taken during the workshop and written notes from individuals and groups will be collected.

If there is something you would not like to be discussed or known, please do not feel any pressure to share it with the research team.

Your name or any other identifying information will not be directly attached to the information you give. Your name will also never be used in presentations or publications of the study results.

Your information and consent form will be kept locked up for at least five years after the study is done. The information will be kept in a secure area at the University. Everything you say will remain confidential and only the research team will see this information, unless a law requires us to share it.

The information gathered for this study may be looked at again in the future to help us answer other questions. If so, the ethics board will first review the study to make sure the information is used ethically.

#### Signatures

Your signature on this form indicates that you have understood to your satisfaction the information regarding your participation in the research project and agree to participate as a participant. In no way does this waive your legal rights nor release the investigators or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time. If you have further questions concerning matters related to this research, please contact:

Amrita Roy	403-220-5330
Dr. Wilfreda E. Thurston	403-220-6940

If you have any questions concerning your rights as a possible participant in this research, please contact The Chair, Conjoint Health Research Ethics Board, University of Calgary, at 403-220-7990.

Participant's Name	Signature and Date
Investigator/Delegate's Name	Signature and Date
Witness' Name	Signature and Date

The University of Calgary Conjoint Health Research Ethics Board has approved this research study.

A signed copy of this consent form has been given to you to keep for your records and reference.

Understanding depression among pregnant Aboriginal women Ethics ID: 24158, PI: Dr. Wilfreda Thurston Version 1 – March 17, 2014 Page 4 of 4

#### Appendix H: *Voices and PHACES* interview guides

First interviews and member-checking interviews, with women and professionals respectively

#### Voices and PHACES INTERVIEW GUIDE FOR THE WOMEN

TURN ON RECORDER. NOTE DOWN START TIME:

*If oral consent is desired by participant:* **I have reviewed the consent form with you. Do you consent to be part of this project?** 

If written consent has been given by participant: Thank you for signing the consent form.

[MAKE SURE PARTICIPANT RECEIVES A COPY OF THE CONSENT FORM]

Thank you very much for agreeing to be part of this project. We hope that the results of this study will help organizations and groups in setting up programs, services and policies to support the health and wellbeing of pregnant Aboriginal women.

So that we can accurately capture everything that you are telling us, we would like your permission to tape record this interview. You may request that the tape recorder be turned off at anytime during the interview. May we have your permission to record? [NOTE DOWN RESPONSE. RECORDER IS EITHER LEFT ON OR TURNED OFF, ACCORDINGLY.]

We know that you are busy, and we appreciate the time you are taking to speak with us. To thank you for your time, and to cover any costs you may have had in order to be here with me today, we would like to give you \$25 in the form of a Safeway gift card. Please initial this form to indicate that you have received this from us. [GET INITIALS ON SUBJECT FEE LOG FORM]

Our conversation will be about an hour, and your participation is completely voluntary. At any point during our interview, you may ask questions, make comments, not answer the question, or stop the interview. You are also free to withdraw from the study at any point. Should you wish to withdraw, please let me know, or please contact the individuals listed on the consent form (I can also give you their contact information again).

If any questions I ask you as part of the interview cause you to feel uncomfortable or upset, you don't have to answer, and you can even end the interview if you want. This is a list of contacts for services that may be helpful, if you need support. [GIVE LIST OF RESOURCES]. [AGENCY NAME] can offer you support as well if you need it. [INSERT NAME OF AGENCY FROM WHICH PARTICIPANT WAS RECRUITED]

Your information and answers will remain confidential. Please note, however, there are limits to confidentiality where I am obligated by law to report: specifically, when there is a reasonable suspicion of abuse and/or neglect to a child under the age of 18 years, we are legally obligated to report this to Alberta Human Services, the ministry responsible for child intervention services.

FOR *CUPS*, *AWO TAAN* AND *INN FROM THE COLD* PARTICIPANTS: In the event of such a disclosure by you, we will first talk to [AGENCY] and get their assistance.

#### Do you have any questions before we begin?

#### ANSWER PARTICIPANT QUESTIONS BEFORE MOVING ON

Section A - Open-ended questions

THIS SECTION OF THE INTERVIEW INVOLVES OPEN-ENDED QUESTIONS. THE FOLLOWING QUESTIONS ARE TO BE USED AS A GUIDE. THE ORDER OR MANNER OF ASKING MAY BE TAILORED TO THE FLOW OF THE CONVERSTATION. PROBE AS APPROPRIATE, BASED ON THE PARTICIPANT'S RESPONSES.

TO "BREAK THE ICE", AND ALSO TO GET SOME INSIGHT ON THE PREGNANCY, YOU MAY WANT TO START BY ASKING HOW FAR ALONG IN THE PREGNANCY SHE IS, AND WHETHER THE BABY WILL BE HER FIRST CHILD. THESE ARE ASKED FORMALLY LATER IN THE INTERVIEW, BUT KNOWING THE INFORMATION HERE MAY BE HELPFUL AS YOU CONVERSE WITH HER ON THE OPEN-ENDED QUESTIONS.

1. Some people think of health and wellbeing as having many aspects. In Aboriginal traditions, these can be thought of as the four directions - physical, emotional, spiritual, and mental, as shown in this circle [SHOW FIRST DIAGRAM]. Taking these four aspects into consideration, how have you been feeling during this pregnancy?

#### If not mentioned, probe about the following:

- a. What leads to feeling good or bad emotionally for you? [probe as needed to get at factors in her life circumstances or experiences, in her social environment, in her physical environment or surroundings, etc.]
  - i. When would you use the term "depression"? What does this term mean to you?
- b. How do you cope with stressful things in life?
  - i. Do you participate in traditional Aboriginal activities to relieve stress?
- c. How do your relationships with the people in your life impact your well-being? [probe both about positive (e.g., supportive) and negative (e.g., stressful) relationships; and, about various types of relationships intimate partner, family, friends, neighbours/community, colleagues, service-providers]
- d. *If she has not already addressed:* Thinking about yourself and other pregnant Aboriginal women who you know, what do you think affects wellbeing during pregnancy?

### 2. How do you feel about the way you are treated in your life as a woman and as an Aboriginal woman?

[Keep in mind the intersections of different aspects of her identity: Aboriginal person, female, pregnant female, etc. Probe as needed to get at these aspects. Let her speak about her life generally at first. Later, if she doesn't make the connections herself, probe about whether she feels there is a connection between her life experiences and her mental wellbeing during her current pregnancy.]

*If not mentioned, probe:* 

- a. What experiences have you had where you have been treated well as a woman and/or as an Aboriginal woman? What about experiences where you have been treated badly as a woman and/or an Aboriginal woman?
- b. Tell me about any experiences of violence in your life.
  - i. How have these affected your well-being?
- c. Does being pregnant change these experiences? [perhaps probe around examples she has given]
- d. Are there ways in which being an Aboriginal woman makes you feel good? *[probe around how her identity might impact her positively]*
- 3. Some people feel that our lives as individuals are connected with the lives of others around us; therefore, our feelings and emotions can be impacted by others, like in this circle, which is based on Aboriginal traditions. [SHOW SECOND DIAGRAM]. Tell me about how experiences that family members, friends, or your community have had that have affected your well-being, both in good ways and in bad ways. [Use the diagram to help ensure all aspects (family/friends/community) are explored. If not raised: Does the residential school history come into this? Possible ways to approach the residential school issue is to ask whether anyone close to her was in a residential school, how that experience appeared to have impacted that person, and how that person's experiences in turn may have impacted her e.g. through the way that person treated her, etc. Can also ask about other occurrences of colonization, depending on the flow of the conversation. For example, can approach the "Sixties Scoop" and other examples of removal of Aboriginal children by asking about whether anyone close to her has had their children taken away (or were taken away from their birth parents), how that experience impacted that person, how it impacted her, etc.]
  - a. Does being pregnant change these experiences? [perhaps probe around examples she has given]

### 4. What programs do you know that already exist to support pregnant Aboriginal women?

*If not mentioned, probe:* 

- a. *Has she used any of these? If yes, what led her to use them? If not, why not? (i.e., What are the barriers and facilitators to use?)*
- b. What worked well for her about the programs? What didn't work well? How could they be improved, in her opinion?
- c. Does she see a physician regularly (in general, and specifically related to prenatal care)? When did she start getting prenatal care during her present pregnancy (and previous pregnancies, if applicable)?
- 5. Of the things you have talked about, which are the first that should be addressed by programs, leaders, Elders or governments?

Section B – Edinburgh Postnatal Depression Scale

Thank you for sharing your thoughts and stories with me. I now have a sheet for you to fill out, with a few short questions about how you've been feeling during the last week. For each of the following ten questions, please think about which answer choice best reflects how you've been feeling during the last seven days. Please feel free to ask me if you any questions about the sheet. [CAN OFFER TO READ OUT THE QUESTIONS AND ANSWER OPTIONS, IF SHE APPEARS TO HAVE DIFFICULTY WITH READING THEM.]

Section C – General questions

We're almost done the interview. I now have a few short general questions about you and your family:

NOTE: DO <u>NOT</u> READ OUT RESPONSE OPTIONS UNLESS THE INSTRUCTIONS SPECIFY OTHERWISE.

- 1. What is your year of birth? \_\_\_\_\_
- 2. When is your baby due, according to your doctor? DD\_\_\_/MM\_\_\_/YY\_\_\_\_
- 3. Do you have other children?
  - □ No  $\rightarrow$  SKIP TO QUESTION 4
  - □ Yes  $\rightarrow$  GO TO QUESTION 3A

3a. How old were you when your first child was born? \_\_\_\_\_

**3b.** How many children are currently living with you (i.e., including adopted children and step-children)?

**3c.** Starting with the oldest child, what are the ages of the children living with you?

1) \_\_\_\_\_ 2) \_\_\_\_\_ 3) \_\_\_\_\_ 4) \_\_\_\_\_ 5) \_\_\_\_\_ 6) \_\_\_\_\_ 7) \_\_\_\_\_ 8) \_\_\_\_\_

**3d. Do you have any biological children who are not living with you? If yes, how many?** [IF NO, ENTER ZERO AND GO TO QUESTION 4; IF YES, ENTER NUMBER AND GO TO QUESTION 3E]

\_\_\_\_\_

3e. If yes, for what reasons are they living elsewhere?



- □ Legally married
- □ Living common-law
- $\Box$  Widowed
- □ Separated
- □ Divorced
- □ Single, never married

#### 5. What is your current employment status?

- □ Employed full-time
- □ Employed part-time
- □ Temporarily laid off
- □ On leave of absence (NOT maternity leave)
- □ Looking for work
- □ Homemaker
- Maternity/ Parental leave
- □ Student
- □ Permanently unable to work (e.g., on AISH)
- □ Other (please specify)\_\_\_\_\_

/YY

#### 6. How far did you go in school?

- □ Elementary
- □ Junior high
- □ High school not completed (completed up to grade: \_\_\_\_\_)
- □ High school completed (diploma earned)
- □ Trades certificate or diploma from a vocational school or apprenticeship training
- □ Non-university certificate or diploma from a community college
- University certificate below bachelor's level
- □ Bachelor's degree
- University degree, certificate or diploma above bachelor's degree (e.g. postgraduate work, professional training, etc.)
- 7. We would like to get an estimate of your total household income for the past year, from all sources, before taxes and deductions. By this we mean income combined from everyone living in the home, from *all* sources including employment, pensions, government support, scholarships, student loans and inheritances. Was your household income greater than or less than \$40,000?
  - □ Greater than or equal to  $40,000 \rightarrow$  GO TO QUESTION 7A, READ THE RESPONSE CATEGORIES OUT
    - 7a. Was your income
      - \$40,000 to under \$60,000
      - \$60, 000 to under \$80, 000
      - **\$80,000 or more**
  - □ Less than \$40,000 → GO TO QUESTION 7B, READ THE RESPONSE CATEGORIES OUT

#### 7b. Was your income

- Less than \$15,000
- \$15,000 to under \$25,000
- \$25,000 to under \$40,000
- Doesn't know
- Chose not to answer

7c. How many people are in your household? \_\_\_\_\_

8. Medically-speaking, depression is when you feel sad or upset for a long time, generally more than two weeks. In addition to feeling sad, other possible symptoms may (or may not) also include things like loss of appetite, weight changes, sleep problems, trouble remembering things, and feeling tired. Have you ever felt depressed?

□ No

- □ Yes  $\rightarrow$  IF PREVIOUSLY PREGNANT, GO TO QUESTION 8A.
  - OTHERWISE, GO TO QUESTION 9 8a. Were you feeling depressed during a previous pregnancy, or within 6 months after giving birth?
    - no
    - yes

## 9. Have you ever been told by a healthcare professional (e.g., a doctor, a nurse, a psychologist) that you were depressed?

- □  $N_0 \rightarrow SKIP$  TO QUESTION 10
- □ Yes → IF PREVIOUSLY PREGNANT, GO TO QUESTION 9A. OTHERWISE, SKIP TO QUESTION 9B

9a. Were you diagnosed with prenatal depression or postpartum depression? (i.e., depression during a pregnancy or within six months after giving birth)

- o no
- yes

#### 9b. Have you been treated for depression?

- o no
- yes
  - medication
  - □ talk therapy
  - both medication and talk therapy
  - other, please specify \_\_\_\_\_

#### **10.** Have others in your family been depressed?

- □ No  $\rightarrow$  SKIP TO QUESTION 11
- □ Don't know  $\rightarrow$  SKIP TO QUESTION 11
- □ Yes  $\rightarrow$  GO TO QUESTION 10A

## **10a.** Were any of your family members told they were depressed by a healthcare professional?

- o No
- o Yes
- Don't know

#### 11. Has anyone in your family ended their own life by suicide?

- □ No
- Don't know
- □ Yes

#### 12. How would you describe your Aboriginal identity?

- **□** First Nations with Indian status
- **□** First Nations without Indian status
- □ Métis
- □ Inuit
- Other, please specify \_\_\_\_\_\_

#### 13. Do you presently live on a First Nations reserve?

No	
0	13a. Do you usually live, or have you previously lived, on a
	First Nations reserve?
	$\Box$ No
	$\Box$ Yes
Yes	

Section D - Concluding thoughts

Do you have anything to add about any of the issues we've talked about, or any other thoughts about the health and wellbeing of yourself, or pregnant Aboriginal women generally?

\* \* \*

Thank you very much for your participation in this study. Do you have any questions, comments or concerns at this time? Just a reminder that you can contact us at any time later, too.

**Would you like to receive a copy of your interview transcript?** [NOTE DOWN RESPONSE. IF YES, INQUIRE WHETHER E-MAIL OR POSTAL MAIL IS PREFERRED, AND GET THE CONTACT INFORMATION FOR SENDING THE TRANSCRIPT.]

We will be interviewing a number of people, and we hope to take the information from all of the interviews and write up our research results. We would like to return to all of our participants to share the results and ask for feedback, to make sure that we have properly understood all of the important issues.

Can we have your permission to contact you in a few months' time, to ask about the possibility of another interview? [NOTE DOWN PARTICIPANT ANSWER] Should we use the same contact information we have on file for you? [NOTE DOWN ANY CHANGES, OR ADDITIONAL OPTIONS (E.G., E-MAIL IN ADDITION TO PHONE).] Is there anyone we could contact in case you are away or have moved at that time? [NOTE DOWN SECONDARY CONTACT.] Is it okay if we leave messages at the phone number(s) you have given?

At the end of the study, we will be sharing our results with community agencies through a report and through presentations. Would you like to receive a copy of the report? [NOTE DOWN HER ANSWER] Would you like to be notified of when and where we are presenting? [NOTE DOWN HER ANSWER]. IF YES TO EITHER OF THE ABOVE QUESTIONS: How should we contact you?

