Perspectives on research and health of individuals with lived experience of opioid use in pregnancy

by

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Abstract

Opioid use in Canada has been on the rise over the past two decades, and many individuals who use opioids are of child-bearing age. Although significant research exists on the effects of opioid use in pregnancy for both the pregnant individual and the child, few studies to date have engaged individuals with lived experience of opioid use in pregnancy to determine research priorities that are important to this population. From November 2022 to August 2023, twelve interviews were conducted with individuals who have used opioid in pregnancy. Participants were given space to share their story and questioned on research priorities that were meaningful to them. Data were coded and analyzed with Dedoose, using a hermeneutic phenomonelogical framework.

Relative to personal experience and research guidance shared by birth parents, five themes were identified: 1) addiction and mental health; 2) impact of Child and Family Services; 3) lack of knowledge within the healthcare system; 4) stigmatizing interactions with the health care system; and 5) recommendations for future research. Individuals articulated the need for positive, trusting, and non-judgemental relationships between researchers, health care practitioners, and patients with opioid-affected pregnancies. Participants expressed the need for detailed information on best practices in opioid use and pregnancy, resources available to parents, and short and long-term effects of opioid use in pregnancy. Majority of participants expressed a desire for further clinical and social research on opioid-affected pregnancies. Future research and health care interactions with individuals with opioid-affected pregnancies must be founded in principles of non-judgemental care, harm reduction, relationship-building and reducing stigma.

Kinanâskomitin (Acknowledgements)

I am extremely grateful to the twelve incredible participants who chose to share their story with me. This thesis and any action that may come after is entirely due to the vulnerability, strength, and resilience that was courageously shared with me. I honour the stories and the experiences of the individuals I spoke with, and humbly aspire to shine light on important health and social narratives of their life stories.

I would like to thank my family who have continually created a space where I was encouraged and supported in pursuing my dreams and ambitions. Kinanâskomitin to my mother, Lisa Steidl, who has always communicated her pride in me and shown up for me in the most authentic ways. To my father, Bryan Hart, who continually teaches me about strength, humility, and courage and has been a strong supporter of all my pursuits. To my stepfather, Gavin Steidl, who is my go-to for a second opinion on anything and everything. To my auntie, Ally Stoneypoint, who has pushed me to grow on my spiritual journey and brought me on this ceremonial path with so much love and compassion. To all of my grandparents, in the Spirit World and in the physical world, who have provided me with endless love and encouragement. To my friends, family, and community… I cannot thank you enough for your belief in me. I would not be where I am today without your love and support.

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Who am I? Where do I come from? Why am I here? Where am I going?

Senator Murray Sinclair posed to the world five important questions when pursuing meaningful engagements: “Where do I come from? Who are my ancestors? Who are my ancestors’ heroes? Where am I going? What happens to me when I die?” In June 2022, I took an Indigenous methodologies course co-taught by Dr. Amanda Fowler-Woods, Dr. Wanda Phillips-Beck, and Dr. Annette Schultz, where they adapted these questions in a research context to “Who am I? Where do I come from? Why am I here? Where am I going?” Qualitative research especially posits that we must outline our beliefs and biases in order to understand the role that our inherent biases can play in our interpretation of data.

In the spirit of relationality, respect, and transparency, I answer these questions. My spirit name is Maskwaseo Maskikihiskwew (Strong Medicine Woman) and the name that my incredible parents gave me is Danielle Hart. I am French, Cree, and Ukrainian. I have family ties to Ottawa, Norway House Cree Nation, and Tolstoi. I have lived in Winnipeg on Treaty One territory for all of my life. I am an avid learner, a traditional and ceremonial individual, a member of the 2SLGBTQIA+ community, and an advocate for my communities. I am here on Mother Earth as a helper; to honour and carry stories, and to use my own lived experiences and the experiences of those around me to create a more equitable society. I don’t know exactly where I’m heading, but I do know that I wish for it to be based in amplifying Indigenous sovereignty, relationship-building, ceremony, and critical inquiry.

It is important that I outline some of my own experiences as it relates to the research outlined here, opioid use in pregnancy. I do not have any children and have never carried a pregnancy to full term. The day before defending my thesis, I had a miscarriage which resonated

with me in a very specific way to this work and research topic. Although relatively early in my pregnancy, I felt the loss that so many people I spoke with throughout this research had experienced. I have battled addictions in my life and can happily state that sobriety has changed my life for the better and continues to do so every single day. I do not think sobriety is the golden ticket to a happy life, and I do not judge anyone on any step of their addiction or recovery. Simply, sobriety was a personal decision I made for myself. I genuinely respect and understand deeply the reasons why people use substances, and acknowledge this as a real form of coping. Throughout this work, I have continually reflected on how my own personal experiences impact my understanding of the stories shared with me, and have worked to engage deeper to understand experiences I do not have. I ask that readers of this thesis attempt to set their biases aside, and to engage in this reading from a spirit of curiosity, empathy, and respect. Kinanâskomitin.

A Note on Terminology & Inclusivity

As a queer researcher and a proud member of the 2SLGBTQIA+ community, I acknowledge from personal experience and the experience of kin that queer and gender-diverse narratives of healthcare are vastly underrepresented. Binary terms are commonly used in perinatal research, specifically words like "mother," or "pregnant woman," and parental relationships are often referred to in a heteronormative context. I resist this cisheteronormativity by intentionally not using these binary and/or heteronormative words where participants did not explicitly identify that this is how they would like to be referred to. I strongly believe that inclusivity of underrepresented and oppressed identities does not equate to exclusivity to identities that are routinely included. I intentionally use terms like "birthing person," and "birth parent" to ensure that all individuals I spoke with are represented. I had the privilege in this research to interview gender-diverse and queer participants and I respect their identities and experiences. Representation in healthcare is extremely important. Many queer, trans, and nonbinary youth do not see representations of people with their identity in positions of power, prestige, or even as older adults. The words we use as academics matter and have strong impact.

Research on birth and reproductive health has historically excluded individuals who identify outside of the female/ male binary; specifically excluding transgender men, Two Spirit and nonbinary individuals (Rioux et al., 2021). "Assigned female at birth" (AFAB) describes people born with reproductive organs that are typically described as biologically female. Although this research project did not aim to describe exclusively the experience of trans and nonbinary individuals who have used opioids while pregnant, this inclusion criteria opens the potential to discover a critically lacking experience and voice in the context of perinatal health and lived experience. The language we use as academics has the power to uplift communities, or

to further perpetuate stigma. As a queer researcher, I stand firm in the belief that inclusive language does not erase identities of non-marginalized individuals, but rather allows for people of all identities to be represented and included.

Terminology

OAT: Opioid agonist treatment. Opioid agonist treatment is used to treat opioid addiction and works to reduce withdrawal symptoms and opioid cravings.

MAT: Medication-assisted treatment. Medication-assisted treatment is the use of medication, such as opioid agonist medications, to treat opioid addiction and reduce withdrawal and opioid cravings.

NAS: Neonatal abstinence syndrome. Neonatal abstinence syndrome occurs when an infant experiences withdrawal from substances they are exposed to in pregnancy, such as opioids.

PWUD: People who use drugs

PPWUD: Pregnant people who use drugs

CFS: Child & Family Services

Birthing parent: The pregnant individual

Cisheteronormativity: A normative societal assumption that an individual identifies as cisgender (aligned with the gender they were assigned at birth) and heterosexual (attracted to the opposite sex).

Binary: Related to gender identity, assuming that biological sex and/or gender is binary; including only males and females. Binary ideologies of gender do not include non-binary, gender-diverse, and gender-fluid individuals.

Heteronormative: A normative societal assumption that an individual identifies as heterosexual (attracted to the opposite sex).

Toxic drug poisoning: I intentionally use the term “toxic drug poisoning” over the term “overdose” as “overdose” insinuates that an individual intentionally took an excess of a substance on purpose, when in reality due to toxic and uncontrolled drug supplies, many people have adverse reactions to substances from an unknown composition of drugs in their substance of choice

Introduction

The sociopolitical climate in Winnipeg plays a critical role into services available and accessible for individuals with addictions and the lens to which addiction is viewed and addressed. In 2022, the topic of safe consumption sites (SCS) became a hot topic as other Canadian jurisdictions implemented SCSs to address increasing and alarming rates of deaths due to toxic drug supply (Caulkins et al., 2019). The province of Manitoba had been under a Progressive Conservative (PC) majority government from 2016 until October 3, 2023, when the New Democratic Party (NDP) was elected as a majority government. The PC government had taken a firm "recovery-oriented" approach that funded exclusively models of abstinence for addictions support, ultimately ignoring extensive evidence supporting the use of a harm reduction lens (Hedrich & Hartnoll, 2021; Manitoba, 2022). This decision was met with significant push back from community organizations rooted in harm reduction approaches who worked with people who use drugs on the front line, such as Sunshine House and Manitoba Harm Reduction Network. This research endeavour was conducted when the PC government was in power and is impacted by the policy decisions implemented at that time.

Winnipeg resides on Treaty 1 Territory and is home to the largest urban Indigenous population in all of Canada (Nejad et al., 2019). Historic and ongoing processes of colonization have created massive discrepancies in social determinants of health in Indigenous peoples compared to non-Indigenous populations (Czyzewski, 2011; de Leeuw et al., 2009; Wispelwey et al., 2023). Historic processes of colonization include the sixties scoop (Sinclair, 2007), residential schools, day schools (Miller, 1996), forced sterilization of Indigenous women (Stote, 2012), introduction of infectious diseases (Kunitz, 1996), mass destruction of animal relative populations (Taschereau Mamers, 2020), laws prohibiting the practice of culture and voting

(Alteo, 2008), and coercion into enfranchisement, among many other generationally detrimental impacts. The continued force of colonization can be seen through the overrepresentation of Indigenous peoples in systems: youth in care, Indigenous peoples in prison, and unhoused Indigenous peoples (Canada, 2018a; Chartrand, 2019; Winnipeg, 2022).