Thank you again for your time, we really appreciate it! TURN OFF RECORDER. NOTE DOWN STOP TIME: \_\_\_\_\_

# **Services in Calgary**

#### FOR IMMEDIATE HELP:

- DIAL 911 for police, fire, or ambulance
- Distress Centre
  - CALL: (24hr) 403-266-HELP (4357)
- HEALTHLink Alberta
  - CALL: (24hr) 866-408-5465
- Connect Family & Sexual Abuse Network
  - CALL: (24hr) 403-237-5888; or TOLL FREE: (24hr) 877-237-5888
- ConnecTeen (Distress Centre)
  - CALL: (5pm-10pm) 403-264-TEEN (8336)
- Alberta Children's Hospital
  - o CALL: 403-955-7211
- Kids Help Phone
  - CALL: (24hr) 800-668-6868

# Or you can dial 211 for further assistance.

#### Voices and PHACES Community Partners:

- Adult Aboriginal Mental Health
  - Offers assessment, treatment and counseling services, information, cultural awareness education and consultation, and referral or outreach support, including access to traditional healing
  - Website: www.albertahealthservices.ca
  - Located at: Sheldon M. Chumir Health Centre, Elbow River Healing Lodge, 7 Floor 1213 4 Street SW, Calgary, Alberta T2R oX7
  - o CALL: 403-955-6645
- Awo Taan
  - Is a full-service women's and children's emergency shelter providing care for women and children suffering abuse
  - Website: <u>www.awotaan.org</u>
  - CALL: (Main) 403-531-1970, ext. 200; or (Crisis) 403-531-1972 or 403-531-1976

#### Calgary Urban Project Society (CUPS)

- Offers collaborative and holistic services in the areas of health care, education and social service
- Website: <u>cupscalgary.com</u>
- Located at: 128-7 Ave SE, Calgary, Alberta T2G oH5
- o CALL: 403-221-8780

#### Elbow River Healing Lodge Society

- Offers a wide-range of services including family medicine, focused primary medical care (women's wellness, prenatal care, care for people with diabetes), foot and wound care, health promotions and immunization, community liaison services, street outreach, traditional wellness counseling, and adult mental health care
- Website: www.albertahealthservices.ca
- Located at: Sheldon M. Chumir Health Centre, Elbow River Healing Lodge, 7 Floor 1213 4 Street SW, Calgary, Alberta T2R oX7
- o CALL: 403-955-6600
- Inn From the Cold
  - Provides emergency shelter, support and programs to homeless families, children and others in need
  - Website: <u>www.innfromthecold.org</u>
  - $\circ$  ~ Located at: Suite 106, 110-11 Avenue SE, Calgary, Alberta T2G oX5 ~
  - o CAL142403-263-8384

#### **For Mental Health Services:**

#### Access Mental Health

- Offers options for mental health support, information, and connection to community resources
- Website: <u>www.albertahealthservices.ca</u>
- CALL: 403-943-1500

#### Calgary Counselling Centre

- Offers counseling and group programs for individuals, families, couples, and children
- Website: <u>www.calgarycounselling.com</u>
- Located at: Suite 200, 940-6 Avenue SW, Calgary, Alberta Canada T2P 3T1
- o CALL: 403-691-5991

#### Suicide Bereavement Program

- Offers a variety of services, including one-on-one counseling, educational support groups, individual peer support, as well as debriefings and educational presentations
- Website: <u>www.cmha.calgary.ab.ca/programs/suicide\_services\_bereavement\_sup</u> <u>port.aspx</u>
- CALL: 403-297-1744

#### For Pregnancy Support:

- Calgary Pregnancy Care Centre
  - Offers peer counseling and advocacy, prenatal instruction, and information on pregnancy options including adoption, parenting, and abortion
  - Website: <u>www.pregcare.com</u>
  - Located at: 205, 925-7 Avenue SW, Calgary, AB, T2P 1A5
  - CALL: (24hr) 403- 269-3110
- Best Beginning
  - Offers prenatal information and support to pregnant women living on a low income or teens of any income
  - Located at: East Calgary Health Centre, 2nd Floor 4715 8 Avenue SE, Calgary, Alberta T2A 3N4
  - o CALL: 403-228-8221

#### For Family Support:

- Children's Cottage Society
  - Offers a wide range of programs for parents and children in Calgary, including a 24hr crisis nursery, respite care, and family support
  - Website: childrenscottage.ab.ca
  - Located at: 845 McDougall Road NE, Calgary, Alberta T2E 5A5
  - o CALL: 403-233-2273

#### Calgary Healthy Families Collaborative

- Offers support to families with newborns through home visitation
- Website:
- www.calgaryhealthyfamiliescollaborative.ca
- Located at: 1847 48 Street SE, Calgary, Alberta T2B 1L9
- CALL: 403-204-0800

#### Collaborative Mental Health

- Is a community-based program to improve the conditions for children's mental health, including consultation, education and advocacy in partnership with community service providers
- Website: <u>www.frfp.ca/professional-</u> <u>resources/program-support-</u> <u>agencies/Collaborative-Mental-Health.htm</u>
- Located at: East Calgary Health Centre 4715 8th Ave, S.E., Calgary, T2A 3N4
- o CALL: 403-955-1010
- Aboriginal Family Violence Prevention Program at North of McKnight
  - Website: www.northofmcknightcrc.ca/
  - Located at: 95 Falshire Drive NE, Calgary, Alberta T3J 1P7
  - CALL: 403-293-0424

## Think about : your health and wellbeing



### Think about:

your family, your friends and acquaintances, your community

Individual

Nation

Family

Community

/YY

As you are pregnant, we would like to know how you are feeling. Please indicate the answer that comes closest to how you have felt IN THE PAST 7 DAYS, not just how you feel today.

#### 1. I have been able to laugh and see the funny side

#### of things

- .....(0) As much as I always could
- .....(1) Not quite as much as now
- .....(2) Definitely not so much
- .....(3) Not at all

#### 2. I have looked forward with enjoyment to things

- .....(0) As much as I always could
- .....(1) Rather less than I used to
- .....(2) Definitely less than I used to
- .....(3) Hardly at all

## 3. I have blamed myself unnecessarily when things

#### go wrong

- .....(3) Yes, most of the time
- .....(2) Yes, some of the time
- .....(1) Not very often
- .....(0) No, never

#### 4. I have been anxious or worried for no good

#### reason

- .....(0) No, not at all
- .....(1) Hardly ever
- .....(2) Yes, sometimes
- .....(3) Yes, very often

#### 5. I have felt scared or panicky for no very good

#### reason

......(3) Yes, quite a lot .....(2) Yes, sometimes ......(1) No, not much ......(0) No, not at all

Please turn over the page for the remaining questions ...

#### 6. Things have been getting on top of me

.....(3) Yes, most of the time I haven't been able to cope at all

.....(2) Yes, sometimes I haven't been coping as well as usual

.....(1) No, most of the time I have coped quite well

.....(0) No, I have been coping as well as ever

#### 7. I have been so unhappy that I have had

#### difficulty sleeping

.....(3) Yes, most of the time

- .....(2) Yes, sometimes
- .....(1) Not very often
- .....(0) No, not at all

#### 8. I have felt sad or miserable

- .....(3) Yes, most of the time
- .....(2) Yes, quite often
- .....(1) Not very often
- .....(0) No, not at all

#### 9. I have been so unhappy that I have been crying

......(3) Yes, most of the time......(2) Yes, quite often......(1) Only occasionally......(0) No, never

#### 10. The thought of harming myself has occurred to

#### me

- .....(3) Yes, quite often
- .....(2) Sometimes
- .....(1) Hardly ever
- .....(0) Never

#### Voices and PHACES INTERVIEW GUIDE FOR PROFESSIONALS

TURN ON RECORDER. NOTE DOWN START TIME:

*If oral consent is desired by participant:* **I have reviewed the consent form with you. Do you consent to be part of this project?** 

*If written consent has been given by participant:* **Thank you for signing the consent form.** 

[MAKE SURE PARTICIPANT RECEIVES A COPY OF THE CONSENT FORM]

Thank you very much for agreeing to be part of our study. We hope that the results of our research will help in the design and implementation of effective programs, services and policies to improve the health and wellbeing of pregnant Aboriginal women.

So that we can accurately capture everything that you are saying, we would like your permission to tape record this interview. You may request that the tape recorder be turned off at anytime during the interview. May we have your permission to record? [NOTE DOWN RESPONSE. RECORDER IS EITHER LEFT ON OR TURNED OFF, ACCORDINGLY.]

We know that you are very busy, and we appreciate the time you are taking out of your day to speak with us. To partially reimburse you (or your organization) for your time, we would like to give you \$25, which you may either keep or give to your organization (as you deem appropriate). Please sign this form to indicate that you have received this from us. [GET INITIALS ON SUBJECT FEE LOG FORM]

Our interview today should be about an hour in length. Just a reminder, your participation is completely voluntary. At any point during our interview, you may ask questions, make comments, refuse to answer any questions, or stop the interview at any time. You are also free to withdraw completely from the study at any point. Should you wish to withdraw from the study, please let me know, or please contact the individuals listed on the consent form. (I can also give you their contact information again).

Your information and answers will remain confidential.

Do you have any questions before we begin?

ANSWER PARTICIPANT QUESTIONS BEFORE MOVING ON

Section A – General questions

We're going to begin with some general questions about you and your work:

- 1. What is the title of your present position? What does your work entail (i.e., duties, workload, types of patients/clients served)? What did you do previously?
- 2. How long (i.e., number of years) have you been working in [TYPE OF WORK] ?
- **3.** During an average month, approximately how many pregnant Aboriginal women do you see as part of your work?
  - a. In which trimester of pregnancy are the women when you see them for the first time?
- 4. Have you worked with pregnant Aboriginal women in your job positions prior to your current one?
- 5. Thinking about your past and present job positions, have you participated in services or programs related to mental health during pregnancy? [IF YES AND IF NOT PROVIDED, PROBE FOR SOME DETAILS ANDWHETHER ANY OF THOSE PROGRAMS INCLUDED ABORIGINAL WOMEN, AND/OR WERE TAILORED SPECIFICALLY TO ABORIGINAL WOMEN]
- 6. What is your year of birth?

Section B – Questions about Aboriginal maternal prenatal mental health

THIS SECTION OF THE INTERVIEW INVOLVES OPEN-ENDED QUESTIONS. THE FOLLOWING QUESTIONS ARE TO BE USED AS A GUIDE. THE ORDER OR MANNER OF ASKING MAY BE TAILORED TO THE FLOW OF THE CONVERSTATION. PROBE AS APPROPRIATE, BASED ON THE PARTICIPANT'S RESPONSES.

- 7. Have you had clients who were Aboriginal women with mental health issues? What sorts of issues? What about depression, specifically? What about prenatal and/or postpartum depression?
- 8. What influences the mental health of Aboriginal women?
- 9. What other factors could influence the mental health of Aboriginal women during pregnancy?
- 10. What factors protect against depression during pregnancy for Aboriginal women?

- 11. What coping mechanisms are employed by pregnant Aboriginal women to help deal with stress and depression in their lives? What factors enable women to successfully cope? What factors impede them in successfully coping?
- 12. [BASED ON RESPONSES TO ABOVE QUESTIONS] Of the factors you've identified, what do you think are the *most significant* risk factors and protective factors for pregnant Aboriginal women? [PROBE TO GET BOTH AT THE MOST SIGNIFICANT FACTORS IRRESPECTIVE OF FEASIBILITY TO EASILY CHANGE, AND ALSO THE FACTORS THAT ARE PRACTICAL TO EASILY ADDRESS.]
- 13. Thinking of the women you have served in your work, how does the historical and present-day social context of Aboriginal peoples in Canada impact the lives of pregnant Aboriginal women? [PROBE IF NOT RAISED: Are violence and abuse significant factors to their mental health? What about the legacy of residential schools, and other present-day manifestations of the history of colonization? What sources of oppression (i.e., unfair treatment, inequities, injustices) do you feel exist in the lives of pregnant Aboriginal women? How do these issues interact or intersect with each other? IF SHE/HE FEELS THAT THESE ISSUES ARE NOT IMPORTANT RELATIVE TO OTHER FACTORS, OR IF SHE/HE CITES THAT MOST WOMEN DON'T TALK ABOUT THEM, PROBE WHY THAT MIGHT BE.]
- 14. What types of existing services do you know of, both at your place of work and through other organizations, that address the factors impacting prenatal depression in Aboriginal women? How successful have these service been, in your opinion? What is done well? What are the areas that need improvement to meet the needs of this population? How well networked are the different agencies, such that referrals or consultations can occur?
- 15. What sorts of issues do you think are important for professionals such as yourself, who work in health and/or social services domains, to understand in order to be able to appropriately serve pregnant Aboriginal women?

#### Section C – Concluding thoughts

Do you have anything to add about any of the issues we've discussed, or any other thoughts or reflections about the factors impacting prenatal depression in pregnant Aboriginal women, or about historical and present-day social context as a determinant in this regard?

#### \* \* \*

Thank you very much for your participation in this study. Do you have any questions, comments or concerns at this time? Just a reminder that you can contact us at any time.

**Would you like to receive a copy of your interview transcript?** [NOTE DOWN RESPONSE. IF YES, INQUIRE WHETHER E-MAIL OR POSTAL MAIL IS PREFERRED, AND GET THE CONTACT INFORMATION FOR SENDING THE TRANSCRIPT.]

We will be interviewing a number of people, and we hope to analyze all of the interviews and write up a draft of our research findings. We would like to return to all of our participants to share this draft and ask for feedback, to make sure that we have properly understood all of the important issues.

Can we have your permission to contact you in a few months' time, to ask about the possibility of another interview? [NOTE DOWN PARTICIPANT ANSWER] Should we use the same contact information we have on file for you? [NOTE DOWN ANY CHANGES]

At the end of the study, we will be sharing our results with community agencies through a report and through presentations. Would you like to receive a copy of the report? [NOTE DOWN HER/HIS ANSWER] Would you like to be notified of when and where we are presenting? [NOTE DOWN HER/HIS ANSWER]. IF YES TO EITHER OF THE ABOVE QUESTIONS: How should we contact you?

Thank you again for your time, we really appreciate it!

TURN OFF RECORDER. NOTE DOWN STOP TIME: \_\_\_\_\_

### Voices and PHACES MEMBER-CHECKING INTERVIEW GUIDE FOR THE WOMEN

TURN ON RECORDER. NOTE DOWN START TIME: \_\_\_\_\_

Thank you very much for agreeing to this follow-up interview. As we discussed, today's interview is a follow-up to the interview in which you participated on [DATE OF PARTICIPANT'S FIRST INTERVIEW]. Today, we are sharing with you the main ideas coming out of all of the interviews we have done, and would like to hear from you about how you feel about those ideas. We are asking for your feedback to make sure that we have properly understood all of the important issues. We hope that the results of this study will help organizations and groups in setting up programs, services and policies to support the health and wellbeing of pregnant Aboriginal women.

So that we can accurately capture everything that you are telling us, we would like your permission to tape record this interview. You may request that the tape recorder be turned off at anytime during the interview. May we have your permission to record? [NOTE DOWN RESPONSE. RECORDER IS EITHER LEFT ON OR TURNED OFF, ACCORDINGLY.]

We know that you are busy, and we appreciate the time you are taking to speak with us. To thank you for your time, and to cover any costs you may have had in order to be here with me today, we would like to give you \$25 in the form of a Safeway gift card. Please initial this form to indicate that you have received this from us. [GET INITIALS ON SUBJECT FEE LOG FORM]

Our conversation will be about an hour, and your participation is completely voluntary. At any point during our interview, you may ask questions, make comments, not answer the question, or stop the interview. You are also free to withdraw from the study at any point. Should you wish to withdraw, please let me know, or please contact the individuals listed on the information pamphlet. [GIVE STUDY PAMPHLET].

If any questions I ask you as part of the interview cause you to feel uncomfortable or upset, you don't have to answer, and you can even end the interview if you want. This is a list of contacts for services that may be helpful, if you need support. [GIVE LIST OF RESOURCES]. [AGENCY NAME] can offer you support as well if you need it. [INSERT NAME OF AGENCY FROM WHICH PARTICIPANT WAS RECRUITED]

Your information and answers will remain confidential. Please note, however, there are limits to confidentiality where I am obligated by law to report: specifically, when there is a reasonable suspicion of abuse and/or neglect to a child under the age of 18 years, we are legally obligated to report this to Alberta Human Services, the ministry responsible for child intervention services.

FOR *CUPS* PARTICIPANTS: In the event of such a disclosure by you, we will first talk to CUPS and get their assistance.

#### Do you have any questions before we begin?

### ANSWER PARTICIPANT QUESTIONS BEFORE MOVING ON

### Section A – General thoughts on framework

READ THE FOLLOWING FRAMEWORK SUMMARY; READING IT VERBATIM, WITH ADDITIONAL CLARIFICATIONS AS REQUIRED, IS SUGGESTED, TO ENSURE THAT ALL KEY POINTS GET CONVEYED. SPEAK SLOWLY, AND CHECK TO MAKE SURE THE PARTICIPANT ISN'T LOST OR CONFUSED. POINT TO THE DIAGRAMS WHILE SPEAKING, TO HELP THE PARTICIPANT FOLLOW THE IDEAS BEING PRESENTED. ALLOW (AND, INDEED, ENCOURAGE) THE PARTICIPANT TO INTERJECT WITH COMMENTS IF SHE THINKS OF SOMETHING WHILE YOU ARE SPEAKING. IN SUCH CASE, REMEMBER TO RETURN TO WHERE YOU LEFT OFF, SO THAT ALL POINTS GET CONVEYED FOR THE PARTICIPANT'S REFLECTION.

We spoke to a total of 13 pregnant Aboriginal women and 12 service-providing professionals to ask their thoughts on the factors that influence depression in pregnant Aboriginal women. I will now summarize for you the overall findings. These are based on the views of everyone we interviewed. We would like to know if you agree with these findings. Please feel free to share your thoughts as they come to you. I will first go over with you what we heard were the main pathways that can lead to depression in some women. Then I will go over negative (or bad) and positive (or good) ways of coping with difficult life circumstances, which we heard were things that could worsen these pathways and make it more likely for women to become depressed, or, on the other hand, block the pathways and make it less likely for women to become depressed. Finally, I will go over what women and service-providers had to say about how services in Calgary are doing for meeting the needs of pregnant Aboriginal women.

[PAUSE TO CHECK IN WITH THE PARTICIPANT.] Once again, please feel free to share your thoughts as they come to you. We can also talk more generally afterwards.

Mental health is not a simple thing to explain. There are lots of factors that can influence it. Not all of the things that influence poor mental health are required to cause depression. Moreover, pregnant Aboriginal women can be different from each other; not all women are going to experience the same things, and not all women will experiences things in the same way. Therefore, what we say here is meant to be a general description of how Aboriginal women's mental health is affected during pregnancy. The results are based on analyzing all of the interviews together.

[REFER TO DIAGRAM # 1.] This first sheet shows the main ways that pregnant Aboriginal women might become depressed.