Birth alerts are a mandatory reporting process for health care providers treating a pregnant individual who is determined to be at risk of not being able to care for their newborn (Wall-Wieler et al., 2019). Although the formal and mandatory process of birth alerts was lifted in 2020 after the provincial government learned that these practices acted as a deterrent for pregnant persons seeking care (Malone, 2022), the legacy of birth alerts and systemic anti-Indigenous racism in healthcare leads to a greater percentage of involuntary involvement with CFS for Indigenous children and parents (Canada, 2018).

The College of Physicians and Surgeons of Manitoba provided a detailed guide on best-practice for treating OUD in pregnancy (Manitoba, 2023); however many healthcare providers are still uneducated about how to navigate substance use and pregnancy. This guide provides both clinical and social guidelines that address misconceptions about pregnant people who use drugs. Currently, there are limited services available in Winnipeg for people using substances who are pregnant. The Women's Clinic offers a low-barrier and inclusive interprofessional clinic rooted in harm reduction philosophy for pregnant people with complicated psychosocial concerns, including addiction. This clinic operates through word-of-mouth referrals and currently does not have the staffing or resources to effectively meet the needs of all pregnant people who use drugs. Manito Ikwe Kagiikwe (the Mothering Project) through Mount Carmel Clinic operates a support and resource program for pregnant or one year (and under) postpartum individuals involved in substances, but also has a limited intake capacity. There are three Rapid

Access to Addictions Medicine (RAAM) clinics that operate on limited hours to provide support in counselling, medication, treatment and medical/ social advice. There are seventeen clinical sites in Winnipeg that provide access to opioid agonist treatment (OAT), and four operating rurally in Powerview-Pinefalls, Dauphin, Gimli, and Pinawa. At this time there are no wrap-around services or programs that directly address housing, medical and perinatal care, addictions support, counselling, and other psychosocial needs. Further, the programs that exist experience a high demand with limited resources to provide services ubiquitously for all people who wish to access them.

In Winnipeg, there are resources and supports available for pregnant people who use drugs if they know exactly which resources exist and how to access them, although many addictions supports have long waitlists (Kaschor, 2017; Silva, 2023). It operates under an "if you know, you know" paradigm where resource availability is not widely disseminated or understood in the general population. As such, many pregnant people who use drugs are left with little information on supports available to them, and a high burden of stigma and fear when attempting to navigate these systems.

This research aimed to hear directly from people who've used drugs in pregnancy to learn about research outcomes that are important to this population, as well as to form recommendations to address systemic inequities in healthcare and social services. There are no studies to date that have engaged with PPWUD to amplify their voices and desires for health policy and research priorities. The goal of this study was to inform future research and health policy based on the lived experiences directly of PPWUD.

Literature Review

The rise of opioid use in Canada over the past two decades is as a crisis and an urgent public health emergency (Belzak & Halverson, 2018; Fischer et al., 2019; George et al., 2022). In 2019 alone, 3923 opioid-related deaths were reported across Canada, equating to over 10 opioid-related deaths per day (George et al., 2022). Fischer et al. (2019) named three contributors to this crisis: an increase in the number and potency of legal opioid prescriptions, tighter drug restrictions, monitoring and dispensing of prescribed opioids, and the increase in demand for "street" (non-prescribed) opioids; resulting in uncontrolled supply and toxic drug exposure. A 2015 report accounted for one in six Canadians having received an opioid prescription in the past twelve months (Belzak & Halverson, 2018), however the prevalence of street-distributed opioids has not been quantified. The potency and toxicity of street opioids are influenced by a rise in fentanyl and carfentanil supply; 53% of opioid-related deaths were fentanyl related in a 2016 survey (Belzak & Halverson, 2018).

Many individuals affected by opioid use are of reproductive and child-bearing age (Hudak et al., 2012). Considerable research on the effects of opioid use in pregnancy has been undertaken over the past ten years (Camden et al., 2021; Homish et al., 2010; Hudak et al., 2012; Jumah et al., 2015; Wong et al., 2011). Uncontrolled opioid use during pregnancy can lead to several adverse health outcomes including restricted infant growth, infant opioid withdrawal, neurodevelopmental damage, stillbirth, and preterm birth (Hudak et al., 2012; Reddy et al., 2017). However, sudden desistance of opioid use after a pattern of continued use during pregnancy can lead similar health outcomes including stillbirth and early labour (Wong et al., 2011). Opioid use in pregnancy can lead to neonatal abstinence syndrome (NAS) which results

in damages to neurologic, metabolic, respiratory and cardiovascular infant systems (Hudak et al., 2012).

Indigenous communities are disproportionately impacted by the opioid crisis and problematic substance use in Canada due to the egregious harms of colonization, systemic racism, and daily structural barriers (Canada, 2015; Russell et al., 2016). The combined effect of intergenerational trauma stemming from residential schools, forced removal of children from their homes, involuntarily sterilization, medical experimentation on children, and cultural suppression and criminalization, and the daily manifestations of colonization through systemic racism such as the over-policing of Indigenous peoples, place Indigenous peoples at greater risk of being impacted by substance abuse (de Leeuw et al., 2009).

Trauma & Addiction

It is important to view addiction through the context of trauma to understand root causes, and to adopt a lens of addiction as a chronic illness. Adverse childhood experiences (ACEs) including neglect, abuse (sexual, physical, verbal, emotional), child welfare involvement and exposure to intimate partner violence are common for people with substance use disorders (Hand et al., 2021; Hubberstey et al., 2022; Nichols et al., 2023). Approximately half of people diagnosed with opioid use disorder have co-occurring diagnoses of anxiety and depression which can increase the risk of other health concerns and drug poisoning (Bukowski & Combellick, 2022). People who use drugs (PWUD) often present with Post-Traumatic Stress Disorder (PTSD), which necessitates more complex addiction treatment and healthcare provision (Eggleston et al., 2009). People with PTSD and substance use disorder (SUD) experience greater frequency of suicidality, suicide attempts and are at higher risk of relapse (Eggleston et al., 2009). Social determinants of health create conditions that increase likelihood of trauma

including racism, poverty, food insecurity, and housing instability (Hubberstey et al., 2022). Individuals with multiple marginalized identities are likely to have traumatic experiences in institutions and systems, such as healthcare (Baah et al., 2019), and are at risk of the possibility of re-traumatization where power imbalances exist (Grossman et al., 2021; Gutowski et al., 2022; Howard, 2016). Approaching pregnant people who use drugs (PPWUD) with a lens of curiosity, anticipation of past trauma, and shifting away from blaming an individual for their substance use is key to rebuild systems of trust between provider and patient (Howard, 2016). Understanding the link between trauma and addiction is vital for healthcare providers to ensure person-centred care (Altman et al., 2021).

Pregnancy can be a strong motivator to seek treatment or reduce substance use for many individuals who use drugs. Increased motivation to address substance use often occurs as a result of concern for the fetus and the extension of potential harms of substance use to another individual (Boeri et al., 2021; Goodman et al., 2020; Nichols et al., 2023; O'Rourke-Suchoff et al., 2020; Proulx & Fantasia, 2021) Goodman et al. (2020) found PPWUD experienced enhanced empowerment to address substance use, courage to disclose substance use to health care providers despite fears of stigma, and an internal motivation to seek care and treatment.

An individual's relationship with their own birthing parent can be another important motivator for seeking addictions treatment. Individuals both with positive and negative experiences of parental support in childhood described using these experiences as motivation to bond and form strong relationships with their children, either due to inspiration from their own relationships with parents, or out of recognition of the limitations of their own paternal bonds in childhood (Rankin et al., 2023)

Pregnancy can present a unique time to work with PPWUD in addressing their goals in terms of treatment options and seeking care. Given the difficulties for PPWUD to disclose substance use to their healthcare providers (Choi et al., 2022; Recto et al., 2020; St Louis et al., 2022), it is important that these instances be handled with compassion, non-judgmental care, and curiosity to empower PPWUD to make decisions regarding healthcare and treatment seeking based in their own autonomy.

Medication-assisted treatment and opioid agonist therapy

Medication-assisted treatment (MAT), or opioid agonist therapy (OAT) is considered best-practice for reducing harms associated with substance use in pregnancy impairments (Ahlbach et al., 2020; Cochran et al., 2019; Howard, 2016; Hudak et al., 2012; Jumah et al., 2018; Nichols et al., 2023; Reddy et al., 2017), such as stillbirth, low birth weight, and neurological impairments (Ahlbach et al., 2020; Cochran et al., 2019; Howard, 2016; Hudak et al., 2012; Jumah et al., 2018; Nichols et al., 2023; Reddy et al., 2017). MAT is commonly in the form of methadone, buprenorphine, or suboxone, and works to deliver a controlled dose of opiods to mitigate withdrawal symptoms. Evidence-based practice supports avoiding withdrawal in pregnancy, noting the risks of withdrawal on the fetus can be fatal and unnecessarily painful for the birthing parent (Ahlbach et al., 2020; Cochran et al., 2019; Howard, 2016; Jumah et al., 2018; Nichols et al., 2023). Addictions treatment using OAT has been shown to increase adherence and engagement in treatment programs, but importantly to reduce risk of unnecessarily painful withdrawals and toxic drug poisoning.

The transfer of OAT medications through breast milk has been shown to be negligible in terms of risk for harm to the infant, and evidence suggests breastfeeding on OAT provides more positive infant outcomes than formula feeding (Huhn & Dunn, 2020). However, the stigma

associated with use of OAT medications and a lack of clarity and universal information about breastfeeding while on OAT from a patient perspective can create uncertainty and hesitancy for PPWUD on using OAT (Altman et al., 2021; Banks et al., 2023; Bukowski & Combellick, 2022) Although OAT prescription is considered best practice (Ahlbach et al., 2020; Cochran et al., 2019; Howard, 2016; Jumah et al., 2018; Nichols et al., 2023), PPWUD may feel hesitant to initiate OAT due to perceived tensions between sobriety and OAT; that is, feeling that using OAT means that they are no longer sober (Altman et al., 2021; Banks et al., 2023; Ostrach & Leiner, 2019).