[POINT TO FIRST BOX IN DIAGRAM # 1.] In our interviews, we heard about how Aboriginal women's lives are still impacted by things that happened in the past to their grandparents and parents, and also by things that happen today, in how communities are organized, the laws of the land, and how services work, such as education or health. The history of domination by settlers, the residential school system, and the fact that so many Aboriginal children are put into foster care, are examples of things that continue to impact Aboriginal women's lives in the present day. Intergenerational trauma is a term used to explain why the children or grandchildren of people who have experienced severe trauma continue to have poor health even after the main traumatic events have passed. The traumatic events are believed to set off a cycle of addictions, violence and impaired parenting (among other issues) that result in the trauma being passed on from generation to generation.

Other factors impacting Aboriginal women's health are racism, sexism, and domestic and sexual violence. Services that don't meet the needs of Aboriginal women, or services where Aboriginal women feel stigmatized, have negative impacts. Taken together, these underlying factors appear to create the pathways to depression.

[PAUSE TO CHECK IN WITH THE PARTICIPANT. YOU COULD ASK "How does this sound to you so far?" IF THE PARTICIPANT SEEMS TO BE REACTING TO WHAT HAS BEEN SAID. OTHERWISE, CONTINUE.]

[POINT TO SECOND BOX IN DIAGRAM # 1.] Three major groups of risks for depression are negative life events or circumstances (impacting the woman, her family or friends, or her community), negative relationships, and socioeconomic factors.

Participants in the study told us about many possible negative life events in the lives of pregnant Aboriginal women. These included struggles with poor physical or mental health in themselves, or others in their lives. The health problems, deaths, addictions, incarcerations of people in the women's lives can have an impact on the women's wellbeing. Stressful times can impact the women's wellbeing – those times can be general life situations or things related specifically to being pregnant or being a parent. Past or present involvement with child welfare services was mentioned a lot in the interviews as something that can impact mental wellbeing. This involvement can be a woman's experience of being in foster care herself during her childhood, or a woman's experience of having her child taken away from her by child welfare. Problems in the communities in which women live – including corrupt leaders, or gang violence – also impact their wellbeing.

While none of the pregnant women we interviewed attended residential schools themselves, almost all had parents or relatives who did attend. The present day behaviour of these family members was affected by their past in a big way. This impacted their interactions with the women we interviewed. In general, negative relationships can severely impact mental health – in addition to parents and family members, other possible negative relationships include abusive husbands or boyfriends, negative interactions with neighbours or community members, negative interactions at school or work, negative

interactions with service-providers, as well as interactions involving racist comments from non-Aboriginal people.

Finally, issues around money are a major factor for depression. These issues include low income, low education and unemployment, and the corresponding problems of not having enough food when it's needed, not being secure with housing and not being sure you can pay the bills and eat. Financial problems can be an ongoing issue in some women's lives; in other women's lives, it can be brought on by pregnancy and the prospect of another mouth to feed. Women who are employed can face job stress. Pregnancy and parenting can also interfere with school or career plans, impacting wellbeing.

[PAUSE TO CHECK IN WITH THE PARTICIPANT. YOU COULD ASK "How does this sound to you so far?" IF THE PARTICIPANT SEEMS TO BE REACTING TO WHAT HAS BEEN SAID. OTHERWISE, CONTINUE.]

[POINT TO THIRD BOX IN DIAGRAM # 1.] In general, a big cause of depression is chronic stress – that is, when you feel constantly worried or overwhelmed. A related issue is trauma, which is extreme stress following a serious negative event. Stress and trauma came up a lot in the interviews as something that can cause depression in pregnant Aboriginal women. All of the factors mentioned before can cause considerable stress and trauma, which seems to connect those factors to depression.

Medically-speaking, depression is when you feel sad or upset for a long time, generally more than two weeks. In addition to feeling sad, other possible symptoms may (or may not) also include things like loss of appetite, weight changes, sleep problems, trouble remembering things, and feeling tired. These symptoms are similar to how the women we interviewed spoke of depression, either in their own lives, or in the lives of others they knew. They used phrases like "hitting rock bottom", and described experiences like feeling helpless, hopeless, worthless, empty, lonely, tearful. They described symptoms like being unable to get out of bed, having trouble sleeping, and losing interest in things.

[POINT TO FOURTH BOX IN DIAGRAM # 1.] Depression itself makes stress and trauma worse, and can cause problems in life. To show this on the diagram, there are arrows leading from depression back to some of the factors discussed. In other words, depression can create a vicious cycle of worsening health and wellbeing, unless something is done about it.

So, I have now finished talking about the main ideas about pathways that can lead to depression in some women. Before I move on to positive and negative factors that can make these pathways better or worse, do you have any thoughts to share? [PROBE AS NEEDED.]

[REFER TO DIAGRAMS # 2, WHILE ALSO KEEPING DIAGRAM # 1 VISIBLE.] We heard in our interviews about ways in which pregnant Aboriginal women cope with stress and negative life events or situations. Negative ways of coping can make the things on this first diagram a lot worse. Negative ways of coping include things like substance abuse, gambling, and violence. These also include a lack of positive ways of coping, which are things like social support, feeling good about yourself and your future, and feeling good about who you are as a person.

[REFER TO DIAGRAMS # 3, WHILE ALSO KEEPING DIAGRAM # 1 VISIBLE.] On the other hand, we also heard in the interviews about a number of positive (or good) protective factors that can stop depression from happening or help to make it less serious. We have divided these factors into four groups: Healthy mind, body, spirit; healthy relationships; healthy environments; and, barrier-free, effective and culturally safe services.

Factors mentioned in the interviews relating to healthy mind, body and spirit include having a good education and having a good a job to make enough money for food, good housing and other life needs; having good diet, exercise, and doing enjoyable activities for fun and relaxation; having good things happen in life; feeling good about the future; feeling proud to be an Aboriginal woman; doing activities related to traditional Aboriginal culture and spirituality as ways of positively coping with difficult situations and stress; and, seeing the pregnancy as a reason to make life changes that lead to better health and wellbeing.

Healthy relationships include positive, meaningful and respectful relationships with one's boyfriend or husband, family, friends, neighbours, coworkers, service-providers. These relationships include relationships involving both emotional support and useful help from husband/boyfriend, family, friends, etc. Avoiding negative relationships (i.e. relationships that cause stress, or that lead to unhealthy behaviours such as substance abuse, etc.) also appears to be important for good mental health, according to the interviews.

Having positive, safe and secure physical and social environments in women's day-to-day lives is important. Finally, clinical and social services that are easy for women to access, that meet the women's needs, and where women can feel comfortable, safe and respected, are also important for good mental health. When patients or clients feel respected and empowered in their relationships with service-providers, they are more likely to benefit from the service and continue to access it.

So, I have now finished talking about negative and positive factors that can make pathways leading to depression worse or better. Before I move on to the topic of services in Calgary and area, do you have any thoughts to share? [PROBE AS NEEDED.]

[REFER TO DIAGRAM # 4.] The final topic is that of how services (both clinical and social services) in Calgary and the surrounding area are doing in terms of meeting the needs of pregnant Aboriginal women. A number of key points arose from the interviews:

- participants felt some services are useful and meaningful and doing a good job in giving women the information, tools, resources or treatments they need
- participants asked for more services to be available specifically for Aboriginal people, that involve Aboriginal culture
- things that make using services hard for women are things like hours of operation, childcare difficulties, and transportation difficulties
- some of the women we interviewed spoke of experiences with service-providers who judged them and made them feel bad

- many women felt that child welfare policies are not working in the best interest of children and families
- service-providers we interviewed said they needed better training on how to make women feel safe and respected
- service-providers wanted to know how to make services more accessible, how to help patients/clients make it to appointments or programs
- service-providers said that services need to be better connected to each other

So, I have finished talking about ideas coming from our interviews about services in Calgary and the surrounding area. Do you have thoughts to share about these ideas? [PROBE AS NEEDED.]

So, please now think of everything overall. I just went through a summary of the main points coming out of all of the interviews we did. Before I get into some specific questions I have for you, do you have any general thoughts you would like to share about these ideas, and the way the different factors have been linked together?

[PROBE AS NEEDED TO CLARIFY PARTICIPANT'S RESPONSE.]

Section B – Specific questions on framework

SOME OF THE FOLLOWING MAY ALREADY GET COVERED DURING YOUR CONVERSATION WITH THE PARTICIPANT IN THE ABOVE SECTION. IF NOT, PLEASE BE SURE TO ASK THE FOLLOWING SPECIFIC QUESTIONS. PROBE AS NEEDED TO CLARIFY THE PARTICIPANT'S RESPONSES.

- 1) Do the ideas I've summarized fit your personal experiences, and/or the experiences of other pregnant Aboriginal women?
- 2) Does the framework seem accurate, thinking both of yourself and of other pregnant Aboriginal women?
- 3) Is there anything that is missing, in your opinion, or that is not emphasized enough?
  - a. What would you add?
  - b. What would you change?
- 4) In terms of providing useful services for pregnant Aboriginal women, what things should be done, in your opinion? [PROBE FOR SPECIFIC EXAMPLES.]
  - a. If we were to recommend a program to meet the needs of pregnant Aboriginal women, where should the emphasis be? What are the most important issues?
  - b. What would you change about how things are currently done in clinical and/or social services?
  - c. What do you think service-providers need to understand about pregnant Aboriginal women, to better meet their needs?

Section C – Concluding thoughts

Do you have anything to add about any of the issues we've talked about, or any other thoughts about the health and wellbeing of yourself, or pregnant Aboriginal women generally?

\* \* \*

Thank you very much for your participation in this study. Do you have any questions, comments or concerns at this time? Just a reminder that you can contact us at any time later, too.

**Would you like to receive a copy of your interview transcript?** [NOTE DOWN RESPONSE. IF YES, INQUIRE WHETHER E-MAIL OR POSTAL MAIL IS PREFERRED, AND GET THE CONTACT INFORMATION FOR SENDING THE TRANSCRIPT.]

At the end of the study, we will be sharing our results with community agencies through a report and through presentations. Would you like to receive a copy of the report? [NOTE DOWN HER ANSWER] Would you like to be notified of when and where we are presenting? [NOTE DOWN HER ANSWER]. IF YES TO EITHER OF THE ABOVE QUESTIONS: How should we contact you? Should we use the same contact information we have on file for you? [NOTE DOWN ANY CHANGES, OR ADDITIONAL OPTIONS (E.G., E-MAIL IN ADDITION TO PHONE).] Is there anyone we could contact in case you are away or have moved at that time? [NOTE DOWN SECONDARY CONTACT.] Is it okay if we leave messages at the phone number(s) you have given?

Thank you again for your time, we really appreciate it! TURN OFF RECORDER. NOTE DOWN STOP TIME: \_\_\_\_\_

### Voices and PHACES MEMBER-CHECKING INTERVIEW GUIDE FOR PROFESSIONALS

TURN ON RECORDER. NOTE DOWN START TIME: \_\_\_\_\_

Thank you very much for agreeing to this follow-up interview. As we discussed, today's interview is a follow-up to the interview in which you participated on [DATE OF PARTICIPANT'S FIRST INTERVIEW]. Today, we are sharing with you the main ideas coming out of all of the interviews we have done, and would like to hear from you about how you feel about those ideas. We are asking for your feedback to make sure that we have properly understood all of the important issues. We hope that the results of our research will help in the design and implementation of effective programs, services and policies to improve the health and wellbeing of pregnant Aboriginal women.

So that we can accurately capture everything that you are telling us, we would like your permission to tape record this interview. You may request that the tape recorder be turned off at anytime during the interview. May we have your permission to record? [NOTE DOWN RESPONSE. RECORDER IS EITHER LEFT ON OR TURNED OFF, ACCORDINGLY.]

We know that you are very busy, and we appreciate the time you are taking out of your day to speak with us. To partially reimburse you (or your organization) for your time, we would like to give you \$25, which you may either keep or give to your organization (as you deem appropriate). Please sign this form to indicate that you have received this from us. [GET INITIALS ON SUBJECT FEE LOG FORM]

Our interview today should be about an hour in length. Just a reminder, your participation is completely voluntary. At any point during our interview, you may ask questions, make comments, refuse to answer any questions, or stop the interview at any time. You are also free to withdraw completely from the study at any point. Should you wish to withdraw, please let me know, or please contact the individuals listed on the information pamphlet. [GIVE STUDY PAMPHLET].

Your information and answers will remain confidential.

Do you have any questions before we begin?

ANSWER PARTICIPANT QUESTIONS BEFORE MOVING ON

Section A – General thoughts on framework

READ THE FOLLOWING FRAMEWORK SUMMARY; READING IT VERBATIM, WITH ADDITIONAL CLARIFICATIONS AS REQUIRED, IS SUGGESTED, TO ENSURE THAT ALL KEY POINTS GET CONVEYED. SPEAK SLOWLY, AND CHECK TO MAKE SURE THE PARTICIPANT ISN'T LOST OR CONFUSED. POINT TO THE DIAGRAMS WHILE SPEAKING, TO HELP THE PARTICIPANT FOLLOW THE IDEAS BEING PRESENTED. ALLOW (AND, INDEED, ENCOURAGE) THE PARTICIPANT TO INTERJECT WITH COMMENTS IF SHE/HE THINKS OF SOMETHING WHILE YOU ARE SPEAKING. IN SUCH CASE, REMEMBER TO RETURN TO WHERE YOU LEFT OFF, SO THAT ALL POINTS GET CONVEYED FOR THE PARTICIPANT'S REFLECTION.

We spoke to a total of 13 pregnant Aboriginal women and 12 service-providing professionals (from both clinical and social services) to ask their thoughts on the factors that influence depression in pregnant Aboriginal women. I will now summarize for you the overall findings, which take into account the views of everyone we interviewed. We would like to know if you agree with these findings. Please feel free to share your thoughts as they come to you. I will first go over with you what we heard were the main pathways that can lead to depression in some women. Then I will go over negative coping strategies and positive protective factors, which we heard were things that could either exacerbate or amplify these pathways, or buffer or block these pathways. Finally, I will go over what women and service-providers had to say about how services in Calgary are doing for meeting the needs of pregnant Aboriginal women.

[PAUSE TO CHECK IN WITH THE PARTICIPANT.] Once again, please feel free to share your thoughts as they come to you. We can also talk more generally afterwards.

Mental health is complex, with lots of factors that can influence it. Not all of the possible factors are required to lead to depression. Moreover, pregnant Aboriginal women as a group are very diverse; not all women are going to experience the same things - nor will they react to, or be impacted by, experiences in the same way. Therefore, the findings described are meant to be a general description of things that can influence mental health during pregnancy in Aboriginal women.

[REFER TO DIAGRAM # 1.] This first sheet shows the main pathways through which pregnant Aboriginal women might experience depression, based on the ideas raised during the interviews.

[POINT TO FIRST BOX IN DIAGRAM # 1.] In our interviews, we heard about how Aboriginal women's lives are impacted by the broader historical and present-day societal context, and the context in institutions such as clinical and social services. The legacy of colonization, including residential schools and the disproportionate involvement with child welfare authorities, continues to impact Aboriginal women's lives in the present day. Intergenerational trauma is a formal theory to understand why populations that have faced mass trauma – such as Aboriginal populations, who faced the events of colonization – continue to have poor health even several generations after the main traumatic events. The traumatic events are believed to set off a cycle of addictions, violence and impaired parenting (among other issues) that result in the trauma being passed on from generation to generation.

Among other factors impacting Aboriginal women's health are racism, sexism, and domestic and sexual violence. Services that don't meet the needs of Aboriginal women,

and/or services where Aboriginal women feel stigmatized, similarly have negative impacts. Taken together, these underlying contextual factors appear to drive the pathways on this diagram, according to the ideas coming out of the interviews.

[PAUSE TO CHECK IN WITH THE PARTICIPANT. YOU COULD ASK "How does this sound to you so far?" IF THE PARTICIPANT SEEMS TO BE REACTING TO WHAT HAS BEEN SAID. OTHERWISE, CONTINUE.]

[POINT TO SECOND BOX IN DIAGRAM # 1.] Three major risk factors for depression identified in the interviews are negative life events or circumstances (impacting the woman, her family or friends, or her community), negative relationships, and socioeconomic factors.

Participants in the study told us about many possible negative life events or circumstances in the lives of pregnant Aboriginal women. These include struggles with poor physical or mental health (of the women themselves, or of others in their lives). The health problems, deaths, addictions, incarcerations or past residential school attendance of people in the women's lives can have an impact on the women's wellbeing. Stressful events or circumstances can impact the women's wellbeing – those things can be general life situations, and/or things related specifically to being pregnant or being a parent. Past or present involvement with child welfare services was mentioned a lot in the interviews as something that can impact mental wellbeing. This involvement can be a woman's experience of being in foster care herself during her childhood, and/or a woman's experience of having her child taken away from her by child welfare authorities. Problems in the communities in which women live – including corrupt leaders, or gang violence – also impact their wellbeing.

While none of the pregnant women we interviewed attended residential schools themselves (most were too young to have been school-aged during that period), almost all had parents or relatives who did attend. The behaviour of these family members was deeply impacted by the experience, which in turn impacted their interactions with the women we interviewed. Therefore, having family members who attended residential school is something that can impact the lives of pregnant Aboriginal women. In general, negative relationships can severely impact mental health – in addition to parents and family members, other possible negative relationships include abusive intimate partners, negative interactions with neighbours or community members, negative interactions at school or work, negative interactions with service-providers, as well as interactions involving racist comments from non-Aboriginal persons.

Finally, socioeconomic factors are major risk factors for depression. These include low income, low education and unemployment, and the corresponding problems of food insecurity, housing insecurity and financial insecurity. Financial insecurity can be an ongoing issue in some women's lives; in other women's lives, it can be brought on by pregnancy and the prospect of another mouth to feed. Women who are employed can face job stress. And, pregnancy and parenting can interfere with school or career progress, impacting wellbeing.