Although MAT is considered the gold standard for harm reduction in opioid-affected pregnancies (Ahlbach et al., 2020), there are other non-pharmacological methods available, such as outreach, drug resting, peer mentoring, education of safer use (Milaney et al., 2022), environmental control (such as rooming in, skin to skin contact, swaddling, dimming lights, bed choices), breastfeeding while on MAT, and soothing techniques (Milaney et al., 2022; Ryan et al., 2019). Simply stated, healthcare grounded in harm reduction practices improves health outcomes for both the birthing parent and the infant (Sutter et al., 2017).

Negative experiences in healthcare

PPWUD often felt that they were not given enough information or were given false or conflicting information regarding perinatal experiences and addictions management (Blair et al., 2021; Howard, 2016). Although breastfeeding while on MAT has been shown to improve infant outcomes over formula feeding, some patients were discouraged against breastfeeding due to their MAT use (Altman et al., 2021). Some physicians and addictions treatment programs require complete abstinence to engage in recovery programs, even though best-practice supports avoiding withdrawal and using MAT (Howard, 2016). Given the inherent power imbalance of

physicians and patients, and the vulnerability of PPWUD engaging with the healthcare system, healthcare providers must be equipped with accurate information on best-practice in opioid-affected pregnancies.

It is well-documented through patient perspectives and the shared narratives of healthcare practitioners that stigma towards PPWUD is embedded within structural systems and physician bias (Alhusein et al., 2021; Blair et al., 2021; Bukowski & Combellick, 2022; Cochran et al., 2019; Kim et al., 2022; Nichols et al., 2023; Radcliffe, 2011; Recto et al., 2020). PPWUD experience stigma in interactions with the healthcare system through differential treatment than people who do not use drugs, judgement from healthcare providers, assumptions made about life circumstances and variability in NOWS scoring: a scoring tool used by healthcare providers to quantify the level severity of neonatal opioid withdrawal (Blair et al., 2021; Kim et al., 2022; Recto et al., 2020).

Self-admissions of implicit bias and internal stigma against PPWUD have been noted in literature. Radcliffe (2011) describes assumptions made by midwives about the personal value characteristics of PPWUD such as missing appointments due to relapse and judgement of life circumstances from physical appearance. Midwives in this qualitative study placed an unfair burden on PPWUD in adherence to treatment, at times assuming that any deviance from expectations was due to involvement with substances or lack of motivation from parents, rather than common life circumstances that can interfere with appointment attendance. Nichols et al. (2023) identified that many healthcare providers have difficulty empathizing with PPWUD due to the knowledge of impacts of opioid-affected pregnancies on infant health. Physicians acknowledged implicit bias in their own practice, and felt that effective treatment for PPWUD required extension of their role outside of their scope of practice.

Other healthcare providers worry about business implications and reputation in treating PPWUD (Alhusein et al., 2021; Bukowski & Combellick, 2022). Here, the public image and how this would be perceived by other patients was a factor in provider willingness to engage with PPWUD. Physicians described a lack of confidence in the motivation and treatment outcomes of PPWUD, already placing a burden and stigma on individuals seeking care (Bukowski & Combellick, 2022).

PPWUD have traumatic and deeply harmful experiences while accessing healthcare and social services, yet have not been approached to determine priorities to investigate and inform policy in any studies to date, furthering the silencing of their voices and the prioritization of researchers and clinicians without this lived experience. Yeo and Moore (2003) coined the phrase "nothing about us without us," acknowledging that individuals at the center of an experience, identity, or phenomenon need to be at the center of decision making. The centering and prioritization of experiences and perspectives of PPWUD has been critically lacking in research and healthcare endeavors, and has primarily been focused on identifying stigma and discrimination in healthcare rather than engaging PPWUD as stakeholders in research inquiry focused on substance-involved pregnancies. Community-based participatory action research, which works with community members of a shared lived experience or identity as equal stakeholders, has not been undertaken with PPWUD.

Structural challenges in providing adequate care

Although many healthcare providers, such as nurses, community pharmacists, midwives, and primary care doctors expressed their own bias in treating PPWUD (Alhusein et al., 2021; Bukowski & Combellick, 2022; Nichols et al., 2023; Radcliffe, 2011), healthcare providers also noted challenges in effectively working with PPWUD outside of internal stigma (Alhusein et al.,

2021; Gulbransen et al., 2022; Shuman et al., 2021; St Louis et al., 2022). Nurses described a lack of formal education in effectively engaging with families with substance-affected pregnancies, as well as the specific health needs of infants with NAS (Recto et al., 2020; Shuman et al., 2021). The elevated demand and attention required by NICU nurses to infants with NAS further imposed burnout and stress on already understaffed and under resourced nurses (Recto et al., 2020; Shuman et al., 2021). Nurses themselves cited inconsistencies among healthcare providers in NAS scoring and desiring a more objective, standardized tool (Shuman et al., 2021). Nurses reflected on empathizing deeper with infants of opioid-affected pregnancies compared to the birthing person, which at times contributed to feelings of resentment and frustration with the parent (Recto et al., 2020). Nurses struggled with a lack of consistency and uniform procedure between departments, such as labour and delivery and NICU, and felt a lack of coordination in the transfer of care (Recto et al., 2020).

Physicians noted external constraints to providing adequate care to PPWUD including structuralized stigma, limited time available, practice burdens, and lack of training (St Louis et al., 2022). Recto et al. (2020) suggest physicians reach beyond education on addictions and trauma exclusively, and include entrenched models of care such as the ACTS model (Acknowledge-Create circumstances for reflection - Teach - Support) (Marcellus & Poag, 2016). This model provides an actionable conversation guide for stigmatizing comments and attitudes in healthcare, and empowers healthcare providers to guide colleagues through non-judgmental care. Structural barriers in healthcare present challenges for patients seeking treatment and psychosocial support, as well as difficulties for health care providers in managing the care and support for PPWUD (Boeri et al., 2021; Choi et al., 2022; St Louis et al., 2022; Sutter et al., 2017). Structural factors such as time constraints in provider practice, child welfare reporting

mandates, program availability, fragmentation in coordinated care, health insurance structures and structural stigma in health care continually pose challenges to providers and patients (Boeri et al., 2021; Choi et al., 2022; St Louis et al., 2022; Sutter et al., 2017). Structural challenges in fostering appropriate psychosocial and primary care create additional challenges for health care providers with already limited education and experience in providing treatment and care to PPWUD.

Patient and provider recommendations to improve healthcare

The lived experiences of PPWUD seeking perinatal healthcare and addictions treatment, and the perspectives of healthcare providers working with substance-affected pregnancies informed many recommendations to improve the ease of healthcare provision. Recommendations from the perspective of patients included a willingness for healthcare providers to be flexible, increasing education for patients around hospital, child welfare, legal protocols and what to expect in pregnancy, delivery, and caring for infants with NAS, provision of empathetic and personal care, and creating spaces of non-judgmental and trauma-informed care (Altman et al., 2021; Blair et al., 2021; Byrne et al., 2018). Recommendations from a healthcare provider perspective included standardizing and using more objective NAS assessments, increasing the role and scope of affiliated providers such as community pharmacists, midwives, and patient navigators and improving access and education around MAT (Alhusein et al., 2021; Jumah et al., 2018). Physicians and researchers also encourage viewing addiction through the lens of a chronic disease that can be treated with medication and psychosocial supports in similar manner other physical health conditions are viewed, such as hypertension (El Helou et al., 2022). From this perspective, a relapse of substance use removes the moral blame from a patient, and views a

substance relapse in the same narrative as a reoccurrence of high blood pressure (El Helou et al., 2022).

Child Welfare Involvement

The involvement of child welfare services is well-documented to instill a fear of disclosing substance use to healthcare providers for PPWUD and create barriers for seeking treatment and healthcare (Altman et al., 2021; Blair et al., 2021; Boeri et al., 2021; Byrne et al., 2018; Frew, 2023; Huhn & Dunn, 2020; Ostrach & Leiner, 2019; Rankin et al., 2023). Variability in mandated reporting legislation exists across jurisdictions, and creates a tension on healthcare providers providing care to PPWUD (Kenny et al., 2022). Many PPWUD are forced to balance their desire to have continued custody of their child and access appropriate healthcare and addictions support.

Parental substance use is the most common reason for child apprehension (Frew, 2023) and contributes to anxieties and reluctances in seeking care and treatment for PPWUD. Child apprehension also poses greater risk for mental health concerns, such as depression and anxiety, and risk of relapse, non-fatal and fatal drug poisoning (Huhn & Dunn, 2020). Further, the physiological positive effects from infant bonding through skin-to-skin contact are lost when children are apprehended, which can worsen the mental health of PPWUD (Rankin et al., 2023).

It is recommended to proactively educate PPWUD on the policies and mandates of child welfare reporting, and provide wrap-around medical and psychosocial support to decrease child welfare involvement (Altman et al., 2021; Byrne et al., 2018). Case managers advocate for support in child reunification and respite care upon discharge for new parents, which could in turn decrease stigma associated for new parents asking for help (Altman et al., 2021). Byrne et al

(2018) found that of families involved in wrap-around support systems, most were able to retain custody of their children.

While child welfare involvement can be a barrier to seeking care for PPWUD, pre-involvement in the child welfare system has been shown to facilitate treatment engagement where treatment is necessary for child reunification (Boeri et al., 2021).

Importance of familial and social support

For PPWUD seeking addictions treatment, the presence (or lack thereof) social and familial supports can be a strong facilitator or barrier to treatment engagement (Asta et al., 2021; Banks et al., 2023; Boeri et al., 2021; Jones et al., 2011). Family members and partners who support an individual's desire for treatment are key facilitators to an individual's engagement and maintenance in addictions treatment (Boeri et al., 2021; Jones et al., 2011). In contrast, relationships with unsupportive partners or partners still in active addiction can create strains in a person's continued adherence to treatment (Asta et al., 2021; Boeri et al., 2021). The isolated nature of many treatment and detox facilities can create barriers to treatment accessibility and access for partnered individuals or those with children in their care (Boeri et al., 2021). PPWUD are forced to balance the care of their children, concern for their partner, and their own desire for treatment in isolation treatment options. External stigma and shame from the use of medication assisted treatment from partners can reduce motivation for treatment for PPWUD, and thus comprehensive education on MAT and treatment for partners and families is essential (Banks et al., 2023). Treatment options for partners of PPWUD can create better support networks for PPWUD (Banks et al., 2023; Jones et al., 2011). PPWUD expressed wanting a partner to be emotionally supportive, flexible and educated on treatment and MAT.

The fear of losing one's social circle by entering treatment and abstaining from substances can be another barrier to treatment (Boeri et al., 2021). Pregnancy, especially for those who use substances, can be an isolating time where social supports are critical. As such, the loss of social networks can create further challenges for PPWUD (Asta et al., 2021).

Wrap-around, holistic support

The availability of holistic, multidisciplinary, and wrap-around support is key to ensure positive health and social outcomes for both PPWUD, infants and families. Wrap-around support models include a myriad of primary health care, perinatal care, addictions support, psychological and psychiatric support, patient navigation through systems, peer support, individual and group counselling, income, housing and food support, case management, parental education, incorporation of culture and an emphasis on dyadic care models (Altman et al., 2021; Burduli et al., 2022; Gulbransen et al., 2022; Newsome, 2021; Stulac et al., 2019). Effective cross-disciplinary coordination is key to effective wrap-around support and can be enhanced through co-location of multiple disciplines. Where same-site care is not possible or available, partnerships with external agencies are key to address all domains of one's health (Hubberstey et al., 2022). Positive outcomes of wrap around support include reduced preterm birth, reduced child apprehension, reduced risk of relapse (Sutter et al., 2017; Welle-Strand et al., 2020). Barriers to effective wrap-around care are almost exclusively structural through lack of funding, lack of coordinated mechanisms of collaboration, and tension in responsibilities to both the birthing parent and the infant (Choi et al., 2022; Hubberstey et al., 2022).

Successful wrap-around supports include entrenched team-based consultation and pre-emptive planning, foundations of compassionate and trauma-informed care, strengths-based narratives to perinatal care and addressing social determinants of health such as housing, food

security and culturally appropriate design (Howard, 2016; Hubberstey et al., 2022; Newsome, 2021; Recto et al., 2020; Stulac et al., 2019).

Summary

Pregnant people who use drugs experience structural and societal barriers when seeking healthcare and addictions treatment. While there are numerous studies that examine patient and provider perspectives in access and experiences in healthcare for substance-affected pregnancies, no studies to date have examined research priorities and outcomes directly that are important to pregnant people who use drugs. The purpose of this study was to explore research outcomes that are important to individuals with lived experience of opioid use during pregnancy to design future research that is aligned with the needs of this population in Winnipeg, Manitoba. This qualitative study sought to answer the questions: 1) What are important research questions for individuals using opioids in their pregnancies? And 2) What direction would individuals with lived experience of opioid use in pregnancy like to see future research go?

Methods

Methodology

A qualitative, phenomenological approach was used to guide this research project, with influences from Indigenous research methodology. Phenomenology is a qualitative research methodology rooted in understanding the core essence of human experience, and the meaning that individuals attribute to their life experience (Husserl, 1970; Wojnar & Swanson, 2007). Phenomenology is typically employed to provide deep, rich understanding of a particular phenomenon through the lived experience of individuals (Husserl, 1970). Since the philosophical conceptualization of phenomenology, many emerging perspectives and evolutions of this methodology have emerged, such as descriptive phenomenology, existential phenomenology, and hermeneutic phenomenology (Embree et al., 1997; Wojnar & Swanson, 2007). Hermeneutic phenomenology builds off phenomenological principles of "the essence" of similar lived experiences, while considering the sociopolitical, historical, and cultural influences of a particular geographical or temporal context (Draucker, 1999). Hermeneutic phenomenology diverges from other subdisciplines of phenomenology by refuting the idea of a universal shared essence of a particular phenomenon, and examines the external influential factors.

Bracketing in phenomenology has been described as the practice of suspending one's personal beliefs, biases and perceptions in order to see a phenomenon for how it truly exists (Husserl, 2001; Wojnar & Swanson, 2007). In qualitative research, the notion of objectivity in research is heavily scrutinized, and it is commonly accepted that the researcher acts as the primary "tool" for data collection; subject to blind spots and biases (Pezalla et al., 2012). All researchers should aim to identify, dismantle, and thoroughly examine their biases that influence all aspects of the research process. In this study, I used bracketing techniques to remove the

weight of my own personal biases; however, I do not claim that this research will be objective as a result.

As an Indigenous researcher, I chose to use pieces of Indigenous methodology, centred around the knowledge that everything and every person is related. Indigenous research methodology effectively addresses both the historic and present context of Indigenous peoples, adheres to both formal (research ethics boards) and cultural ethical protocols, is centred around Indigenous methods and ways of knowing, engages in community-based research, uses strengths-based approaches and develops strong and lasting relationships (Hyett et al., 2018). I have contemplated deeply the use of exclusively Indigenous methodologies for this project; however I do not feel that the timeline of a Master's degree allows for the necessary components of Indigenous methodology in a genuine or meaningful way. Instead, I utilize pieces of Indigenous methodologies and draw on the strengths of these ways of knowing.

In this study, I use hermeneutic phenomenology to understand the essence of lived experience of opioid use in pregnancy in the specific urban context of Winnipeg, Manitoba. Winnipeg provides unique context both temporally, culturally, politically, and spatially through the tension of issues of poverty, addictions, systemic oppression, reconciliation, and governmental approaches and reactions to these concerns. This study specifically examines opioid use in pregnancy in the Winnipeg area, and thus is specific and contextual.

Research Design and Participant Recruitment

Participants were recruited through community organizations and addictions facilities using purposive and snowball sampling. Recruitment began in November 2022 and ended in July 2023. Recruitment posters listed inclusion criteria, and my contact information. Recruitment posters were then distributed to member of the Interprofessional Maternal and Perinatal group

for Leveraging Empowerment & Services – Substance Use Division (iMAPLES) and further distributed to patients and clients of this interdisciplinary maternal health group (Figure 3). iMAPLES is a group comprised of health professionals in the fields of obstetrics, midwifery, addiction medicine, neonatology, nursing, Indigenous health, psychiatry, social work, and pharmacy. Recruitment pamphlets were distributed from iMAPLES health professionals to their patients and community members. Recruitment posters were displayed in person at the Indigenous Family Centre, Addictions Foundation of Manitoba (AFM) Women's Detox Centre, Rapid Access to Addictions Medicine (RAAM) Bannatyne clinic, and West Central Women's Resource Centre (WCWRC). Recruitment posters were displayed on Facebook, Instagram, and X (formerly Twitter). Recruitment was most significant from AFM Women's Detox Centre, WCWRC, and then subsequent word-of-mouth engagements.

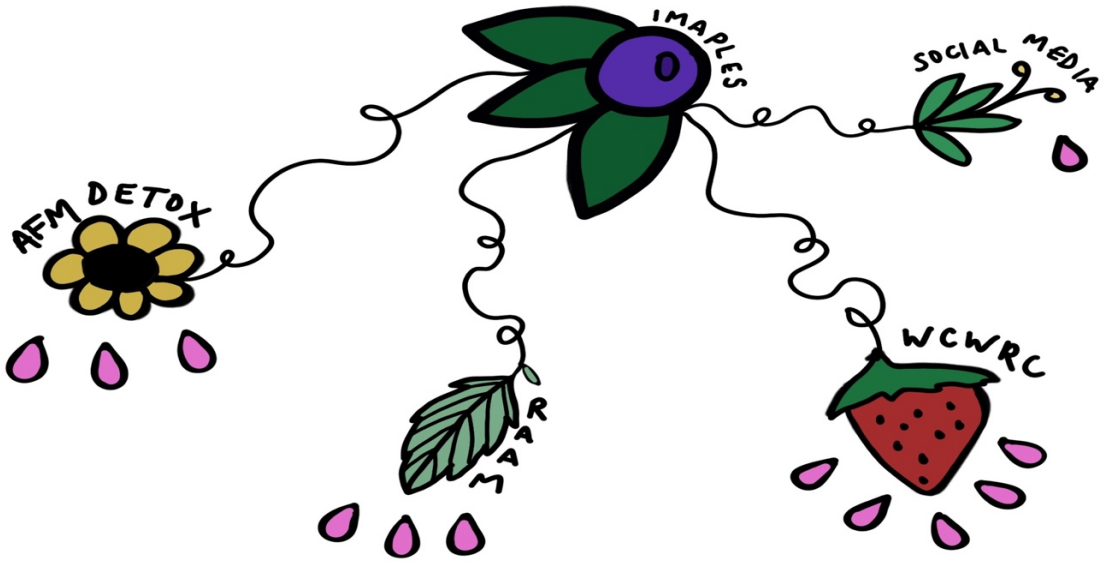

Figure 3. Network Map. Three individuals were recruited from the Addictions Foundation of Manitoba Women's Detox Centre, three from the Rapid Access to Addictions Medicine clinics, give from the West Central Women's Resource Centre, and one from social media. Recruitment began through interprofessional connections through iMAPLES (Interprofessional Maternal and Perinatal group for Leveraging Empowerment & Services – Substance Use Division) and became more robust through social networks and word of mouth referrals.

A total of twelve participants enrolled and completed interviews. Interviews took place where participants were most comfortable and were conducted by myself. Three interviews occurred virtually over Zoom. Three interviews occurred at my office on campus in a private room. Three interviews occurred in a private room at WCWRC. Two interviews occurred at AFM Women's Detox, and one interview occurred at AFM's residential secondary treatment location. The recruited sample size of twelve was consistent with Guest, Bunce & Johnson's (2006) determination of frequent qualitative data saturation at approximately twelve interviews. Indeed, data saturation was evident after twelve interviews, as similar and repeating themes were evident in subsequent interviews.

Table 1. Inclusion and exclusion criteria for birth parents in this study. The recruitment poster for this study used simplistic language to describe gender and sexual identity terms (Appendix E).