[PAUSE TO CHECK IN WITH THE PARTICIPANT. YOU COULD ASK "How does this sound to you so far?" IF THE PARTICIPANT SEEMS TO BE REACTING TO WHAT HAS BEEN SAID. OTHERWISE, CONTINUE.]

[POINT TO THIRD BOX IN DIAGRAM # 1.] In general, one of the principle risk factors for depression is chronic stress - that is, when one feels constantly worried or overwhelmed. A related issue is trauma, which is extreme stress following a serious negative event. Stress and trauma came up a lot in the interviews as something that can cause depression in pregnant Aboriginal women. All of the factors mentioned before can cause considerable stress and trauma, and it is believed that such a pathway is the main one that connects those factors to depression as a mental health issue.

Medically-speaking, depression is when one feels sad or upset for a long time, generally more than two weeks. In addition to feeling sad, other possible symptoms may (or may not) also include things like loss of appetite, weight changes, sleep problems, trouble remembering things, and feeling tired. These symptoms are similar to how the women we interviewed spoke of depression, either in their own lives, or in the lives of others they knew. They used phrases like "hitting rock bottom", and described experiences like feeling helpless, hopeless, worthless, empty, lonely, tearful. They described symptoms like being unable to get out of bed, having trouble sleeping, and losing interest in things.

[POINT TO FOURTH BOX IN DIAGRAM # 1.] Depression itself worsens stress and trauma, and can also negatively impact life circumstances. To show this on the diagram, there are arrows leading from depression back to some of the factors discussed. In other words, depression can create a vicious cycle of worsening health and wellbeing, unless interventions are applied.

So, I have now finished talking about the main ideas about pathways that can lead to depression in some women. Before I move on to positive and negative factors that can influence these pathways, do you have any thoughts to share? [PROBE AS NEEDED.]

[REFER TO DIAGRAMS # 2, WHILE ALSO KEEPING DIAGRAM # 1 VISIBLE.] We heard in our interviews about ways in which pregnant Aboriginal women cope with stress and negative life events or circumstances. Negative ways of coping can exacerbate or amplify (that is, make worse) the pathways in the first diagram. These include maladaptive coping strategies such as substance abuse, gambling, and violence. These also include a lack of positive coping mechanisms, which are things like self-esteem, social support, optimism and hope, and a sense of identity.

[REFER TO DIAGRAMS # 3, WHILE ALSO KEEPING DIAGRAM # 1 VISIBLE.] **By** contrast, a number of protective factors were identified in the interviews that can buffer or block the pathways leading to depression; in other words, they can stop depression from happening or help to make it less serious. We have divided these factors into four

categories: Healthy mind, body, spirit; healthy relationships; healthy environments; and, barrier-free, effective and culturally safe services.

Factors mentioned in the interviews relating to healthy mind, body and spirit include having socioeconomic security; having good diet, exercise, and pursuing enjoyable recreational or leisure activities; experiencing positive life events; having a positive outlook, including optimism and hope; experiencing pride from one's identity as an Aboriginal woman; pursuing traditional Aboriginal culture and spirituality as ways of positively coping with difficult circumstances and stress; and, viewing the pregnancy as an inspiration (or catalyst) for positive changes that lead to better health and wellbeing.

Healthy relationships that can offer protection include positive, meaningful and respectful relationships with one's partner, family, friends, neighbours, coworkers, service-providers; and, relationships that involve both emotional and practical support from partner, family, friends, etc. Avoiding negative relationships (i.e. relationships that cause stress, or that lead to unhealthy behaviours such as substance abuse, etc.) also appears to be a key protective strategy, according to the interviews.

It is protective to have positive and secure physical and social environments in women's day-to-day lives. Finally, clinical and social services that are easy for women to access, that meet the women's needs, and in the context of which women can feel comfortable, safe and respected, are also important protective factors. Cultural safety is a concept that, when applied to service provision, refers to the patient or client being made to feel empowered and respected. When patients or clients feel this way, they are more likely to benefit from the service and continue to access it.

So, I have now finished talking about negative coping strategies and positive protective factors. Before I move on to the topic of services in Calgary and area, do you have any thoughts to share? [PROBE AS NEEDED.]

[REFER TO DIAGRAM # 4.] The final topic is that of how services (both clinical and social services) in Calgary and the surrounding area are doing in terms of meeting the needs of pregnant Aboriginal women. A number of key points arose from the interviews:

- some services were described as effective, meaningful
  - they were described as effective in giving women the information, tools, resources or treatments they need
- more Aboriginal-specific services were requested
- barriers to access include hours of operation, childcare and transportation constraints
- women spoke of experiences with negative, judgmental service-providers
- women expressed concerns about child welfare policies not working in the best interest of children and families
- service-providers expressed a need for better training and resources in order to create a safe, stigma-free environment

- service-providers expressed an interest in knowing how to make services more accessible, how to help patients/clients make it to appointments or programs
- service-providers suggested that services need to be better networked

**So, I have finished talking about ideas coming from our interviews about services in Calgary and the surrounding area. Do you have thoughts to share about these ideas?** [PROBE AS NEEDED.]

So, please now think of the overall framework: I just went through a summary of the main points coming out of all of the interviews we did. Before I get into some specific questions I have for you, do you have any general thoughts you would like to share about these ideas, and the way the different factors have been linked together?

[PROBE AS NEEDED TO CLARIFY PARTICIPANT'S RESPONSE.]

Section B – Specific questions on framework

SOME OF THE FOLLOWING MAY ALREADY GET COVERED DURING YOUR CONVERSATION WITH THE PARTICIPANT IN THE ABOVE SECTION. IF NOT, PLEASE BE SURE TO ASK THE FOLLOWING SPECIFIC QUESTIONS. PROBE AS NEEDED TO CLARIFY THE PARTICIPANT'S RESPONSES.

- 1) Do the ideas I've summarized fit your experiences?
- 2) Does the framework seem accurate, thinking of the pregnant Aboriginal women with which you've worked?
- 3) Is there anything that is missing, in your opinion, or that is not emphasized enough? a. What would you add?
  - b. What would you change?
- 4) What kinds of recommendations would you make in terms of providing meaningful services to pregnant Aboriginal women? [PROBE FOR SPECIFIC EXAMPLES.]
  - a. What would you change about how things are currently done in clinical and/or social services?
  - b. What would help you, and/or other service-providers, to better meet the needs of pregnant Aboriginal patients/clients?

Section C – Concluding thoughts

Do you have anything to add about any of the issues we've discussed, or any other thoughts or reflections about the factors impacting prenatal depression in pregnant Aboriginal women?

\* \* \*

Thank you very much for your participation in this study. Do you have any questions, comments or concerns at this time? Just a reminder that you can contact us at any time later, too.

**Would you like to receive a copy of your interview transcript?** [NOTE DOWN RESPONSE. IF YES, INQUIRE WHETHER E-MAIL OR POSTAL MAIL IS PREFERRED, AND GET THE CONTACT INFORMATION FOR SENDING THE TRANSCRIPT.]

At the end of the study, we will be sharing our results with community agencies through a report and through presentations. Would you like to receive a copy of the report? [NOTE DOWN ANSWER] Would you like to be notified of when and where we are presenting? [NOTE DOWN ANSWER]. IF YES TO EITHER OF THE ABOVE QUESTIONS: How should we contact you? Should we use the same contact information we have on file for you? [NOTE DOWN ANY CHANGES, OR ADDITIONAL OPTIONS (E.G., E-MAIL IN ADDITION TO PHONE).] Is there anyone we could contact in case you are away or have moved at that time? [NOTE DOWN SECONDARY CONTACT.] Is it okay if we leave messages at the phone number(s) you have given?

Thank you again for your time, we really appreciate it! TURN OFF RECORDER. NOTE DOWN STOP TIME: \_\_\_\_\_

## Appendix I: Depression and mental health in pregnant Aboriginal women: Key results and recommendations from the Voices and PHACES study

Final report to stakeholders and community members

## DEPRESSION AND MENTAL HEALTH IN PREGNANT ABORIGINAL WOMEN

Key Results and Recommendations from the

## **Final Report**

Fall 2015

Amrita Roy,

Wilfreda E. Thurston,

and the

Voices and PHACES Study Team

Calgary, Alberta, Canada

## Voices and PHACES Study

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# Depression and Mental Health in Pregnant Aboriginal Women KEY RESULTS AND RECOMMENDATIONS FROM THE VOICES AND PHACES STUDY

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The study's Research Team consisted of academic team members from the University of Calgary, and representatives from the five core partner community agencies located in Calgary: Inn from the Cold, Calgary Urban Projects Society (CUPS), Awo Taan Healing Lodge, Elbow River Healing Lodge of Alberta Health Services, and the Adult Aboriginal Mental Health Program of Alberta Health Services.

Research Team members from the University of Calgary were Amrita Roy, Dr. Wilfreda E. Thurston (Principal Investigator), Dr. Scott Patten, Dr. Suzanne Tough, Dr. Lynden (Lindsay) Crowshoe, and Dr. Tanya Beran. Research Team members from the five community partner agencies were Alana Heise (CUPS and Awo Taan Healing Lodge), Dayton English and Linda McLean (Inn from the Cold), J. Gale Getz (Adult Aboriginal Mental Health Program), and Nicole Eshkakogan (Elbow River Healing Lodge). In addition to the Research Team, the following individuals supported the study on its Oversight Committee: David Turner (community member and Oversight Committee co-chair), Bonnie Healy (community member and Oversight Committee co-chair), Marion Lerat (Elder), Lloyd Ewenin Jr. (Elder), and Suzanne Anselmo (Alberta Human Services).

In addition to the five core community partner agencies listed above, twelve other agencies in the Calgary area came aboard the study as recruitment sites:

Northeast Calgary Women's Clinic Isis Women's Health Clinic Riley Park Maternity Clinic Tsuu T'ina Nation – Health and Wellness Centre Closer to Home and its prenatal program Kiwehtata Brenda Strafford Centre for the Prevention of Domestic Violence University of Calgary Native Centre Mount Royal University Iniskim Centre Alberta Health Services Calgary and Area Aboriginal Hospital Liaisons program EFW Radiology's maternal-fetal medicine clinics in Calgary Alberta Health Services Community Health Centres Métis Child and Family Services Aboriginal Parent Link Centre

We thank the staff at all of the community agencies involved, for their assistance and enthusiasm. We also appreciate the networking opportunities provided to us by Bev Renaud and the monthly Native Info Exchange meetings.

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# Depression and Mental Health in Pregnant Aboriginal Women KEY RESULTS AND RECOMMENDATIONS FROM THE VOICES AND PHACES STUDY

## ABSTRACT

**BACKGROUND:** Depression is a major clinical and public health issue that carries serious consequences for wellbeing. In pregnant and postpartum women, the health consequences of depression also extend to the baby and other family members, making it an important maternal-child and family health concern. Chronic psychosocial stress is considered a prime risk factor. Aboriginal populations in Canada experience health and social inequities relative to other Canadians. Many of the risk factors and health consequences associated with prenatal depression are more common among Aboriginal populations, suggesting that prenatal depression may be a concern. However, research on depression among pregnant Aboriginal women is limited. Given the unique historical and present-day societal context involved, it would be erroneous to assume that the results of studies in non-Aboriginal populations can be directly applied to Aboriginal populations. The societal context of Aboriginal women involves intersecting stressors from race and gender, social exclusion, and intergenerational trauma from residential schools and other legacies of colonization. Failure to consider the influence of societal context on health can result in the overlooking of key pathways to target for meaningful and enduring primary prevention, and in the investment of funds into ineffective programs that are inappropriate to the needs of the target group.

**STUDY METHODS AND OBJECTIVES:** To address the above gap in knowledge, a qualitative constructivist grounded theory study (*Voices and PHACES*) was conducted in Calgary, with academic researchers from the University of Calgary working in partnership with local health and social services and with the involvement of Aboriginal community

members and Elders. The study aimed to understand the risk factors, the protective factors and the societal context of prenatal depression in Aboriginal populations. It also aimed to examine how services in Calgary are doing, and how they can be improved, in meeting the needs of this population. The study involved personal interviews with pregnant Aboriginal women and with service-providing professionals who work with pregnant Aboriginal women, as well as focus-groups with stakeholders.

**KEY RESULTS:** Chronic life stress and trauma were identified as key causes of depression, and were influenced by negative life events and circumstances, negative relationships, and socioeconomic factors. Driving these determinants were upstream, systemic factors related to historical and presentday societal context (e.g., racism, sexism, social exclusion, and intergenerational trauma from residential schools and other occurrences of colonization). Substance abuse was found to be a common coping mechanism for stress, trauma, and depression, indicating that mental health issues need to be addressed in order to effectively manage addictions. Social support and traditional Aboriginal healing practices were identified as protective, and thus may be key intervention strategies. While services in Calgary appear to be working well in certain ways, a need was identified for more culturally-appropriate services, better networking among agencies, and better training of service-providers to reduce stigma and enhance a safe and empowering healing environment for patients and clients.

**KEY RECOMMENDATIONS:** Aboriginal-specific prenatal and parenting programs are recommended – particularly those in group format that allow pregnant Aboriginal women to meet each other and develop supportive friendships. Additionally, programs that support Aboriginal fathers-to-be are warranted, to help them support their partner and children. Further research is required into ways that accessibility to services might be improved; possible solutions might be longer hours of operation, drop-in services instead of appointments, and availability of childcare. Better systems of referrals and communication between different services and organizations are required, to ensure continuity and comprehensiveness in care. Additionally, there is a need for more culturally-appropriate services for Aboriginal patients and clients, as well as better training of service-providing professionals on how to create safe, stigma-free, and respectful service environments for patients and clients. Finally, there is a critical need for programs, services, and policies that better address the social determinants of health, racism, sexism, domestic violence, addictions, personal trauma and mental health concerns, and the intergenerational effects of residential school trauma.

# Depression and Mental Health in Pregnant Aboriginal Women KEY RESULTS AND RECOMMENDATIONS FROM THE VOICES AND PHACES STUDY

## SUMMARY

## THE "VOICES AND PHACES" STUDY

Good mental health during pregnancy is extremely important for the health and wellbeing of mothers and their unborn children, as well as other family members. While there has been some research on depression during pregnancy (prenatal depression), very little has looked at the issue specifically among Aboriginal women. The purpose of this study was to understand the risk factors, protective factors, and societal context for prenatal depression in pregnant Aboriginal women. We also wanted to know how services in the Calgary area are doing in meeting the needs of this population, and how they can be improved. To answer these questions, we interviewed pregnant Aboriginal women and health and social services professionals in the Calgary area, between 2012 and 2014. We called the study "Voices and PHACES", with "PHACES" standing for "Prenatal Health for Aboriginal Communities and EnvironmentS".

For this research, academic researchers from the University of Calgary partnered with five organizations in Calgary that serve pregnant Aboriginal women: Inn from the Cold, Calgary Urban Project Society / CUPS, Awo Taan Healing Lodge, Elbow River Healing Lodge (Alberta Health Services), and the Adult Aboriginal Mental Health Program (Alberta Health Services). Additionally, there was an Oversight Committee which included two Elders, two respected Aboriginal community members who are active in leadership and research, and one representative from the Government of Alberta. The Oversight Committee helped us to make the research ethical, respectful of Aboriginal communities, and meaningful for the development of policies, programs, and services.

## STUDY RESULTS

## Pathways that can lead to depression

Mental health is complex, with lots of factors that can influence it. Not all of the possible factors are needed together to lead to depression in any one person. Moreover, pregnant Aboriginal women as a group are very diverse; not all women are going to experience the same things – nor will they react to, or be impacted by, experiences in the same way. Therefore, the findings described are meant to be a general description of things that can influence mental health during pregnancy in Aboriginal women. The connections between these factors are shown in Figure 1 in this report.

## Underlying factors in society

We heard about how Aboriginal women's lives are impacted by both the history and present-day situation of Aboriginal peoples, and the way medical treatment and social services are set up. The legacy of colonization, including residential schools and the role of child welfare, continues to impact Aboriginal women's lives in the present day. Intergenerational trauma is a way of explaining how populations that have faced mass trauma – such as Aboriginal populations – develop poor health even in several generations after the main traumatic events. The traumatic events set off a cycle of addictions, violence, and breakdowns in relationships (among other issues) that result in the trauma being passed on from generation to generation.

Among other factors impacting Aboriginal women's health are racism, sexism, and domestic and sexual violence. Services that do not meet the needs of Aboriginal women, and/or services where Aboriginal women feel stigmatized, judged, or singled out, similarly have negative impacts. Taken together, these underlying factors appear to drive the pathways leading to depression.

## Negative life events or circumstances - self, family, community

Participants in the study told us about many possible negative life events or circumstances in the lives of pregnant Aboriginal women. These include struggles with poor physical or mental health (of the women themselves, or of others in their lives). These health problems, along with deaths, addictions, incarcerations, or past residential school attendance by people in the women's lives can have an impact on their wellbeing. Stressful circumstances can impact the women's wellbeing; those things can be general life situations, and/or things related specifically to being pregnant or being a parent. Past or present involvement with child welfare services was mentioned a lot in the interviews as something that can impact mental wellbeing. This involvement could be a woman's experience of being in foster care herself during her childhood, and/or a woman's experience of having her child taken away from her by child welfare. Problems in the communities in which women live – including corrupt leaders, crime, or gang violence – also impact their wellbeing.