Variable	Inclusion Criteria	Exclusion Criteria
Age	18 years or older	17 years or younger
Gender	Cisgender females or transgender males AFAB or non-binary individuals AFAB	Transgender women, cisgender males, and non-binary individuals AMAB
Pregnancy	Pregnancy carried to term and birth or pregnancies ended due to miscarriage, abortion, stillbirth, or any other interruption to pregnancy	Individuals who have not been pregnant
Opioid use	Individuals who have used opioids in the form of OAT and/or in the form of street drugs and/or directly prescribed opioids and/or used opioids in conjunction with other drugs	Individuals who have not used opioids while pregnant
Place of pregnancy	Pregnancy duration occurred in Winnipeg	Pregnancy duration occurred outside of Winnipeg

Participants may have had experience with opioid use during pregnancy through medical (ie OAT, prescribed opioids) or non-medical (street drug) forms. Participants did not need to be pregnant or using opioids at the time of interview to participate in this study. Participants may have also had experience using opioids and other substances during pregnancy.

This study was limited to the urban (Winnipeg) context. Access to support, treatment, and other resources for individuals using opioids during pregnancy is unfortunately limited in a rural and/or reserve context. Limiting recruitment to the urban context acknowledged the varying context, while allowing for greater opportunity for referrals to treatment and resources for under-supported participants. Certainly, there needs to be further research on community and health care perspectives on opioid use in pregnancy, and increased education and resources for opioid-affected pregnancies should be prioritized in rural, reserve and remote settings.

I met with interested participants to discuss details of the study and go over consent forms in-person, over the phone, and/or virtually; dependent on the comfortability of the participant. Participants were made aware of potential risks and benefits of participation, time commitment, ability to withdraw from the study at any time, confidentiality procedures, the intended use of data, and member checking procedures. Participants were also informed of the option for an individual interview or focus group. All twelve participants opted for an individual interview; therefore no focus groups were initiated.

Participant Demographics

Of the twelve participants, ten identified as Black, Indigenous, or a Person of Colour (BIPOC). The remaining two participants did not disclose their identity. Eight of the ten participants identified as Indigenous, one participant identified as Afro-Indigenous, and one participant identified as Black. Four of twelve participants identified as a member of the

2SLGBTQIA+ community; five participants did not identify as a member of the 2SLGBTQIA+ community, and three participants did not disclose if they identified as a member of the 2SLGBTQIA+ community. One participant identified as non-binary, and eleven participants identified as cisgender women. All participants lived in Winnipeg at the time of their opioid-affected pregnancy, and eleven out of twelve participants continued to reside in Winnipeg. One participant had moved to another province at the time of interview.

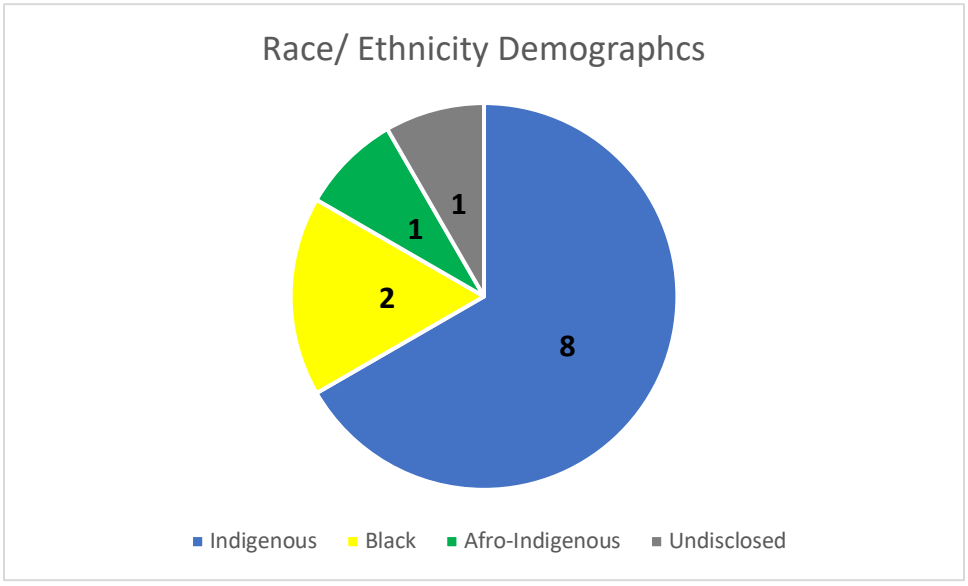

Figure 1. Research participant race/ethnicity demographics. Eight birth parents were Indigenous, two birth parents were Black, one birth parent was Afro-Indigenous, and one birth parent did not disclose their ethnicity.

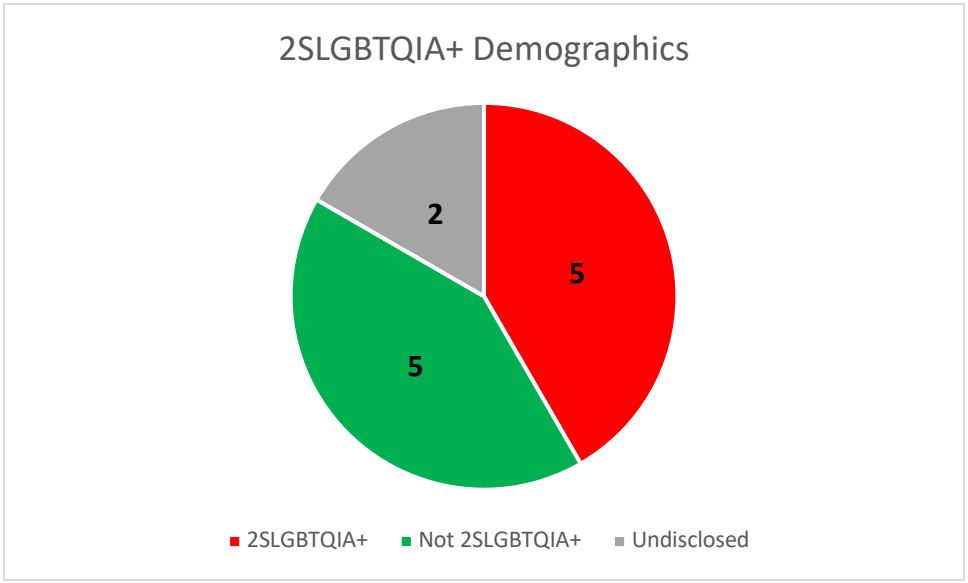

Figure 2. 2SLGBTQIA+ community representation of research sample. Five birth parents identified as 2SLBTQIA+, five did not identify as 2SLGBTQIA+, and two did not disclose.

Starting in a Good Way

An opening pipe ceremony was conducted with Carey Sinclair at the Indigenous Family Centre (470 Selkirk Ave) to begin this research in a good way. Interested participants were invited to attend the opening ceremony, however no participants attended. The spirit of the opening ceremony remained important to approach upcoming interviews with humility, respect, and to honour the stories shared. The teachings I have been given by many Elders over the years have consistently shared messages in approaching relationships and endeavours in a good way, and asking Creator for guidance and support. The opening and closing ceremonies of this research honors the relational approaches that are inherent in Indigenous tradition, and provide a basis of respect rooted in ceremony and spirituality that honours the experiences of the individuals I spoke with, and the lives of individuals who have passed on due to toxic drug poisoning. In both the opening and closing ceremonies, I prayed that the individuals I spoke with

would find healing, community love, and empowerment from our conversations. This sacred ceremony with Spirit marked a commitment to carry these stories with grace and respect, and to assist me to be a good relative and researcher in using these messages to enact change.

Interview Process

Tobacco and a $300 honorarium for each pipe ceremony was offered to Carey Sinclair for her spiritual work on this project. It was initially anticipated that focus groups would be selected by some portion of the eligible participants, and that her presence during and after focus groups would assist in debriefing and spiritual distress; however as no participants opted for a focus group, this was not necessary. Participants were compensated $50 in cash for their participation in the interview. This honorarium was provided the day of the interview, and always before the interview began. Participants were reminded of their right to withdraw from the study at any time, and were encouraged to take breaks in the interview process as necessary.

The interview guide was developed through consultation with my thesis committee and intentionally left space for individuals to share their story. For many individuals, these interviews were the first time they had spoken about their experiences of opioid use in pregnancy, and sharing their story was an important part of their healing and empowerment. Through hearing the stories of individuals, many research, healthcare, and policy implications can be brought to light. The semi-structured nature of the interview guide was designed to hear the lived experience and narratives of participants and to be conversational in nature. This allowed for follow up questions about research specifically, or to probe for more information about specific topics.

Accommodations for transportation, meals, child care, and knowledge keeper support with Carey Sinclair were planned for through the use of paid child care staff at the Indigenous

Family Centre, bus tickets, access to traditional Indigenous medicines, and meals; however, none of these accommodations were required or requested.

Interviews were audio-recorded with an independent audio recording device, which were deleted after transcription. The interview was primarily comprised of open-ended questions, with three short closed-ended questions relating to research priorities (Appendix A).

Data Analysis

Hermeneutic phenomenological analysis was used when interpreting data, searching for the broad themes and essence of the data while considering the social, political, and cultural context that existed at the time of the interviews. I became familiar with the transcripts of the interviews through reading and re-reading over several weeks, allowing me time to sit with the content and interpret meaning and key messages. I used a reflexive journal while reading transcripts and coding to identify any biases or thoughts that came up while interpreting the data. Throughout the entire analysis process, I aimed to interpret the stories and recommendations shared with me through the lens of the birth parents' personal lived experience, and how they situated themselves within the world, which became especially relevant as it related to cultural identity, experiences with poverty, and local drug sub-cultures in Winnipeg. Having my own personal experiences in all of these domains allowed me to sit with the broader essence of the stories that were shared with me. I viewed each birth parent as an expert in their own experiences, and interpreted the data in a way that was reflective of their expertise. I routinely familiarized myself with the implementation and concept of hermeneutic phenomenology by referring to Sloan and Bowe (2014) guide on the use of hermeneutic phenomenology in data analysis while reading and coding transcripts.

Data were transcribed using Otter.ai and edited as necessary by myself. Data were then imported into Dedoose and were coded by myself and two additional coders. I met with all additional coders prior to coding, to go over expectations of reflexivity, utilization of hermeneutic phenomenology, data familiarization, and cohesiveness of coding. The first eight interviews were coded by myself, Dr. Sara Matyas, and Sophia Mbabaali. The last four interviews were coded by myself, Jessica Steer, and Zina Zaslawski.

Rigour

Qualitative research is generally evaluated by the criteria of credibility, transferability, dependability, and confirmability (Shenton, 2004). Credibility refers to the alignment of the data with the true nature of the phenomenon and is enhanced in qualitative research through the use of well-established methods, member checking, triangulation (using multiple data collection methods), familiarity with the literature on a topic, the inclusion of researcher reflexive commentary and the provision of detail to describe methods and observations (thick description) (Shenton, 2004). This study aimed for credibility using hermeneutic phenomenology methods, offering both individual interviews and focus groups, continuous reflexive journaling, extensive literature review on the topic, and robust description of the context and methods of this study.

Transferability refers to the ability of the findings of one study to applied to another setting. Dependability refers to the ability for the study to be reproduced with similar results. Both transferability and dependability can be challenging to achieve in qualitative research where contextual variations exist (Shenton, 2004). Due to the specific sociopolitical, cultural and temporal context of opioid use in pregnancy in Winnipeg, transferability and dependability may not be well-achieved on paper; however, the thick description of methods and procedures can aid in compensation and identification of the specific context of this study.

Confirmability speaks to the relative objectivity of the research, or the competency of the researcher to suspend one's own perceptions and identify a non-biased picture of the phenomenon in question (Shenton, 2004). Confirmability was be enhanced through reflexive journaling, the writing out and ongoing reference to prior assumptions and beliefs, bracketing, and clearly identifying limitations of the study. At the start of this research, I wrote a document outlining what I expected to see based on my own knowledge, experiences, and biases. I engaged in reflexive journaling throughout the data analysis process and noted especially when I felt surprised at the results. I continually referenced my initial reflexive document to ensure that my interpretations of the data were not a product of my own expectations or biases.

The use of ceremony and relational approaches to this research provided rigour in an Indigenous methodological context, as in ceremony we know that Creator hears our genuine intentions. I engaged in opening and closing ceremonies to offer my commitment to amplify the voices of those I spoke with and to hear these stories with respect and humility. Offering ceremonial and spiritual promise is a strong commitment to this work.

Transcriptions of interviews were made available to all participants through password-protected documents via email, virtual access or in-person access. A total of four participants responded to prompts for member-checking. Two transcripts were gone over in person where minor revisions were made. One transcript was reviewed over a series of Facetime calls, allowing for a number of days or weeks in between subsequent calls. This process of member checking through multiple conversations was decided between myself and the birth parent to lower the emotional burden of reviewing painful stories, and reduce to chance of retraumatization. One transcript was dropped off to a participant in treatment and no revisions

were made. Eight participants did not respond to prompts (via email, phone, or Facebook Messenger) to member checking.

Reciprocity

It was important to me that participants experienced a level of reciprocity that extended beyond contributing to meaningful research. Reciprocity was apparent through different needs of participants. I provided resources to some participants such as community legal services, and free food services. I provided participants with a ride to their next destination after their interview if required. I provided traditional medicines (sage, sweetgrass, tobacco, and cedar) to participants who expressed interest or need. One participant had recently been evicted from her apartment and did not have access to any of her clothing. I was able to provide her with clothing donations in that moment.

Knowledge Translation

On November 23, 2023, a knowledge translation event (titled Drugs, Pregnancy & Harm Reduction) was held at Thunderbird House, a local community hub at the core of downtown Winnipeg. I shared the results of this study and invited other researchers, clinicians, students, community organizations and advocates to share knowledge. Two individuals I interviewed are prominent speakers on issues of equity, colonization, racism, and substance use. I invited them to present at this event and share any piece of their story that was relevant to them, and received consent from them both to include their names on the event poster (Appendix C). The Drugs, Pregnancy and Harm Reduction event was open to virtual attendees, and included attendees from across Turtle Island who are involved in relevant community, clinical, and social organizations. There were approximately 80 virtual attendees and 35 individuals attending in person. Feast Café Bistro, a locally owned Indigenous restaurant, catered this event with bison stew, vegetarian

chili, and an assortment of bannock. All leftover food was donated to a neighbouring community organization. Presenters were gifted sweetgrass I picked over the summer and both presenters who were interviewed in this project were given an honorarium. Over the summer of 2022, I picked sage, cedar and sweetgrass and sewed medicine bags to gift to community members and attendees of the event. Throughout this research project, the lack of public and interprofessional dialogue about substance use and pregnancy became extremely clear. The goal of this event was to bridge the gap between professionals in the field of social and perinatal care to community members, and share knowledge from multidisciplinary perspectives. The inclusion of individuals with lived experience of opioid use in pregnancy was central; ensuring that the primary benefit of this research and related knowledge would be to people who have used or use drugs in pregnancy. All birth parents who were interviewed in this project were invited to attend. My hope was to show the impact that their vulnerability and storytelling created, and to disseminate the important messages and themes that were shared with me. The newly elected Minister of Health, Seniors, and Long-Term Care, Uzoma Asagwara and the Minster of Housing, Addictions, and Homelessness were both invited to attend and were able to be present at the event. I was able to have discussions with both Ministers and was asked to coordinate an initial meeting between myself and colleagues in addictions medicine. One of the lived experience presenters shared the sentiment upon reflection of the event:

> *"Today, I had the immense pleasure of doing a spoken word performance at an event put on at Thunderbird House. When I tell you that you could feel the love, community, and graciousness in that room… it was palpable. It's been a journey and a half to get to a point where shame didn't rule a large portion of my life. Shame has to be one of the loudest emotions in my body. Today, a chapter of my life was closed, and the shame that*

has compounded this small body was released all at once. Danielle, the kindness you have shown me through this process has healed something in me. I will forever be grateful for you, and what you have done for me."

I share this not to pat myself on the back, but to demonstrate the healing capacity and importance for future knowledge translation in including lived experience presenters in presentations and conferences. The lived experience presenters brought significant meaning and context to the event through their stories and created a learning space that was emotional and rooted in the humanity and vulnerability of opioid use in pregnancy. Throughout their presentations, there were many tears shed by the audience and supportive and encouraging words offered through the Zoom chat.

Ethical Considerations

Although this research is not specific to Indigenous peoples in Manitoba, due to the higher burden of adverse health outcomes faced by Indigenous peoples in Canada as a result of colonization and systemic racism (Allan & Smylie, 2015), a disproportionate number of Indigenous participants were included in this study. This study was grounded in relational approaches to research using opening and closing ceremonies and knowledge keeper consultation.

There are two prominent guiding frameworks for any research involving Indigenous Peoples: the Tri-Council Policy Statement on Ethical Conduct for Research Involving Humans (Canada, 2018b), and Principles of Ownership, Control, Access and Possession (OCAP) (Centre, 2007). These frameworks were developed in response to colonial research projects *on* instead of *with* Indigenous communities that have deepened social inequities and further perpetuated harmful stereotypes and discriminations.

The TCPS 2 outlines many requirements for ethical research processes involving Indigenous Peoples. This study does not exclusively involve Indigenous Peoples or one specific Indigenous community. From an Indigenous context, Winnipeg (Treaty 1) is home to Cree, Oji-Cree, Anishinaabe, Dakota, Dene and Métis people, as well as many individuals from nations across Canada that have moved to this territory. Indigenous nations are unique and distinct, although commonalities in traditions and worldviews include wholistic views of health, and understanding that everything and everyone is connected. As a result of the diversity of the Winnipeg population (Indigenous and non-Indigenous), there does not exist a single authority over the data of all participants, such as a Band or Grandmother's Circle of First Nation governance. As a traditional and ceremonial Indigenous person, I am well-acquainted with traditional protocol, ceremonial practice, and the practice of safeguarding sacred oral knowledge, and respected these principles through availability of traditional medicines, consultation myself with a knowledge keeper, and approaching interviews from the foundation of relationality. In research involving Indigenous peoples, mutual benefit and reciprocity for individuals and communities involved must be prioritized. This research is directly explored with participants the research that they would like to see take place, and as a result is relevant to participants' and related community's interest. Participants also had the opportunity to become involved in further research opportunities through community advisory boards.

Principles of Ownership, Control, Access and Possession recognize the collective right and self-determination of Indigenous communities to own and control their own data and information (FNIGC, 2014; 2020). This research was not specifically tied to one Indigenous community, or aimed towards exclusively Indigenous participants, and so the implementation of OCAP principles could not entirely able to be upheld; however the spirit of many of these

principles was honoured where possible. Ultimately, the University of Manitoba will own and possess the data from this study. As previously stated, all sacred knowledge will be omitted from written text. The use of relational, traditional research methods such as opening and closing ceremonies, sharing circles and pipe ceremonies aimed to create a culturally safe space for Indigenous participants. I have participated in many sharing circles with non-Indigenous peers and have heard first-hand the empowering and compassionate space this has provided to them.

The purpose of this research, along with potential risks, benefits, and expectations of participating in the study was discussed at the beginning of each individual interview. Participants were invited to ask questions and were reminded of their ability to withdraw consent at any time. Consent forms were reviewed in detail verbally and signed prior to data collection. Confidentiality was upheld through the deidentification of names and other identifying information during data analysis. Pseudonyms were assigned to all birth parents throughout this text to ensure confidentiality.

Individuals with addictions often have a background of trauma and experience significant discrimination in medical, legal, and social institutions (Kramlich & Kronk, 2015; Peacock-Chambers et al., 2020).Information discussed in interviews was at times sensitive, challenging to discuss, and/or retraumatizing. Participants were made aware that they were able to pause, step out, or withdraw from the study entirely should the content become too challenging. Participants had the option to end the interview and recommence at another time, or withdraw from the study entirely.

Results

Analysis on the interviews about past experiences with opioid use and pregnancy revealed five themes: 1) “addiction comes from pain”: experiences of trauma, mental health and addiction 2) “everything just went downhill”: impact of Child & Family Services 3)“my main problem here was information”: lack of knowledge within the healthcare system 4) “beat down, bullied, betrayed”: stigmatized treatment by healthcare providers and 5) “I would like to know that something’s being done about it”: recommendations for future research. These experiences informed the ways in which participants chose to seek out healthcare and support, often leading to isolation and shame within their pregnancies. Participants described a trend of having to learn relevant perinatal medical information on their own, and a general sense of sadness in the stigmatizing and demoralizing treatment they experienced in their past pregnancies.