### Negative relationships

While none of the pregnant women we interviewed attended residential schools themselves (most were too young to have been school-aged during that period), almost all had parents or relatives who did attend. The behaviour of these family members was deeply impacted by the experience, which in

turn impacted their interactions with the women we interviewed. Therefore, having family members who attended residential school is something that can impact the lives of pregnant Aboriginal women. In general, negative relationships can severely impact mental health. In addition to parents and family members, other possible negative relationships include abusive intimate partners, negative interactions with neighbours or community members, negative interactions at school or work, negative interactions with service-providing professionals, as well as interactions involving racist comments from non-Aboriginal persons.

## Socioeconomic factors

Money factors are major risk factors for depression. These include low income, low education and unemployment, and the related problems of food insecurity, housing insecurity, and financial insecurity. Financial insecurity can be an ongoing issue in some women's lives; in other women's lives, it can be brought on by pregnancy and the prospect of another mouth to feed. Women who are employed can face job stress. As well, pregnancy and parenting can interfere with school or career progress, impacting wellbeing.

## Chronic stress, trauma, and depression

In general, one of the principal risk factors for depression is chronic stress – that is, when one feels constantly worried or overwhelmed. A related issue is trauma, which is extreme stress following a serious negative event. Stress and trauma came up a lot in the interviews as something that can cause depression in pregnant Aboriginal women. All of the factors mentioned previously can cause considerable stress and trauma, and it is believed that such a pathway is the main one that connects those factors to depression as a mental health issue.

From a medical doctor's point of view, depression is when one feels sad or upset for a long time, generally more than two weeks. In addition to feeling sad, other possible signs may be things like loss of appetite, weight changes, sleep problems, trouble remembering things, and feeling tired more than usual. These symptoms are similar to how the women we interviewed spoke of depression, either in their own lives or in the lives of others they knew. They used phrases like "hitting rock bottom", and described experiences like feeling helpless, hopeless, worthless, empty, lonely, and tearful. They described signs like being unable to get out of bed, having trouble sleeping, and losing interest in things.

Depression can worsen stress and trauma, and can also negatively affect other aspects of life. In other words, depression can create a vicious cycle of worsening health and wellbeing, unless a woman gets the help or support she needs to stop it.

## Negative coping mechanisms

We heard in our interviews about ways in which pregnant Aboriginal women cope with stress and negative life events. Negative ways of coping can make the factors leading to depression worse. These include unhealthy coping strategies such as substance abuse, gambling, and violence. These also include a lack of positive coping strategies, things like self-esteem, social support, optimism and hope, and a strong sense of identity.

## Positive protective factors

By contrast, a number of protective factors were identified in the interviews that can buffer or block the pathways leading to depression; in other words, they can stop depression from happening or help to make it less serious.

## Healthy mind, body, spirit

Factors mentioned in the interviews relating to healthy mind, body, and spirit include having financial security; having good diet, exercise, and pursuing enjoyable recreational or leisure activities; experiencing positive life events; having a positive outlook, including optimism and hope; experiencing pride from one's identity as an Aboriginal person and a woman; pursuing traditional Aboriginal culture and spirituality as ways of positively coping with stress; and viewing the pregnancy as an inspiration for positive changes that can lead to better health and wellbeing.

## Healthy relationships

Healthy relationships that can offer protection include positive, meaningful, and respectful relationships with one's partner, family, friends, neighbours, coworkers, service-providing professionals; and relationships that involve both emotional and practical support from partner, family, friends, etc. Avoiding negative relationships (i.e., relationships that cause stress, or that lead to unhealthy behaviours like substance abuse) also appears to be a key positive action.

## Healthy environments

Having positive, safe, and secure physical and social environments in women's day-to-day lives can reduce or prevent depression. These should include places where women live, study or work, seek programs or services, or otherwise spend time. Positive physical environments are those that allow women to feel safe and comfortable, and that allow easy access to resources like transit, groceries, and health and social services. Positive social environments are those that involve positive interactions with others, where women can feel respected, supported, appreciated, and connected.

## Barrier-free, effective, and culturally safe services

Finally, health and social services that are easy for women to access, that meet the women's needs, and are set up so that women can feel comfortable, safe, and respected are also important positive factors. Cultural safety is a concept that, when applied to services, refers to the patient or client being made to feel equal to and respected by staff and others. When patients or clients feel this way, they are more likely to benefit from the service and continue to access it.

## Services in Calgary and Area

We asked both women and service-providing professionals about how they felt services (both health and social services) in Calgary and the surrounding area are doing in terms of meeting the needs of pregnant Aboriginal women. A number of key points were made. Some services were described as very helpful because they give women the information, tools, resources, or treatments they need. More Aboriginal-specific services were requested, such as access to Elder support, and programs that use Aboriginal culture and views on healing. Barriers to accessing services include hours of operation, childcare, and lack of transportation.

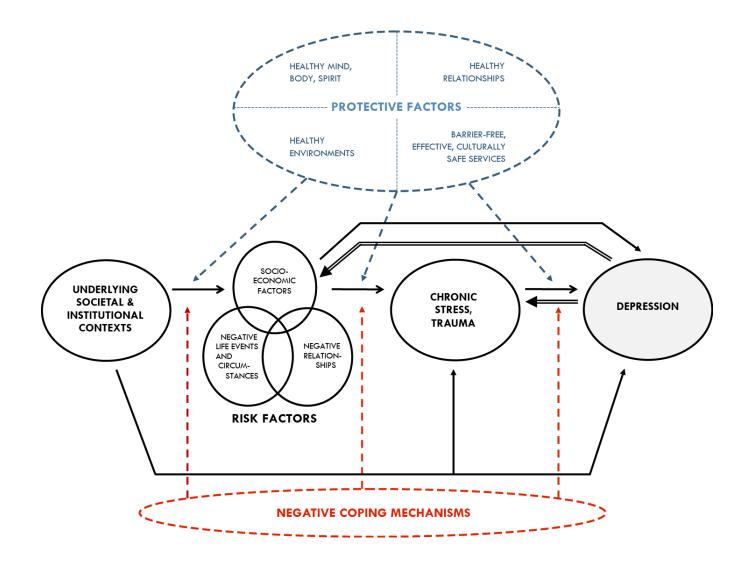
Women also spoke of experiences with negative, judgmental professionals, which discouraged them from using pregnancy-related and other services. Women also expressed concerns about child welfare policies not working in the best interest of children and families, and spoke of fear of child welfare as a reason for not using services.

Service-providing professionals expressed a need for better training and resources in order to create a safe, stigma-free environment. They expressed an interest in knowing how to make services more accessible, and how to help patients and clients make it to appointments or programs. Professionals suggested that services need to be better networked so that service systems can fully meet all of the needs of patients and clients in a comprehensive, holistic way.

## KEY RECOMMENDATIONS

- Aboriginal-specific prenatal and parenting programs particularly those in group format that allow pregnant Aboriginal women to meet each other and develop supportive friendships.
- Programs that support Aboriginal fathers-to-be, to help them support their partner and children.
- Further research into ways that accessibility to services might be improved. Possible ways
  might be longer hours of operation, drop-in services instead of appointments, and availability
  of childcare.
- More culturally-appropriate services for Aboriginal patients and clients.
- Better systems of referrals and communication between different services and organizations.
- Better training of service-providing professionals on how to create safe, stigma-free, respectful service environments for patients and clients.
- Programs, services, and policies that better address the social determinants of health (including income, education, employment, social support, and physical and social environments), racism, sexism, domestic violence, addictions, personal trauma and mental health concerns, and the intergenerational effects of residential school trauma.

## FIGURE 1: A FRAMEWORK FOR UNDERSTANDING THE DETERMINANTS OF PRENATAL DEPRESSION IN ABORIGINAL WOMEN



# Depression and Mental Health in Pregnant Aboriginal Women KEY RESULTS AND RECOMMENDATIONS FROM THE VOICES AND PHACES STUDY

## REPORT

## INTRODUCTION

Good mental health during pregnancy is extremely important for the health and wellbeing of mothers and their unborn children, as well as other family members. While there has been some research on depression during pregnancy (prenatal depression), very little has examined the issue specifically among Aboriginal women. As a first step to address this gap, we launched the *Voices and PHACES* study (with PHACES standing for Prenatal Health for Aboriginal Communities and EnvironmentS). The purpose of the *Voices and PHACES* study was to understand the risk factors, protective factors, and societal context for mental health issues in pregnant Aboriginal women. Key results and associated recommendations are summarized in this report. We hope that this information will help programs and services to meet the needs of pregnant Aboriginal women and their families.

## **BACKGROUND & SIGNIFICANCE**

Depression is a major public health issue that carries serious consequences for health and wellbeing. Depression during pregnancy can have negative impacts on the health of both the mother and the unborn child; these include adverse pregnancy outcomes such as low birthweight and preterm birth (Korebrits et al., 1998; Swaab, Bao, & Lucassen, 2005; Szegda et al., 2014; Wadhwa et al., 1996), increased risk of subsequent postpartum depression in the mother (Beck, 2006; Bowen & Muhajarine, 2006), and increased risk of mental health problems in the child later in life (Swaab, Bao, & Lucassen, 2005). Furthermore, maternal depression can impact the mother's interactions with her baby, her partner, and her other children, yielding negative effects on the children's long-term cognitive and behavioural development. Thus, good maternal mental health is critical for the physical, mental, and psychosocial health of the entire family; it has ramifications for healthy child development and for the maintenance of a stable home environment (Letourneau et al., 2012). As such, mental health during pregnancy can be seen as a meaningful early-intervention point for a series of concerns related to maternal health, child health, and family wellbeing.

Depression is believed to have multiple and diverse risk and protective factors, including biological factors and psychosocial factors. Chronic stress, from life events and socioeconomic and/or sociocultural circumstances, is believed to be a key risk factor for depression. Although largely psychosocially determined, chronic stress has biological consequences in the body. As such, stress falls at the interface between the pathophysiology of depression (and countless other disorders) and the social determinants of health (Roy & Campbell, 2013).

Aboriginal populations in Canada experience poorer health and greater social inequities relative to non-Aboriginal populations (First Nations Centre, 2005; Bennett, 2005; Adelson, 2005). Many of the risk factors and health consequences associated with prenatal depression are more prevalent among Aboriginal populations, suggesting that prenatal depression may be a pressing health concern (First Nations Centre, 2005; Bennett, 2005; Adelson, 2005). However, research on prenatal depression in Aboriginal populations is very limited (Bowen et al., 2014). Given the unique historical and present-day societal context involved, it would be erroneous to assume that the results of studies in non-Aboriginal populations can be directly applied to Aboriginal populations. Notably, Aboriginal women experience intersecting issues like racism and sexism, social exclusion, and intergenerational trauma from residential schools and other legacies of colonization (Roy, 2014). These factors likely influence mental health during pregnancy, potentially in complex ways. Failure to consider the influence of societal context on health can result in the overlooking of key pathways to target for meaningful and enduring primary prevention, and in the investment of funds into programs that are not effective due to being inappropriate to the needs of the target group. Targeted research is crucial for the development of effective and evidence-based policies, programs, and services for this population.

# **RESEARCH OBJECTIVES**

The Voices and PHACES study sought to understand:

- the risk and protective factors for depression during pregnancy in Aboriginal women;
- the societal context of Aboriginal women's lives; and
- the appropriateness and adequacy of existing programs and services in Calgary, and how these programs and services can be improved or expanded.

For the purposes of this study, the term 'Aboriginal' is being used broadly as an umbrella term for the Indigenous peoples of Canada, including First Nations (status and non-status), Métis, and Inuit. While a broad definition was adopted for the purpose of this urban-based study's objectives, it is important to recognize the diversity between and within these groups.

# COMMUNITY-BASED RESEARCH

A community-based approach was used in the study, involving academic-community partnerships between University of Calgary researchers, community organizations (social services agencies and health clinics) in the Calgary area, and members of local Aboriginal communities. Such an approach was taken to help ensure that the research would be valid, ethical, meaningful for knowledge translation, and respectful of the principles of Ownership, Control, Access and Possession (OCAP) in Aboriginal research. The latter is a key framework for research involving Aboriginal peoples; it mandates full partnership and self-determination regarding all aspects of research, and requires that all research involving Aboriginal peoples be done in ways that bring benefit (First Nations Centre, 2007). Five community organizations in Calgary served as core partners in the research:

- Inn from the Cold;
- Calgary Urban Projects Society (CUPS);
- Awo Taan Healing Lodge;
- Elbow River Healing Lodge of Alberta Health Services; and
- Adult Aboriginal Mental Health program of Alberta Health Services.

Along with assisting in the recruitment of participants, representatives from these five organizations served on the study's Research Team, alongside the University of Calgary researchers. Twelve other organizations, as listed in the Acknowledgements section of this report, chose to be involved as recruitment sites only.

In addition to the involvement of community partners on the Research Team, the study also had a separate Oversight Committee involving four Aboriginal community members (two of whom were Elders), and a representative from Alberta's Ministry of Human Services. A project governance structure, involving regular meetings and consultations, was implemented to ensure a collaborative approach throughout all stages of the study (Roy et al., 2014).

# STUDY METHODS

The study was approved by the Conjoint Health Research Ethics Board of the University of Calgary. A method of qualitative research called "constructivist grounded theory" was used for this study. "Grounded theory" seeks to develop a theory regarding a phenomenon, based on data gathered. In "constructivist" grounded theory, the researchers seek the standpoints of the participants, as well as the historical circumstances and social experiences that shape their opinions. A constructivist approach recognizes the existence of multiple interpretations of a situation according to societal context (Charmaz, 2009).

Personal (one-on-one) interviews were conducted with pregnant Aboriginal women and professionals who provide health and social services accessed by the women. Participants (pregnant women and professionals) were recruited from partner community organizations. Pregnant women were eligible

to participate if they were 18 years of age or older, were in the second or third trimester of pregnancy, self-identified as Aboriginal, resided in the Calgary area, and consented to be involved. Professionals were eligible to participate if they worked in health and/or social services in the Calgary area, and consented to be involved. Interviews were approximately one hour in length, and were conducted face-to-face with an interviewer in a safe location convenient to the participant (e.g., at the community partner agencies). A \$25 fee was given to each participant as a thank-you and to cover any costs to attend the interview, such as parking or childcare. After analysis of the data from the initial round of interviews was completed, participants were contacted about their interest in a second interview to go over the findings, for confirmation and further feedback (member-checking).

Following completion of member-checking interviews, a community gathering was held in Calgary. Invitees to the event included study participants, other Aboriginal community members, staff and management of health and social service agencies in the Calgary area, and other stakeholders. The preliminary results of the study were shared at the event, followed by a presentation by one of the study's Aboriginal women participants about her experiences. Focus-group-style discussions were then held to seek audience reactions and reflections on the study results and on possible recommendations for policies and programs.

# PARTICIPANTS

Personal interviews were conducted with 13 pregnant Aboriginal women and 12 professionals from health and social services in Calgary between March 2012 and August 2013. Of these 25 participants, seven subsequently participated in member-checking interviews (three of the women and four of the professionals). Eleven individuals attended the community gathering for stakeholders held in March 2014. Participants in all components of the study were diverse, allowing for many perspectives and experiences to be heard. Details on participant characteristics are summarized in the appendix at the end of the report.

# SUMMARY OF STUDY RESULTS

## Pathways that can lead to depression

The breadth and depth of responses corroborate the complexity of mental health issues like depression. A large number, and diverse range, of influencing factors were discussed by participants. It is of note that not all of these possible factors are required to lead to depression in an individual. Moreover, pregnant Aboriginal women as a group are very diverse; not all women are going to experience the same things – nor will they react to, or be impacted by, experiences in the same way. Therefore, the findings presented below are meant to be a general description of factors that can influence mental health during pregnancy in Aboriginal women. The pathways through which possible determinants interrelate to yield depression are summarized in the framework reflected in Figure 1.

### Depression

Medically-speaking, depression is when one feels sad or upset for a long time, generally more than two weeks. In addition to feeling sad, other possible symptoms may include loss of appetite, weight changes, sleep problems, trouble remembering things, and feeling tired (APA, 2013). These symptoms are similar to how the women we interviewed spoke of depression, either in their own lives or in the lives of others they knew. They used phrases like "hitting rock bottom", and described experiences like feeling helpless, hopeless, worthless, empty, lonely, tearful. They described symptoms like being unable to get out of bed, having trouble sleeping, and losing interest in things. One woman described depression as "when you're not yourself [because] a spirit that shouldn't be there ... takes over your body and your mind and lets you think all these awful things and makes you do awful things." Two women reported experiencing depression during or after a previous pregnancy. As one of these women described:

I isolated myself. I didn't eat. I couldn't sleep. I was getting anxiety attacks. ... My Mom kept coming over trying to get me to leave my house but I wouldn't leave. I didn't sleep in my room. I moved to my living room. ... I just lost interest in everything. ... I was like that for a whole month and I was always crying.

Nearly all of the professionals we interviewed described interacting with Aboriginal patients or clients with confirmed or suspected mental health issues, with clinical depression being particularly common. Other mental health issues encountered included anxiety, post-traumatic stress disorder, eating disorders, chronic pain, and substance abuse; multiple professionals noted that the latter was a correlate and indicator of poor mental health. Some professionals reported encountering prenatal and postpartum depression among their Aboriginal patients or clients; they noted the heightened ramifications of mental health issues during pregnancy, due to possible health consequences for both the mother and the unborn child.