Specific to research, participants generally had positive perceptions of the need for further research on opioid use and pregnancy and identified a number of strategies to ensure that research was approachable and comfortable for individuals with opioid-affected pregnancies. Research-specific recommendations were to ensure that interactions with patients and participants came from a trauma-informed lens and prioritized participant autonomy and comfort. Methods of suggested knowledge translation included through hospitals, emails, social media, parenting programs, and community spaces such as shelters. Participants were generally comfortable with researchers collecting biological samples, if genuine informed consent was given and trust had been established with the researcher. Participants expressed a number of preferred terms to describe their birthing and parenting experience; including more commonly accepted terms like “mother,” and more inclusive terms such as “special person” and “birthing person.”

1. “Addiction comes from pain”: Experiences of Trauma, Mental Health & Addiction

Adverse childhood experiences including emotional abuse, sexual abuse, and neglect, were stated by many birth parents to be painful experiences that contributed to their addictions. Birth parents described growing up without reliable caregivers and without feeling dependable love in their lives as children. These experiences left individuals with a foundational level of emptiness and pain that made them vulnerable to addiction later in life. Indeed, many birth parents connected experiences of trauma to encounters with addiction. As Kiara stated:

> I think that it's important to know that people don't set out, wake up one morning and say, Hey, I'm gonna hurt my baby and hurt my family and use drugs. I think addiction comes from pain, childhood trauma. And girls aren't gonna stop using until those things are addressed.

Birth parents described the experience of addiction in the context of mental health struggles, experiences of abuse, intergenerational and childhood trauma, and significant experiences of loss and grief, noting the underlying root cause of addiction was pain and attempts to numb this pain. Trauma was present in many stories of addiction. The need to understand the root cause of addiction was highlighted by several birth parents. Addiction and experiences of substance use were often described as the only time in participants’ lives that they felt any relief at all. Jessica described:

> Because it was the first time in my life where I felt any relief. Because I smoked weed and I drank. But when I started doing opiates, it was like I just didn't have to feel pain anymore. And it just my life like and I just wanted more and more of like I didn't ever want to ever feel pain again.

Carol described how using opioids provided relief from symptoms of schizophrenia:

> The reason I started using it was because I experienced a mental health problem called schizophrenia and the schizophrenia was just as intense as the high of an opiate. It was a struggle for real because like, I only took a couple of puffs and I was like, wow, I never felt like this before. I usually always felt unhappy.

For many, using opioids was the only time in their life that they felt any relief from constant reminders of past trauma and pain. Birth parents related experiences of abuse in their lives; at the hands of caregivers, parents, correctional officers, intimate partners, and family members. All birth parents who relayed stories of abuse had correlated these experiences to the root cause of their addiction and their emotional pain. In many cases, using drugs was the only release from the intense pressures and violence that individuals were experiencing. Kiara expressed:

> I had a pretty rough childhood. One of my mom's boyfriend's pretty much didn't end with the sexual molestation. So, I mean, I feel that addicts are just in pain underneath everything. You're not a happy person. You don't set out to go numb yourself. So I mean, why... not why the addiction? You know, but why the pain?

Falon similarly stated:

> The majority of my substance use at that time was fueled by trying to cope with what was going on around me. I had been in a relationship with someone who basically systematically raped and abused me for about three years.

The use of opioids and other substances was described in response to deep pain and traumatic life experiences from an early age. Intimate partner violence, sexual abuse, childhood abuse, and experiences growing up in the child welfare system all contributed to trauma that individuals carried throughout their lives. The impact of these traumas contributed to feelings of

low self-esteem, worthlessness, and despair that was felt in subtle ways every day. All birth parents described a sense of self-forgiveness and empathy for their younger selves; realizing that their addictions were built on a foundation of circumstances outside their control. Similar to the sentiment that Kiara and Falon shared, individuals reflected on their journey of addiction through a lens of past trauma and coping.

Birth parents described experiencing abuse while they were using opioids and at times, abuse during their pregnancy. Falon described the progression of their substance use and experiences of intimate partner violence during pregnancy:

> I would smoke cannabis to like, not be so shocked when I was screamed at because sometimes I would just get yelled at and it would, I would get like prickly feelings at the bottom of my stomach. And my, my shoulders would tense up and I felt like that was just me. Like literally just giving nervousness like pass through my body. Yeah. And I also found that like, as my pregnancy progressed, I found that he became more violent because I became more passive. I didn't want to engage. And he almost accepted that as like a challenge.

Abuse was experienced beyond domestic partnerships; Carol described verbal abuse and bullying from corrections officers while incarcerated due to their addictions. She stated, “Yeah, they [corrections staff] started accusing me of all of this thing like I'm a skin beefer, or like I'm a pedophile. And like, like, you know, when you do that drug it's like raping her.”

Carol described this bullying by corrections staff as directly related to her substance use, insinuating that her opioid use was as harmful as sexual violence to a child. Stigmatizing labelling, such as a child abuser or pedophile, was described as putting an individual at risk for violence and social isolation within correctional systems, due to the internal social beliefs and

outlook held against incarcerated people charged with these offences. This participant felt as though these labels were intentionally placed on her to cause her harm, due to correctional officer's personal biases surrounding opioid use.

Biases and stigmatization of opioid use were also experienced in community settings where substances were used by others. Tamara described abuse and taunting from other people who use drugs, due to societal stigma attached to using opioids.

> I feel that the last of my pregnancy was on fentanyl and meth that I came to suicidal because I was called and bullied because of the fentanyl… Mostly men bullying woman using like probably the drug dealers cutting the meth with fentanyl bullying the pregnant person.

Intergenerational trauma was a strong factor in experiences of addictions for Indigenous birth parents. Historic colonial trauma experienced by family members and ancestors, and present-day mechanisms of colonization, such as overrepresentation of Indigenous children in care, contributed heavily to vulnerability to addiction. At the end of one of the interviews, Phoenix asked me if I would be writing and encapsulating the role that trauma in all forms plays in addiction. She shared, "But the link, I feel like - I feel like it almost can't be a paper on opiates without including trauma somehow, because they're so closely related"

Intergenerational trauma was experienced through personal experiences growing up in the child welfare system; proximity to alcohol and drugs in childhood; familial experiences of addictions, abuse, and violence. Jessica reflected on the role of familial trauma in her life, "How much of our family's trauma are we carrying around? We put that on our kids. And I didn't want to do that. I didn't realize that I didn't want to do that."

Birth parents varied in their descriptions of support throughout their pregnancies. Some participants described strong and reliable familial and community support as being vital to their wellness during their perinatal experiences. Other birth parents felt well-supported through social and perinatal health supports, such as an addictions specialist OBGYN or addictions-specific supports through community detoxification sites. Birth parents in this study positively described these community connections as a space free of judgement and having positive impacts on their prenatal experiences. As Phoenix shared regarding her experience with an addictions-specialist OBGYN,

> She said we don't report people for getting help for a disease. You know, like, we're not gonna go to CFS, Or you for because she said you're because you you're sick. You have an illness, and you're coming to get help. And it wouldn't have been like that 15 years ago.

This experience resonated with this participant particularly due to previous experiences in healthcare that were traumatizing, judgemental, and uninformed on best practices in harm reduction for opioid-affected pregnancies. For birth parents with multiple pregnancies in different stages of opioid use (i.e., using street drugs versus using OAT), positive experiences with health care professionals were experienced in their later pregnancies and were deeply valued. Two birth parents had multiple pregnancies and were using OAT medications for harm reduction in their later pregnancies after being informed of these options. These two individuals were not made aware of the use of OAT in pregnancy for their first pregnancies.

Feelings of shame were common across birth parents. Individuals expressed shame for staying in abusive relationships, experiencing addiction, accessing opioid agonist treatment, using opioids for pain management, and experiences of child apprehension. Shame was noted as both an external force; as felt by medical and social systems and society generally, and an

internal force of self-blame and self-judgement. Shame contributed to negative self-image, feelings of powerlessness, anger at oneself, and self-doubt. Birth parents described this shame as an even greater force than the shame that was felt with experiencing an opioid addiction. As Jessica explained,

> And like, what are they learning from me? It's like I'm an absentee mother because I didn't deal with my own shit, you know, my own trauma from a long time ago. Like, I'll come back to my question like, should anybody be having this? It's like, how can you raise somebody up when [you're hurting].

Jessica went on to describe shame and guilt she felt for being in different stages of recovery throughout her multiple pregnancies:

> But once I found out I was pregnant with him. I was like, Okay, no, more smoking weed, no more smoking cigarettes, and no more drinking. And just, you know, I carry a lot of guilt. Because why couldn't I do that with my daughter?

External shame was a large factor in birth parents' feelings about themselves and willingness to disclose their opioid use to their social supports and health care team. Birth parents experienced external shame for being addicted to opioids and especially for experiencing addictions while pregnant. Individuals experienced shame even after they had sought formal addictions support and started taking OAT as recommended by their health care provider, due to a lack of comprehensive community knowledge on best-practice in opioids-affected pregnancies. Phoenix humanized experiences of addiction:

> There's a lot of shame and a lot of stigma and a lot of people having opinions on you know, as in my experience of being addicted to opiates. Most of the people that I knew didn't take them to get high, they took them because they were in pain.

Phoenix further reflected on her use of Suboxone while pregnant, describing the advice of an addictions professional,

> [They said] you have to be on Suboxone. And she said baby will get Suboxone from breast milk too when baby's born. So that's really good. I'm happy. I'm really happy about that. I just, there's a lot of shame around it still.

Claire described external shaming and stigma she experienced from people in her community:

> Um, yea stigma. I experienced that. Not everyone will actually understand what you're going through. So some will go ahead and, you know, talk all sorts of stuff to you or about you and trying to encourage you to, you know, to just stop doing what you're doing, and maybe they don't really understand the reason as to why you're using the drugs.