## Chronic stress and trauma

Chronic stress – the state of feeling constantly worried or overwhelmed due to life circumstances – was linked by all the women to negative emotions and poor mental health. Trauma – extreme stress following a serious negative event – also came up in the interviews as linked to depression. One woman, whose daughter was removed from her care due to concerns about her mental health, described how it took her some time to recognize the point where life stress led to depression:

I think the hardest [thing] was my daughter being apprehended from me. I was going through depression because I had just gotten out of a recent abusive relationship from my daughter's biological father. I [had] just got out of the [women's] shelter, got my own place. My daughter has [a serious chronic illness]. I was on my own, just me and her in an apartment, dealing with bills, dealing with her [illness], dealing with the threats from ... [her] biological father, and it just became too much for me. I didn't realize that I was depressed. ... I just thought, okay, I'm just stressed, just stressed. I didn't understand the signs of depression. I didn't realize that I was isolating myself. I didn't realize that I was affecting my daughter's health, as well. ... Social Services [took my daughter because] they just want me to be stable and understand signs of depression. Both the women and professionals cited various negative life factors that can contribute to depression via the stress and trauma they cause. These risk factors are categorized and described below. It was apparent from the women's interviews, in particular, that many of these factors interact and overlap with each other in complex ways. To indicate this complexity, the three categories are shown in Figure 1 as interlaced circles. While depression is the outcome of interest for the purpose of this study, the interview data also pointed to the vicious cycle that can be set off between negative life factors, stress and trauma, and depression. To depict this cycle, arrows leading from depression back to points earlier in the pathways are included in Figure 1. Underlying contextual factors that appear to drive the pathways leading to poor mental health, according to the ideas coming out of the interviews, are positioned on the very left in Figure 1.

### Underlying societal and institutional context

Participants reflected at length about how Aboriginal women's lives are impacted by the broader historical and present-day societal context, and the context in institutions such as health and social services.

The atrocities committed against Aboriginal peoples over the course of colonization have resulted in "massive losses of lives, land, and culture" (Brave Heart & Debruyn, 1998, p.60). The legacy of colonization, including residential schools and the disproportionate involvement with child welfare authorities, continues to impact Aboriginal women's lives in the present day. Intergenerational trauma is a formal theory to understand why populations that have faced mass trauma – such as Aboriginal populations, who faced the events of colonization – continue to have poor health even several generations after the main traumatic events. The traumatic events set off a cycle of addictions, violence, and impaired parenting (among other issues) that result in the trauma being passed on from generation to generation (Sotero, 2006).

The Indian Residential School system was designed with the explicit objective of assimilating Aboriginal children into mainstream Canadian society, by breaking their links with family, community, and culture. Additionally, students were mistreated and neglected, as well as physically, sexually, and psychologically abused; survivors thus left the schools highly traumatized (Truth and Reconciliation Commission of Canada, 2015). Many of the women we interviewed reflected about the intergenerational impact of residential schools, including one woman who noted its link with her partner's abusive behaviour:

[My spouse is mean]. He's always angry and mad and he takes it out on me. He doesn't know how to deal with himself, he doesn't know how to deal with addictions or his anger, so he turns to drugs and alcohol. ... I think it's because his Dad was really mean too and his Dad was raised in residential [school]. ... They were raised really strict and they were really abused with, like, sticks – you know, still getting raised in the residential [school] way. They never broke out of that and it just stuck with them until this day, it's still like that. It's passed on ... generation [to] generation.

Other women spoke of the intergenerational impacts of residential schools in their own birth families, including one woman who reflected about its role in contributing to substance abuse and other dysfunctional behaviour among her family members:

My mom [was never around] for me and my siblings. ... [Her mom], my Grandma, was in residential school and she said what she got out of it was she didn't know how to love, ... how to show affection. ... She wasn't there for none of her kids. All my uncles [are] in and out of jail through their whole lives. ... My aunties drink a lot and my mom smokes weed. ... I was [also] following in that pattern of drinking and not caring.

Another woman reflected on the role of residential schools in both family and community relationships:

My mom just doesn't know how to hug, she doesn't know how to show [affection]. She's [even] not capable of ... praising me, and being like 'oh I'm so proud of you.' ... I just think that [the residential school system] really interrupted our traditional way of living. [It] had an extremely detrimental effect on us as an individuals and also how we function as a community. We're very dysfunctional [because of it].

Among other factors impacting Aboriginal women's health are racism and sexism. As one woman explained: "[As] both [a woman and an Aboriginal woman], I feel second class. [I] don't get as much respect." Experiences of domestic and sexual violence came up repeatedly in the interviews; the experiences described by the women encompassed the full spectrum of physical, psychological, emotional, financial, and sexual abuse. Experiences of racism and sexism – both implicit and highly overt – were also shared by the women, in settings including schools, workplaces, neighbourhoods, and when seeking health or social services. The women noted the convergence of racism and sexism in the discrimination they faced as pregnant Aboriginal women, who are often stereotyped as bad mothers who party, who abuse substances, and who are promiscuous. As one woman explained:

[We] are constantly being asked by anyone and everyone if we're using drugs, alcohol or smoking during pregnancy. They're assuming that we are. And also the assumption that each of our children have different fathers. ... I don't see [women from] other cultures being asked 'Oh, do your kids have the same Dad?' or 'Who's that [one's Dad], who's your first child's Dad, who's your second child's Dad?' But I'm constantly asked 'Oh, do your kids have the same Dad.' ... It's doctors, social workers, people I meet on the street [who are asking these questions].

Another woman described the impact of such stereotypes on her mental health:

I guess people may be looking at me as an Aboriginal woman that's pregnant. They're judging me, I guess, like 'Oh, she's probably drinking or smoking.' I'm learning not to care what people think, but then it kind of takes a little overwhelming toll on me [because] I do care, I'm human.

Professionals, too, shared stories that reflected racism and racialized sexism in health and social service settings; multiple professionals shared shocking anecdotes of overtly judgemental comments made by their colleagues behind the backs of patients or clients (this is discussed in greater detail later in this report). The professionals' interviews thus confirmed the suspicions shared in the women's interviews about the stigma Aboriginal women face in service systems.

### **Risk factors**

#### NEGATIVE LIFE EVENTS AND CIRCUMSTANCES - SELF, FAMILY, COMMUNITY

Both the women and professionals told us about many possible negative life events and circumstances in the lives of pregnant Aboriginal women. These included struggles with poor physical or mental health (of the women themselves, or of others in their lives). Exhaustion came up frequently in the women's interviews. While some attributed it to the physical effects of pregnancy, most noted the various stressors in their lives which led to them feeling overwhelmed and worn out. The health problems, deaths, addictions, incarcerations, or past residential school attendance of people in the women's lives were reported as having had an impact on the women's wellbeing. One woman explained how her partner's alcoholism severely impacted her mental health:

I'm really ... down ... when my spouse drinks. ... I feel hurt or sometimes I feel lonely or I'm just like confused. I don't know what to do but there's nothing I can do because I can't change somebody, ... but it still affects me 'cause they're like my partner and I've been with them for so long.

Health problems of children, other family members, or friends were cited as stressors, both due to the worry created and to stress from practical caregiving responsibilities. Deaths of close family members, friends, or community members were also discussed as particularly difficult to overcome. Several women described individuals close to them dying in disturbing circumstances, including suicide, gang or other violence, and drug overdoses. For some of these participants, the death of someone close to them, occurring often in tandem with other difficult life events and circumstances, pushed them into extreme depression and dysfunction. As one woman shared:

I actually had a breakdown. ... [In addition to being abused by my boyfriend and his family], my late brother passed away, ... so it was too much for me. ... I drank two bottles of vodka, 'cause I didn't care. I blacked out [and ended up in hospital] and my Mom even told me I was trying to kill myself.

Some of the deaths cited in the women's interviews occurred long before the women became pregnant; however, the memories and ramifications of the deaths were still felt, even years later. Other deaths were experienced during pregnancy; one woman explained: "It was really hard to focus on my pregnancy [after that]."

References to residential school attendance by family members, including parents, siblings, grandparents, and great-grandparents, came up repeatedly in the interviews. The resultant trauma in these family members was cited as a source of distress among the women. The women had to cope both with the challenging nature of their relationships with these individuals as a result of their trauma (including abuse and neglect), and with other ramifications of these individuals' dysfunctional behaviour. Some women noted that their abusive partners' family members attended residential school, and that this was likely at the root of their partners' abusive behaviour.

Stressful events or circumstances that impact the women's wellbeing can be general life situations, and/or things related specifically to being pregnant or being a parent. Examples mentioned in the interviews included cumulative day-to-day stressors; having no time to relax or unwind; stress from parenting existing children; socioeconomic insecurity; negative relationships; dysfunctional family and

community dynamics; and other life circumstances such as domestic violence, involvement in the criminal justice system, and involvement in the child welfare system.

Past or present involvement with child welfare services was mentioned a lot in the interviews as something that can impact mental wellbeing. This involvement can be a woman's experience of being in foster care herself during her childhood, and/or a woman's experience of having her child taken away from her by child welfare authorities. As one woman explained in describing her fear around her current pregnancy: "I don't really want to bring another baby into this world just for the baby to get apprehended again."

Beyond family and friends, problems in the community were cited as impacting the wellbeing of Aboriginal women during pregnancy. These included negative community dynamics such as gossip, corruption among community leaders, and crime (including gang violence). Living in communities with a high prevalence of negative issues such as addictions, suicide, and poverty were also noted to have an impact on women, regardless of whether there was personal experience of the issues, due to the poisoned social environment. Problems were noted both in reserve communities and in urban communities where Aboriginal women lived. Multiple professionals reflected about the experiences of women leaving reserves to move to the city. They noted that, on one hand, women leaving reserves often lose their positive support networks, which can heavily impact their mental health. On the other hand, the tight-knit nature of small communities can also adversely impact mental health when the communities experience detrimental social dynamics. As one professional (a nurse), commented:

[Because of the legacies of] residential schools and colonization ... reserves [are not always] healthy environments. ... Living together [in a community can be good, but] there has to be that healthiness there. ... Living in a small town ... where everybody knows everybody's business ... can make it harder to live in that type of environment.

Negative dynamics were also cited in urban communities, where Aboriginal women can also be impacted by community-level poverty and crime, in addition to racism.

#### NEGATIVE RELATIONSHIPS

Almost all of the women spoke at length of negative relationships with past or present intimate partners. Physical, sexual, verbal, emotional, and financial abuse came up repeatedly in the women's interviews, as well as the professionals' interviews. Other difficult relationship dynamics, such as infidelity, strained communication, and immature or irresponsible behaviour on the part of the partner, were also cited by participants. Many women were no longer in a relationship with their baby's biological father; his absence was generally deemed as positive by these women, in light of the negative nature of their relationship. However, the women still expressed regret at the lack of partner support in their lives. As one woman explained:

A lot of the time I wish my baby's Dad was part of it. He's not so I'm basically doing this on my own. ... [I feel lonely] when she's kicking, like at nighttime. I sleep by myself, you know, and I see all these couples, with the Dad being there and feeling the kicks and, you know, worrying and stuff like that. (Chuckle) It's having the partner there – that's what I kind of want, but [I don't have that].

Professionals also noted that many of their pregnant Aboriginal patients or clients did not have their baby's father in their lives. One professional (a family counsellor) speculated that the men were abandoning their pregnant partners out of fear of being a father, due to themselves hailing from homes where fathers were not present:

Usually [the male partners] are not there. They're just scared and they're gone or maybe they just didn't want to be there because, you know, there's going to be a baby coming and they're not ready to go there: 'I don't know how to be a Dad. No I didn't want to be a Dad. Now I gotta be a Dad. Oh, I'm outta here. I don't know how to do that.' ... Maybe they're just not prepared [because] ... they probably had similar family backgrounds.

A lack of positive friendships, or the existence of negative friendships (i.e., built around unhealthy activities like partying, drinking, or drug use) were also discussed by the women and professionals as a contributor to poor mental health. Many women described having to cut off negative friendships once they found out they were pregnant, since they could no longer do things like party or drink; such a decision left them lonely and isolated, without support or camaraderie of any kind.

Negative relationships with family members also came up repeatedly in both the women's interviews and professionals' interviews. Dynamics described in this regard ranged from abusive (including physical, sexual, verbal, emotional, and financial abuse), neglectful, and exploitative, to otherwise not supportive or nurturing. Family members included parents, siblings, grandparents, aunts, uncles and cousins. Family members of intimate partners were also cited.

Negative interactions with neighbours, community members, and colleagues at school or work were mentioned in the interviews. Racist comments from non-Aboriginal persons were also cited. Finally, negative relationships with health and social services providers were described as having a particularly severe impact on wellbeing. The women described instances of experiencing stigma, judgment, or having otherwise unhelpful interactions when seeking services. Professionals described witnessing or overhearing their colleagues speak or behave in ways that were clearly judgmental; they expressed concern about the impact on the wellbeing of the patient or client. As one professional (a physician) stated:

Patients aren't stupid. They can recognize when someone's judging them for the circumstances they are in. ... The interaction [between service-providing professional and patient or client] is, in my opinion, key to an effective therapeutic relationship. So [when I] see these kind of underlying ... prejudiced ideas [among service-providing professionals], I think [they] have an impact on patient care.

#### SOCIOECONOMIC FACTORS

Socioeconomic factors are major risk factors for depression at any time of life, in any population. These include low income, low education, and unemployment, and the corresponding problems of food insecurity, housing insecurity, and financial insecurity. One woman described spending an extended period of time at a crowded homeless shelter during her pregnancy, followed by living temporarily with her partner's family, who emotionally abused her. She identified her housing insecurity as a major source of stress in her life. Another woman described how she was dependent on food banks to feed herself and her family, and was concerned about getting adequate nutrition during her pregnancy.

For some women, financial insecurity was an ongoing issue in their lives; for others, it was brought on by pregnancy and the prospect of another mouth to feed. In the case of one woman, her considerable morning sickness led her to reduce her work hours, leading to financial strain: "[My] stressors [include] financial [stressors]. After I slowed down at work I wasn't making enough to pay my bills and I was getting last notices for rent and utilities and stuff." Her reduced work hours also led to considerable conflict with her boss, who was unhappy about her reduced availability and impending maternity leave – further compounding her stress levels.

Pregnancy and parenting can interfere with school or career progress, as described to us by multiple women who were working and/or students. In addition to impacts on current and future financial security, the corresponding stress and uncertainty can also significantly impact wellbeing.

## Negative coping mechanisms

We heard in the interviews about ways in which pregnant Aboriginal women cope with stress and negative life factors. Negative ways of coping can exacerbate or amplify (that is, make worse) the pathways in Figure 1. These include maladaptive coping strategies such as substance abuse, gambling, and violence. These also include a lack of positive coping mechanisms, which are things like self-esteem, social support, optimism and hope, and a sense of identity.

Substance abuse and addictions came up repeatedly in the women's interviews and professionals' interviews as negative coping mechanisms to stress. Professionals reflected that abuse of substances such as alcohol, cigarettes, marijuana, or other illicit drugs might be "an easy escape for the time being" for women in highly stressful or traumatic circumstances. Some professionals suggested that, in their experience, women often made a conscious attempt at stopping alcohol consumption upon finding out that they were pregnant; cigarette-smoking, on the other hand, might be harder for women to give up, because it may be "all they have to cope" – particularly if they have eliminated alcohol or other illicit drugs due to their pregnancy.

The women described how they abused substances in an attempt to cope with overwhelming life circumstances. One woman spoke of how she turned to alcohol after a series of traumatic events in her life:

I turned to alcohol. I started drinking heavily after that. [It] was really a hard time in my life. I just pretty much gave up on everything. ... I just gave up. I was mad at the world, I was mad at my family. I just didn't care.

Substance abuse, however, inevitably worsened life circumstances, leading to more despair and worse mental health for the women. In the case of the woman quoted above, her alcoholism led to her children being taken away from her by child welfare authorities. Another woman described finding herself in a vicious cycle of worsening binge drinking and depression:

I was drinking [when I] was in a bad depression, and it just kept leading me to binge drink, and then that led to more depression.

Thus, negative coping mechanisms such as substance abuse appeared to exacerbate the pathways leading to depression, as depicted in Figure 1.

One woman explained how she was able to break free of her addictions when she learned healthier ways of coping:

Before, ... when I was mad or angry, I would turn [right away] to alcohol or drugs. ... [I] used to drink by myself. ... Now, when I'm mad or stressed out, I talk about it [with family or friends].

Thus, negative coping mechanisms such as substance abuse appeared to be used when positive coping mechanisms were lacking for the women.

### **Positive protective factors**

Both the women and professionals pointed out that, while a lot of focus is placed on the negative circumstances underlying Aboriginal women's lives, it is also important to note the resilience and strength displayed by many Aboriginal women. Adjectives like "strong", "proud", "innerly beautiful", and "courageous" were used in the interviews to describe Aboriginal women who effectively cope with, and overcome, their circumstances. While diverse stressors exist in Aboriginal women's lives, not all women become clinically depressed; and, of those who do reach the point of clinical depression, some are able to recover more readily than others. The women and professionals discussed a number of protective factors that serve as buffers along the pathways connecting negative life factors, stress and trauma, and depression; in other words, these factors can stop depression from happening or help to make it less serious.

As with the negative life factors, positive protective factors appear to intersect with each other in complex ways. While these factors have been grouped into four categories below and in Figure 1, the categories overlap substantially.

## Healthy mind, body, spirit

Interview data suggested that key to resilience in the face of difficult circumstances is the maintenance of a healthy mind, body, and spirit. Of course, negative life factors can make maintenance of such a state difficult. Even in the face of other negative circumstances, socioeconomic security and positive life events (even small positive occurrences) can help facilitate the practical and psychological resources required to remain resilient, and act as protective factors against depression.

The women reported various positive coping strategies used in the face of stressful circumstances to maintain a healthy mind, body, and spirit. "Keeping busy" through activities like housework, schoolwork, or employment work was cited by multiple women as a way to "keep [one's] mind off things"; in other words, use of distraction to avoid ruminating about difficult life circumstances. Accomplishing tasks, even small housework tasks, was cited as a way to feel emotionally better, even if only temporarily. Other activities enjoyed by the women included reading, sewing, traditional beading, and crafts. Making time to relax and getting enough sleep were also listed as protective by the women and professionals, as were activities such as walking, running, yoga, and other forms of exercise. A healthy diet was similarly cited as contributing to wellbeing, and thus protective against depression.

The women spoke of coping cognitively with stress by keeping a positive outlook and remaining optimistic, calmly rationalizing through difficult situations ("take a step back"), and learning to "calmly ... walk away and ... let it be" when dealing with difficult individuals. Maintaining a sense of humour was also cited ("laughter is sometimes the best medicine"). Some women learned these skills through mental health and/or addictions counselling, highlighting the role of programs and services in facilitating positive coping skills. Others learned the importance of positive thinking from Elders or other spiritual leaders. As one woman explained:

Like the elders always say, when you put your mind on good things, then good things will come. [The] Creator has a way of, the Universe has a way of, working it out. You gotta know where you're going, who you're going with, and where you come from.

The women and professionals noted that spirituality helps some women maintain a positive outlook. The approaches to spirituality and prayer do not need to be grounded in organized religion; one professional (a nurse) described spiritual components to programming at her organization that avoided reference to specific religions, to ensure comfort of all. A few women described themselves as practising Christians, and engaged with spirituality through attending church and reading the Bible. Others engaged in traditional Aboriginal practices such as smudging, sweatlodges, powwows, and other ceremonies. One woman, who overcame significant traumatic life events in her past, described how she found peace in the spiritual significance of the prophesy of the White Buffalo. Thus, her spirituality and connection to traditional Aboriginal healing approaches were helping her to find peace with the difficult circumstances of the past, and remain optimistic for a healthier future – both for herself, and for her First Nations people.

Finally, multiple women spoke about how they drew confidence from their identities as Aboriginal women, citing the "rich cultural heritage" and "the connection with the Creator". One woman stated:

I feel proud to be Aboriginal because there's no one like us [and] the culture is beautiful. I'm pretty proud and I wouldn't want to be anything else, even though we go through so much as people.

The strength shown by Aboriginal women to overcome obstacles was also cited by some of the women we interviewed as sources of pride. As one woman explained:

Aboriginal women are starting to stand up for themselves and stand up for other Aboriginal women and be independent and do things on their own.

### Healthy relationships

The women and professionals spoke of the importance of positive relationships with intimate partners, family members, friends, neighbours, coworkers, and service-providers. Emotional and practical support from others was cited as key mechanisms for coping positively with negative life factors. Spending time with pets was also mentioned by a couple of the women as being a stress-reliever in their lives. In regards to healthy relationships, one woman expressed:

Relationships are a really big part of life and having good relationships can make you or break you. If you're in a positive environment with good relationships, then you tend not to be depressed. In the context of pregnancy, relationships with older women who have experienced pregnancy and parenting, or peers who are going through such experiences concurrently, were cited by the women and professionals as particularly important. One professional (a prenatal nurse who serves many Aboriginal patients in her work) described how she saw herself as "a mother and grandmother" to her patients, in addition to being their nurse. She explained that because of residential school trauma, many of today's pregnant and parenting Aboriginal women do not have positive relationships with their mothers and grandmothers; accordingly, she finds herself dispensing pregnancy and parenting advice that normally would have come from a woman's own mother or other older female relatives. Professionals involved in group-based prenatal education programs noted the camaraderie that often develops among program participants, who bond over their shared experiences and reach out for mutual support. One woman explained the value of such relationships:

When they're going through the same thing as me, or they have gone through the same thing as me, it definitely helps that they understand a little more.

In addition to seeking out positive relationships, avoiding negative relationships was also described as protective by both the women and professionals. Multiple women described how they broke off friendships built around unhealthy activities such as alcohol or drug use, so as not to get enticed into such unhealthy activities during their pregnancy. Professionals shared anecdotes of female Aboriginal patients or clients whose pregnancies led them to re-evaluate difficult relationships with their intimate partners, and "set limits" on what they would tolerate. Such steps promoted wellbeing by reducing sources of stressors in the women's lives.

#### Healthy environments

The women and professionals spoke of how positive physical and social environments – places where women live, study or work, seek programs or services, or otherwise spend time – can help buffer the impact of negative life events. Positive physical environments were described in the interviews as those that allowed women to feel safe, secure, and comfortable, and that permitted easy access to resources (e.g., close proximity to transit, grocery stores, health and social services).

Positive social environments were described as involving positive interactions with others, as well as positive attributes that permitted women's psychosocial wellbeing. These included positive interactions with colleagues at school or work, wherein the women felt respected, supported, and appreciated. The women used words like "tight-knit" and described moments like "having tea together, just talking" to describe positive social connectedness in their neighbourhoods and home communities. Some women spoke of traditional language and culture binding community members together; they expressed a desire for their children to learn the language and culture, in order to be a part of that connection. One woman described rallies and walks for suicide awareness that occurred in her home community, where suicide rates were high:

[It was] inspiring because a lot of young kids that [were] suicidal came out and signed pledges not to [commit suicide]. Just seeing all the kids be happy for the day was good enough, you know? [My community] is plagued with suicide, ... there's a funeral every week or something. That's the negative part of our community. But the positive part is when the people come together.

Thus, even in communities with difficult dynamics, positive social interactions can make a difference.

# Barrier-free, effective, and culturally safe services

Finally, health and social services that are easy for women to access, that meet women's needs, and where women can feel comfortable, safe, and respected are also important protective factors. Cultural safety is a concept that, when applied to service provision, refers to the patient or client being made to feel empowered and respected. When patients or clients feel this way, they are more likely to benefit from the service and continue to access it. Further discussion in this regard is offered in the next section, and also in the Recommendations section of this report.

## Services in Calgary and area

We asked both the women and professionals about how they felt services (both health and social services) in Calgary and the surrounding area are doing in terms of meeting the needs of pregnant Aboriginal women. A number of key points arose from the interviews. Some services were described as effective and meaningful in giving pregnant Aboriginal women the information, tools, resources, or care they need. More Aboriginal-specific services, however, were requested by the women, particularly as a way to meet other Aboriginal women with shared experiences. As one woman articulated:

I can't really think of any other Aboriginal programs that I could attend, like you know just for Aboriginals to come and be together and you know just talk and bring your babies like, there's none of that.

Other Aboriginal-specific services requested included Elder support, designated spaces in clinics and hospitals for cultural healing practices such as smudging, and support for incorporating traditional Aboriginal perspectives on healing into services.

Barriers to access of services included issues not specific to Aboriginal peoples, such as hours of operation, childcare needs, and transportation constraints. The women who were pursuing education or employment noted the difficulty of attending appointments scheduled during business hours. As one woman explained:

I [go for the] latest appointment just so I don't have to take too much time off work. ... I'm sure not going to miss work [because] I'm still on probation [at work].

Both women and professionals cited childcare availability as a barrier to seeking services and to attending medical appointments. One professional attending the community gathering suggested that widespread availability of childcare at all services (health and social) for families was warranted, but that funding was required:

As an organization, if we had specific, dedicated funding for childcare, I think that would be helpful. Like we have some programs where we can do that, but I think every program that serves ... mothers as clients should or could have childcare ... provided.

The need for services to be easily accessible by transit was highlighted by multiple women, who cited impediments to travel such as Calgary's cold winters, being accompanied by small children, and the physical discomforts of pregnancy: "especially being big and pregnant and tired, ... you just want to be able to get there and go back." Similarly, a need was cited for services to be available throughout the city, so that women could access resources within their local areas. As one woman stated:

You know a lot of resources right now are way [on the other] side of town which is so difficult to get there (chuckle). ... I think there should be more places where you could go ask for help. I haven't found anything yet right now [in my area].

The women spoke of experiences with negative, judgmental service-providers, and also of feeling like they could not always trust service-providers to genuinely care about their needs. One woman gave an example of a time she declined accessing services because of this distrust:

When I was fifteen I was physically and sexually abused. I suffer from severe depression from that. I wasn't diagnosed, though, because I refused to go see a doctor. ... I didn't want to talk to a stranger, because I've had it in my head that they were only doing it for the money. They didn't really care about how I actually felt. They didn't really care that I was actually hurt.

Professionals also acknowledged the existence of racism, stigma, and judgement in service systems. They shared examples of such behaviour among their colleagues, occurring notably behind the backs of patients or clients. One professional (a nurse) gave the following example:

There was a patient who was a young Aboriginal woman with a toddler that was crying quite a lot, it turned out to have an ear infection, and so she's sort of pacing around, it's quite a large waiting room, with the toddler. And [my colleague] comes to me, speaking sternly, and says, "I've got my eye on that patient, they're sneaky you know" and then I realized she meant because she was Aboriginal. And she's speaking sternly, says "All of a sudden you'll probably see her drinking the hand sanitizer" or something like that.

There was particular concern expressed about child welfare policies. The women felt that child welfare policies were not working in the best interest of children and families. One woman described her frustrations with the system:

I get really frustrated sometimes with the system. [Child welfare authorities are] judging me over what is written [about my past behaviour]. That's not right – they should actually get more involved with the parent and talk to them face-to-face, oneon-one, to understand what they've been through and what they're going through and why they did the things that they did in life. ... It's our kids suffering for it, for being stereotyped. ... There's nothing we can do to change [the past] but it's good to know [about it] so it can help the parents change in the future.

Another woman explained how fear of child welfare authorities led her to avoid accessing certain services: "You know that's not right for them to [do], for families to go there and end up getting their kids apprehended, [but that's what happens]."

Professionals expressed similar concerns about the child welfare system not doing enough to support parents who are struggling to care properly for their children. One professional (a nurse) expressed frustration:

It drives me nuts [that] they're willing to put a baby in foster care and pay for the foster parent to have a baby ... [but] they're not willing to give [the birth mother] a dime to help her, or to provide a safe place for Mom and baby to learn and [get support]. The supports are just bad.

Professionals expressed a need for better training and resources in order to create a safe, stigma-free environment. In both the personal interviews and in the focus-group-style discussions at the community gathering, it was emphasized that many professionals have little understanding of colonization and intergenerational trauma (or, for that matter, personal trauma). One professional (a counselor), who was herself Aboriginal, exclaimed:

Colleagues that I work with ... do not know their history, don't know about the Treaties, don't know about residential school, don't know about the sixties scoop. Don't know about the whiskey traders. ... Alcohol use ... wasn't a part of our culture, ... it's such a big thing now because it's a learned behavior.

Professionals also expressed an interest in knowing how to make services more accessible, and how to help patients or clients make it to appointments or programs.

Finally, professionals were almost unanimous that better networking is needed between services, to ensure continuity of care and to ensure that no one slips through the cracks. Some professionals who work at non-profit agencies raised the issue of having to compete for funding as a major barrier to cooperation with other agencies. Multiple professionals raised the issue that much of service delivery is oriented towards managing acute, emergency situations, such that the underlying issues in women's lives do not generally get addressed. Multiple professionals (notably physicians) spoke about how they wished they could do more in this regard, but were limited by the very specific job they had the training and capacity to do. They felt that better networking and a stronger system of referrals between services would help professionals to connect the patients or clients with appropriate help for such other issues.

### Pregnancy as a meaningful intervention point

Some women described their pregnancy as a motivation for positive change in physical health behaviour; the women reported making efforts to improve their diet, get more exercise, and give up alcohol and drugs for the sake of their baby's health. The women also reported that their pregnancy helped change their attitudes and perspectives, improving their mental wellbeing and helping them to seek more positive coping strategies. One woman explained how "it took [getting] pregnant [for her] to realize" that she needed to stop drinking and "take a different route" to coping with stress and trauma. She realized that she needed to take better care of herself for the sake of her children:

Mentally ... you're on a whole different level. Before I was pregnant I, I was only thinking about myself. [But then] this little person comes into your life and it's different. It makes you see the world differently. I think about death a lot [because] I don't want to leave my son behind.

Another woman spoke of how her baby "saved her":

I dealt with depression a lot of years. I'm finally feeling better. I finally feel like I have a purpose in life now. [My baby] pretty much saved me, she's the reason I'm still here. She keeps me motivated.

The women reflected about motherhood in light of their complex, often difficult, relationship with their own mothers. One woman reflected how her pregnancy has helped her to forgive her mother for not being a good parent to her:

Pregnancy has been an emotional time for me. ... For a long time I really hated my mom and was mad at her. But now I have a better understanding of what she experienced [in residential school]. ... You have to be empathetic and be the bigger person and end the cycle of abuse.

This woman spoke about feeling blessed to be pregnant, because it was giving her the chance to break the cycle of trauma in her family:

My mom, because she was in residential school, didn't know how to be a mom. I feel really blessed that I can [now] be a mother and [do things differently], and be present in my baby's life. [My pregnancy has been] a healing process for me.

Professionals spoke about how pregnancy can be a key intervention point for health and wellbeing because pregnancy leads to increased contact with health services, thus creating opportunities for meaningful interventions. However, professionals also noted that, in some cases, pregnancy may discourage women from accessing services; they spoke of cases where women are afraid of being judged for their lifestyle (e.g., addictions), or afraid that contact with services will lead to their baby being taken from them. Thus, while women may be more motivated to make positive life changes during pregnancy, health and social services systems need to address the above fears in order to successfully facilitate access and benefit from programs and services.

# SUMMARY OF RECOMMENDATIONS

The determinants of prenatal depression in Aboriginal women are diverse and complex; like many population health issues, they warrant a multi-pronged, multi-sectoral approach to adequately and effectively address them at both individual and population levels. As can be seen in Figure 1, the points along the pathways at which the negative coping mechanisms can exacerbate development of depression are also the points at which protective factors can act to buffer the development of depression. Thus, despite the complexity of contributing factors, scope for intervention and prevention does exist. Some recommendations are offered below. While specific examples have been cited where possible, it is clear that further research is required to better understand how to best execute these recommendations. Moreover, the best means of acting on these recommendations will vary based on local context.

# Addressing social support

The results of this study corroborate other research that has shown the significance of social support as a protective factor against depression. The importance of social support from the intimate partner, and from peers (other pregnant and parenting Aboriginal women), were strong themes in the results. Accordingly, interventions that facilitate social support from these sources are warranted.

 Programs targeted to Aboriginal fathers-to-be may help facilitate their role in positively supporting their pregnant partner, and in playing a positive role in parenting after the birth. Programs targeting other Aboriginal males significant in pregnant women's lives (e.g., her father, uncles, brothers) are also warranted. Such programs would serve to counter the damage that colonization, assimilation, and intergenerational trauma have inflicted vis-à-vis the role of Aboriginal men in families (Manahan & Ball, 2007).

- Similarly, interventions that help foster positive relationships between pregnant Aboriginal women and their own mothers and/or mothers-in-law would also help to expand availability of social support.
- Aboriginal-specific group-based prenatal and parenting programs may help Aboriginal women to meet and draw mutual peer support in healthy environments, addressing the striking lack of positive friendships reported in the interviews. Multiple women and professionals suggested doing an Aboriginal version of Best Beginnings, a prenatal education program offered under Alberta Health Services. Another program mentioned in the interviews that could be adapted specifically for Aboriginal women was Centering Pregnancy, a groupbased model of prenatal care (McNeil et al., 2012).

### Addressing practical barriers to service access

Several practical barriers were raised in the interviews. Potential actions are as follows:

- Given the concerns expressed around hours of operation (from women's interviews) and high
  rates of missed appointments (from professionals' interviews), recommendations might
  include having longer hours of operation (including evenings and weekends), and having
  services that are drop-in rather than appointment-based.
- Additional targeted research is warranted to examine specifically if Aboriginal patients or clients access services less often, and if so, why; and to examine if they miss scheduled appointments more often, and if so, why. The goal would be developing concrete actions to address the issues.
- Given concerns expressed around patients or clients 'slipping through the cracks' between
  referrals, it is recommended that procedures be implemented to follow up women and ensure
  continuity of care across referrals. Suggestions offered in professionals' interviews included
  things like having a single point of entry (i.e., centralized access to services) to enable follow
  up, and the use of electronic records that 'travel' with the patient or client. Further research to
  examine possible solutions is required.
- The need for better networking between services, within and across the various health and social service sectors, came up repeatedly in the interviews. Many of the service-providers expressed frustration about the current systems that remain fairly fragmented in practice. Better networking, coupled with a stronger system of referrals and care coordination, may allow women to receive more holistic support. Other institutional barriers and reasons for 'slipping through the cracks' also need to be identified and addressed.
- Better transportation arrangements are recommended to assist patients or clients to access services, particularly for women living on reserve who need to access services in the city. Childcare considerations are also important for pregnant and parenting populations seeking services. Programs where the service-providers go to women's homes might be considered.
- The need for more accessible culturally-appropriate services came up frequently for example, better availability of Elders, and of opportunities to engage in traditional Aboriginal cultural practices aimed at healing and wellness.

## Addressing stigma and lack of safety in health and social services

In service delivery, there is need to create a safe, stigma-free environment where patients or clients can feel comfortable and respected. Cultural competency refers to the ability of service-providers to work effectively across cross-cultural settings (NAHO, 2008). Cultural safety focuses on structural inequities stemming from various sociocultural factors, and the resulting power differentials in relationships – particularly that between service-providers and patients or clients. Cultural competency and cultural safety are particularly important when working with Aboriginal patients and clients, given the lack of trust that stems from the fact that Aboriginal peoples' historical relationship with health and social services is entrenched in colonization (NAHO, 2008; ANAC, 2009, Roy, 2014).

- In their interviews with us, multiple professionals called for better training in this regard. Training in cultural competence and cultural safety should be considered in both initial education of new professionals (including, but not limited to, physicians, nurses, and social workers), and in continuing education of already-working professionals. Training of serviceproviders needs to include concrete steps that can be followed in the context of the work that they do (e.g., training on how to communicate better, how to frame questions in an appropriate way, etc.). If simple, concrete, actionable steps are not offered as part of education on these issues, service-providers may be left feeling uncomfortable, ill-equipped, or defensive. Training should address their specific concerns around how to pragmatically execute culturally competent and culturally safe care. For example, there may be a fear among service-providers of coming across as discriminatory if questions to patients or clients appear to correlate with stereotypes. Thus, training on communication is essential, particularly on how to broach sensitive topics. Additionally, there may hesitance on the part of serviceproviders to ask about life issues, because they are not necessarily trained or prepared to address disclosures if/when they occur. Thus, better training on the response to disclosures, and better networking between resources (for referrals), are warranted.
- That many health and social services professionals have limited knowledge or understanding of the history of colonization, of residential schools and its intergenerational impacts, and of issues such as racism and sexism was discussed in both the professionals' interviews and in the community gathering focus-group-style discussions. In this regard, a theme that emerged from the analysis of the interviews was that of a tension between individual-level service provision and population-level understanding of Aboriginal health. Better training on how practitioners should apply the latter to the former may help. A population-level understanding of Aboriginal health allows a comprehension of context for the higher rates of health and social problems in Aboriginal communities. It should not be used to judge or stereotype individual patients or clients, though it may offer context on some of the problems that individual patients or clients may be facing.
- In addition to training professionals, implementation of cultural competency and cultural safety should be considered in other aspects of health and social systems, including the physical environment of clinics or offices (e.g., messaging in posters and pamphlets displayed in waiting areas), training of support staff, and availability of culturally-appropriate services such as Elder support and traditional healing practices.

 Many of the women we interviewed expressed concerns around service-providers reporting suspected child abuse and neglect to authorities; the women said the above dissuades them from seeking services, due to fear of losing children as a result. The disproportionate number of Aboriginal children in the care of social services supports their fears. Positive, strengthsbased, culturally appropriate and culturally safe care around pregnancy and parenting, and attention to healing intergenerational trauma, could address these concerns.

# Addressing trauma, addictions, and mental health issues in health and social services

Mental health issues, addictions, and a history of trauma are often correlated. Pregnancy may galvanize positive life changes and present new opportunities for intervention around these issues. A positive, loving, accepting environment in which a pregnant woman's strengths are recognized and complimented, and in which her pregnancy is celebrated, can go a long way in promoting good mental health during pregnancy. Taking a positive, culturally safe, and strengths-based approach in service-provision is thus recommended.

- Aboriginal women may be at increased risk for mental health concerns. A number of studies
  regarding prenatal mental health in the general pregnant population have called for the
  implementation of routine screening of *all* pregnant women for symptoms of depression and
  anxiety (Milgrom, & Gemmill, 2014; Stuart-Parrigon & Stuart, 2014). Screening all women
  during clinical or social service encounters (and communicating at time of asking the
  screening questions that all women are routinely screened) could decrease concerns around
  stereotyping Aboriginal women.
- Similarly, implementing screening practices during clinical or social service encounters for *all* women about domestic violence, social support, substance use, etc. and explaining to patients or clients at the time of screening that these are routinely asked of all women would also increase the comfort level of both practitioners and patients or clients around these sensitive topics. Screening must, however, be accompanied by the availability of appropriate, culturally-safe services to address disclosures.
- In terms of treating clinical depression in pregnant Aboriginal women, psychotherapeutic approaches should be applied in ways that reflect an understanding of context; recognition of what is culturally appropriate, recognition of intergenerational trauma and the legacy of colonization, and recognition of multiple sources of personal trauma, for example, are all important in order for counselling to be successful.
- Given the prevalence of trauma in the experiences of Aboriginal women, a trauma-informed approach to all services is warranted. A trauma-informed approach to care is one which recognizes the role of trauma to a patient's health or life issues, supports healing from trauma, and avoids re-traumatization (Arthur et al., 2013; Elliott et al., 2005; Klinic Community Health Centre, 2013). The results of this study suggest that more needs to be done to address the trauma underlying substance abuse, mental health problems, and poor parenting issues among Aboriginal women. The above applies particularly in the context of the child welfare system.

# Addressing the social determinants of health and underlying societal context

Multiple professionals spoke about how much of service-delivery is oriented towards managing acute, emergency situations, such that the underlying issues in the women's lives do not always get addressed. Given the key role of the social determinants of health, interventions that address the negative life factors that are the sources of chronic stress in women's lives are warranted. Moreover, the underlying societal context that drives such issues is also important to address. Ultimately, meaningful and enduring primary prevention necessitates targeting these upstream structural and systemic factors through population-level programs and policies that bridge multiple sectors.

- Poverty, food insecurity, housing insecurity, lack of education and employment opportunities, inadequate childcare, and negative physical and social environments in communities all influence mental wellbeing, and need to be addressed through systemic change.
- Racist and sexist attitudes and stereotypes among the general population about Aboriginal women need to be actively challenged.
- Interventions aimed at addressing domestic violence in Aboriginal communities are required including support and protection for victims, interventions for perpetrators, and initiatives for primary prevention that include challenging its normalization. Homefront, a special court in Calgary, has piloted a culturally appropriate, community-based program for women, men, and children with experiences of domestic violence. It could be further tested as a sustainable model (Homefront, 2012).
- Nearly all of the women we interviewed reported having one or more relatives who attended
  residential schools, including parents, older siblings, uncles and aunts, and grandparents. The
  intergenerational impacts of residential school attendance are well documented, and need to
  be addressed with individual-level, family-level, and community-level interventions aimed at
  healing. The Aboriginal Healing Foundation has published extensively on the topic of
  interventions to address intergenerational trauma (Aboriginal Healing Foundation, 2006).

# CONCLUSIONS

The Voices and PHACES study sought to address a key gap in the research literature concerning the determinants of depression during pregnancy in Aboriginal women. We hope that the key results summarized in this report, the framework illustrated in Figure 1, and the list of recommendations provided offer a meaningful contribution to efforts to provide appropriate, effective, and evidence-based services for pregnant Aboriginal women. We are particularly hopeful that the academic-community collaborations established for this study will enable further research and action on this topic.

Despite significant forces of oppression and continued marginalization, Aboriginal individuals and communities – and Aboriginal women in particular – have shown considerable strength and resilience. Drawing on this strength and resilience to facilitate healing is important to addressing prenatal depression and other pressing public health issues affecting Aboriginal populations.

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# APPENDIX: CHARACTERISTICS OF STUDY PARTICIPANTS

#### Pregnant Aboriginal women

Thirteen pregnant Aboriginal women participated in the personal interviews. Eleven of these women identified as First Nations with status, one identified as First Nations without status, and one identified as Métis; none were presently living on a First Nations reserve. Most were in their 20s, but ranged in age from 22 to 45 years. Seven women had at least one other child; for these women, age at birth of first child ranged from 15 to 21 years old. Of these seven women, three had none of their kids living with them due to removal by child welfare authorities.

Of the 13 women, one was legally married, three were living common-law, and the rest were single (never married). Three were employed full-time, one was employed part-time, two were students, and the seven others were not employed. Six had not completed high school, four had earned their high school diploma, two had a trade certificate or completed apprenticeship training, and one had completed a university degree. Three had household incomes at or over \$40,000, and 10 had less than \$40,000; of those 10 women, seven had incomes less than \$15,000.

Of the 13 women, eight self-reported experiencing symptoms consistent with the clinical definition of depression at some point in their lives, and two of these indicated it was during a previous pregnancy or postpartum period. Five had been formally diagnosed with depression, and four of these had received some sort of treatment for it. As part of the interview, women were administered the Edinburgh Postnatal Depression Scale (EPDS), a commonly used screening tool for depressive symptoms in pregnant and postpartum women. Of the 13 women, six scored 10 points or higher on the EPDS, indicating probable clinical depression; two of these six scored higher than 13 points, indicating a high probability of clinical depression. Of these six women, only one had been told by a health professional that she was depressed.

When asked whether they had family members who had experienced depression, six women indicated yes, four indicated no, and three indicated that they did not know. Of the six who said yes, four indicated that the family members in question had been formally diagnosed by a health professional. Of the 13 women, six had family members who had ended their lives by suicide.

#### Service-providing professionals

Twelve service-providing professionals participated in personal interviews. Most (11) were female, with one male. Most (11) were non-Aboriginal, with one Aboriginal participant. Participants ranged in age from about 25 years old to about 55 years old. Professions were as follows: two family support workers, one dietician, one family counsellor, one residential counsellor, three nurses, three family physicians, and one obstetrician-gynaecologist. The length of time in their current employment position ranged from six months to 20 years. The number of pregnant Aboriginal women seen in a typical month ranged from zero to 60.

#### Stakeholders at community gathering

Eleven stakeholders attended the community gathering. Two were First Nations Elders, and one was an Aboriginal woman who had participated in the study as an interviewee during her pregnancy. The remaining attendees were either frontline professionals, or managers or administrators, from various health clinics and social service agencies in Calgary.

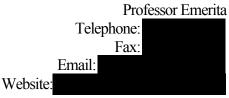
#### Appendix J: Letters and e-mails pertaining to copyright

Signed letters from co-authors of results manuscripts (Chapters 3, 4, 5), and e-mails from First Peoples Child and Family Review and University of Regina Press indicating consent to reprint published papers in Appendix A and Appendix B.



### CUMMING SCHOOL OF MEDICINE Department of Community Health Sciences

#### WILFREDA E. THURSTON



April 21, 2017

To whom it may concern:

Amrita Roy is submitting her PhD thesis to the University of Calgary's Faculty of Graduate Studies, entitled "Understanding depression in pregnant Aboriginal women". Her thesis was written in manuscript-based format, with the results chapters formulated as multi-author manuscripts as cited below:

Roy, A., Patten, S., Thurston, W., Beran, T., Crowshoe, L., Tough, S. Race as a determinant of prenatal depressive symptoms: Analysis of data from the "All Our Babies" study.

Roy, A., Thurston, W., Patten, S., Tough, S., Crowshoe, L. A framework for understanding prenatal depression in Aboriginal women: data from the "Voices and PHACES" study.

Roy, A., Thurston, W., Patten, S., Tough, S., Crowshoe, L. Towards barrier-free and culturally-safe services for pregnant Aboriginal women: data from the "Voices and PHACES" study.

As a co-author on the above, this letter confirms my permission for the chapters to appear in her thesis. In addition to submission of the thesis to the Vault repository of the University of Calgary, I am aware that Amrita Roy has signed a Theses Non-Exclusive License that authorizes Library and Archives Canada to preserve, perform, produce, reproduce, translate theses in any format, and to make available in print or online by telecommunication to the public for non-commercial purposes.

Yours sincerely,



Wilfreda E. Thurston, PhD Professor Emerita Dept. Community Health Sciences Cumming School of Medicine

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April 20, 2017

To whom it may concern:

Amrita Roy is submitting her PhD thesis to the University of Calgary's Faculty of Graduate Studies, entitled "Understanding depression in pregnant Aboriginal women". Her thesis was written in manuscript-based format, with the results chapters formulated as multi-author manuscripts as cited below:

Roy, A., Patten, S., Thurston, W., Beran, T., Crowshoe, L., Tough, S. Race as a determinant of prenatal depressive symptoms: Analysis of data from the "All Our Babies" study.

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Roy, A., Thurston, W., Patten, S., Tough, S., Crowshoe, L. Towards barrier-free and culturally-safe services for pregnant Aboriginal women: data from the "Voices and PHACES" study.

As a co-author on the above, this letter confirms my permission for the chapters to appear in her thesis. In addition to submission of the thesis to the Vault repository of the University of Calgary, I am aware that Amrita Roy has signed a Theses Non-Exclusive License that authorizes Library and Archives Canada to preserve, perform, produce, reproduce, translate theses in any format, and to make available in print or online by telecommunication to the public for non-commercial purposes.

Sincerely,



Scott B. Patten, MD, FRCP(C), PhD Professor, Cumming School of Medicine, University of Calgary.

#### **CUMMING SCHOOL OF MEDICINE**



Pediatrics and Community Health Sciences 3330 Hospital Drive NW Calgary, AB, CANADA T2N 4N1

medicine.ucalgary.ca

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Sincerely,

Respectfully,

Suzanne Tough Phd Professor, Cumming School of Medicine University of Calgary Alberta Innovates Health Solutions: Health Scholar Scientific Director: Alberta Centre for Child Family and Community Research April 20, 2017

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Sincerely,



Lynden (Lindsay) Crowshoe MD, Associate Professor Dept of Family Medicine, Cumming School of Medicine University of Calgary April 20, 2017

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Sincerely,	
[SIGNATURE]	
[NAME] Tanya Beran	
[AFFILIATION] Cumming Sche	ool of Medicine
[CONTACT INFO]	

# RE: request to include my article in my PhD dissertation

Andrea Auger

Tue 2016-01-05 7:02 AM

To:Amrita Roy < >;

Hi Amrita,

Since you have copyright of your article, it is yours to do as you wish. I think as long as you cite where it is published, that is fine by me!

Thank you so much for checking in though!

Good luck with your PhD defense - that is a long journey and something to be proud of!

All the best, Andrea

Andrea Auger Reconciliation and Research Manager Coordinating Editor - FPCFR First Nations Child & Family Caring Society of Canada

From: Amrita Roy [mailton and a second sec

Dear Andrea,

Thank you again for all your help with our article that was published in the most recent issue of First Peoples Child and Family Review (FPCFR).

I am writing at this time with a request regarding another article of mine that was published in FPCFR in 2014:

Mail -

**Roy A**. Intergenerational trauma and Aboriginal women: implications for mental health during pregnancy. *First Peoples Child and Family Review*. 2014; 9(1): 7-21.

I am currently preparing to submit my PhD dissertation for defense. As the above article represents a component of my PhD work, I would like to include it, in full, in the dissertation document to be submitted (with citation of its publication in FPCFR, of course). Given that I, as author, retained the copyright, and given FPCFR's openness to allowing articles to be reproduced for educational purposes (as per: <u>http://journals.sfu.ca/fpcfr/index.php/FPCFR/about/submissions#copyrightNotice</u>), I trust this will not be a problem. I just wanted to run the issue by you, however; please let me know if there any forms or process I would need to follow vis-à-vis securing permission from the journal, if required in this instance. I would be grateful if this could be permitted.

Thank you so much for your help!

Regards, Amrita (U of Calgary)

# Re: requests re book chapter in PhD dissertation

Donna Grant <	>
Thu 2016-01-07 8:36 AM	
PhD schoolwork	
To:Amrita Roy <	>; Dr. Dorothy Badry < >;
Cc:Dr. Wilfreda Thurston <	>;

Hello Amrita (and Dorothy),

From our perspective, your use of the chapter in your PhD dissertation indeed fits the criteria for "reprinting without permission."

I can locate a pdf file for you and will send it as soon as we've heard from Dorothy.

Sincerely,

Donna Grant

\*\*\*\*\*\*

Donna Grant Senior Editor / Managing Editor University of Regina Press University of Regina Regina, SK S4S 0A2

Check out our books: <a href="http://www.uofrpress.ca/">http://www.uofrpress.ca/</a>

>>> Amrita Roy < >>>> Dear Dorothy and Donna,

Happy New Year! I hope you are both well.

I am writing with two requests in regards to the book chapter I authored in the 2014 Reinvesting in Families book:

<!--[if !supportLists]-->• <!--[endif]-->**Roy A**, Thurston W, Crowshoe L, Turner D, & Healy B (2014). Research with, not on: Community-based Aboriginal health research through the "Voices and PHACES" study. In Badry D, Fuchs D, Montgomery H, & McKay S (Eds.), *Reinvesting in Families: Strengthening Child Welfare Practice for a Brighter Future: Voices from the Prairies* (pp.111–132). Regina, SK: University of Regina Press. I am presently preparing to submit my manuscript-based PhD dissertation ahead of my oral defense. This chapter represents a component of my PhD project, and I would thus like to include the full text as part of my dissertation document. I have two requests to this end:

1) In the copyright info page of the book, it is stated that the book "may be reprinted or copied, in whole or in part, for educational, service, or research purposes without permission". I am assuming that reprinting as part of my (the author's) PhD dissertation document would fit this criteria (I of course will cite in full that the chapter was published in this book). Could you please verify whether there is any formal process I need to follow to secure permission in this instance?

2) I was wondering if I might have an electronic version (PDF or Word file) of my chapter in its final form (i.e., the text as published). There is mention on the copyright info page of the book of being able to download the whole book, free of charge, from the website, but I wasn't able to find any such file.

I look forward to hearing from you. Thank you so much for your help! Regards, Amrita ---Amrita Roy, MSc MD-PhD student, Leaders in Medicine program (PhD Candidate in Population & Public Health) Faculty of Medicine, University of Calgary Department of Community Health Sciences 3rd Floor, TRW Building 3280 Hospital Drive NW Calgary, Alberta T2N 4Z6 Canada tel (office)