Societal narratives around substance use and pregnancy played a large role in pregnant individual's feelings of safety when accessing support, both formally through medical and psychosocial outlets, and informally through their own communities. Birth parents outlined a narrative of doing the best they could with the information that they had at the time, but feeling regret and internal shame for not knowing of other options that could have been available to them. This shame and stigma was alleviated by the few individuals who were connected to addictions specialists and supportive networks.

2. "Everything just went downhill": Impact of Child and Family Services

The impact of shame and stigma transcended interactions with the medical system and external support networks and was deeply felt through interactions with Child and Family Services (CFS). The authoritative ability for CFS to apprehend children from families where

substances were used, and stigma entrenched within CFS, ultimately lead to fear, distrust, and careful consideration of disclosure of substance use and help-seeking.

Some individuals had previous traumatic experiences of child apprehension with their young children due to their addictions. This often resulted in a further destabilizing impact that led to participants' experiencing their addiction more intensely. Birth parents described a general lack of support from Child & Family Services (CFS) to help parents through their addictions, and in the pursuit of reunification with their children who had been apprehended. These experiences were described to have a profound impact on the mental health and self-image of birth parents, igniting intense feelings of guilt, shame and sadness. As Falon explained: "So I got my kid apprehended. And after that happened, everything just went downhill with addiction, and with trying to cope with what happened"

Some birth parents also described the experience of being a parent as a protective factor and a motivator to manage substance use. The responsibility of looking after a child was described as an influence in moderating the use of substances such as opioids. As Jessica expressed,

> So yeah, she was like, I'm like, why would you take my son for me like, and it was like, I feel like if I if he had not gone, I would have been more likely to pull my shit together at the time.

Fear and distrust played a significant role in the way that birth parents interacted with the health care system and how honest they felt they could be with their health care provider due to the potential for reporting to CFS. Individuals expressed that they chose not to disclose their substance use out of fear of having their child apprehended, and in turn did not access any social or medical care at all for their perinatal health. As Kiara explained, "I mean, you're scared.

You're scared to say what you've done because you're grew up in a system where one bad thing and CFS is coming."

Birth parents described fear of CFS involvement and ultimately, child apprehension, based on their own lived experiences as children, the removal of younger children of theirs, and experiences of friends and family. Parents were forced to decide between accessing help for themselves and their children, or risk their child being permanently removed. Birth parents commented on the increased stigma and CFS involvement that was experienced by People of Colour, Black, and Indigenous families. As Kiara narrated,

> So I would go to the doctor and say, I was taking these pills, and then I'm pregnant and this and that but then I was scared, right? Because the stigma of CFS for Native people is totally high. Very high.

And as Falon explained,

> And like, I, I just felt like I was so…I don't know if it had to do with the fact that I am a person of color. And like, I've been wrestling with this one for years, but it's like, I don't know if my race or my ethnicity was directly correlated to how I was treated by both police officers and CFS workers. Because like, I want to believe that that doesn't matter. But like it was also 2009.

Individuals felt as though their substance use and race automatically put them at a disadvantage in dealing with CFS. The fear of potential CFS involvement impacted the safety in which people felt that they could access medical care. CFS was never viewed positively and was the primary reason that individuals explicitly chose not to seek out medical support.

3. "My main problem here was information": Lack of Knowledge within the Healthcare System

Throughout their perinatal experiences, birth parents did not feel that they had adequate information to make informed decisions about their own health and the health of their child. Two individuals were prescribed opioids during their pregnancies due to injury, and both individuals described wishing they would have had complete information about the addictive properties of opioids before deciding to take them. As Janelle shared,

> My main problem here was information. I think the only thing that he [the doctor] didn't do well was like, give me information. That's my only big challenge ahead. Because I think if I had the information, I would not really take those drugs. I think I would get a better option.

She further explained, "I think my doctor didn't tell me that. These drugs, that I would get addicted. Because I think if I was told that before I took them, I think I could have like declined."

Birth parents whose addiction started through using prescribed opioids of an external source (not prescribed directly to them) also expressed being unaware of the strong addictive properties of opioids; exemplifying a general lack of public education and health knowledge on the risks of opioids. Kiara explains:

> And I've found that if I took one, I could clean my house, I could do this, do that do that. I had no idea that there was addiction there that you can get physically addicted to them. I had no idea.

This lack of supportive information from medical professionals manifested as self-doubt within birthing parents. Individuals internalized the lack of information that was available to them and experienced self-blame and guilt. Jessica described, "And you know, my little girl was

struggling to live because she was in withdrawal. And I didn't know that that's what was happening to her. Because I was uneducated about what I was doing to myself"

All but two birth parents also had experienced addiction to opioids prior to being pregnant and thus were aware of the addictive properties of opioids. However, no one felt that they had received adequate information as it relates to opioid agonist treatment (OAT), harm reduction, and general health knowledge as it relates to perinatal health and opioid use. Leslie shared:

> I wish I knew about Suboxone way back then. Because that actually would have prevented my kids from being born with health problems. And it would have made me stop using opioids a long time ago. Like I could have been a recovery opioid addict from 2010. That could have been 13 years instead of just three, four years.

Individuals who opted to disclose their opioid use to their health care provider described instances where they were given misinformation, conflicting information, or felt that their health care provider simply was not adequately educated on the topic of opioid use and pregnancy. Leslie spoke about access to OAT in her home community and recalled, "They still didn't know anything to do with opioid addictions or pregnancy. They just automatically tell them that you need detox and treatment."

Leslie describes a glaring issue in rural and remote communities of not only a lack of knowledge in best practice for opioid-affected pregnancies, but an approach that endangers the health of both the birther and the fetus. Individuals often felt that they had to do their own research and at times, educate their health team on best practices in the field of harm reduction in substance-involved pregnancies. In many cases, birth parents became aware of the benefits of OAT through community members, and not through their health care provider. Phoenix

described a positive interaction with a specialized addictions obstetrician gynaecologist that provided reassurance on the use of OAT in pregnancy.

> She said Suboxone was the best thing that I can do for baby. She's like when you're withdrawing, the placenta is withdrawing too. So is the baby - she says. So, like, if you've been an opiate user for years before you get pregnant, you cannot just stop it.

Phoenix, Claire and Jessica were the only three individuals who had some form of access to a harm reduction approach in their pregnancies, although Claire experienced two pregnancies before having this support available. The rest of the nine people were not aware of and did not access any support for their pregnancies. Claire reflected on her ability to access wrap-around support in her pregnancy with gratitude:

> So, I had a lot of questions. And lucky enough, I had someone that could answer, you know, all of them. And give me extra information or how I can access information. I had someone that I could call, let's say, for example, I'm not close to a hospital setting, and I need assistance and need consultation. I had someone that was, you know, that was all always ready to receive my call and answer and maybe help me, you know

Claire, Phoenix and Jessica described the positive impact of having non-judgemental and supportive medical and psychosocial care in their pregnancies that many birth parents simply did not have. Having an understanding and informed healthcare provider was central to empowering birth parents to make informed decisions about their healthcare. Conversely, the lack of healthcare providers informed by best-practice and a harm reduction lens contributed to further ostracization from healthcare and addictions treatment settings and feelings of shame, doubt, and low self-worth. Birth parents expressed regret and feelings of grief for not having an experience in accessing healthcare that came from a foundation of compassion and understanding.

4. "*Beat down, bullied, betrayed"* Stigmatized Treatment By Healthcare Providers

The experience of being stigmatized and discriminated against in health care was unfortunately common experience for birth parents. They described experiences of stigmatized treatment from health care providers for their substance use and specifically for their Indigenous identity. Stigma was also described beyond the context of health care in broader structures, such as the criminal justice system and society as a whole. As Carol noted, "Or like [society] rarely see me as a mom. They just see me as an opioid user."

Almost all individuals experienced direct derogatory interactions with health care providers. April recalled a time when she was in medical crisis due to a miscarriage and attending the emergency room for urgent medical care, having lost almost eighty percent of her blood. April described:

> For days, I couldn't eat. I couldn't drink anything. So I was like, no wonder they can't find a vein in me like and then this lady's [hospital staff] calling me a junkie, this and that, and I'm just like Oh my God... "Another junkie here". And you know, I'm like, it looks like I'm out but like I can hear her, I'm still conscious.

April cried while sharing this traumatic part of her story. She described wanting to avoid hospitals at all costs due to experiences like this. April was not alone in this sentiment. Past experiences of stigmatized treatment for substance use contributed to feelings of unsafety and fear in seeking health care for other individuals. Phoenix shared, "Because I know, I've definitely met doctors that believe that addiction is a choice."

Individuals often gained empowerment and self-compassion in their journey with addiction despite their discriminatory experiences in health care, viewing addiction as a complex

health condition and not as a behavioural or personal morality issue. Jessica described her experience with methadone and managing her addiction:

> It's also keeping me accountable. Because I have to get up and I have to get my drink every day. And it's, you know, yes, it's, it's going to be difficult and hard on my, my body and my mind. But it's like, addiction is a disease. Disease is addiction.

Methods to promote harm reduction through the use of OAT, non-judgemental and accessible health care, and availability of therapeutic supports were suggested by participants. Birth parents noted the need for support beyond the individual pregnant person, and the need to include supports to partners and people close to them. Tamara noted the impact of social networks and relationship ties to an individual's ability to participate in treatment, "I think it's the fentanyl definitely, but I think it's the person you're using with that's the stronger hold. That helps you say, "No, I'm not going to treatment."'"

Providing support for the partner of the birthing person, if applicable, was a key message. Individuals noted that their partners did not always have accurate information on the role of interventions such as OAT and at times pressured them to stop using opioids all together, despite conflicting suggestions from health care professionals. Birth parents also noted that partners needed a better understanding of the impact of opioid use and potential impact of withdrawal on the baby, so that parenting units could work together to moderate use and care for their children. April reflected:

> So I think, not only the mother, does need some counseling. I think if there - if the father is around and wants to build a family, I think, you know, it's important for them to just, like, take that step into the opioid use and to just realize how important it is when that baby comes out. How much pain the poor little baby's in.

Individuals with stigmatizing and/or degrading experiences while accessing health care as a person with an addiction stressed the immediate need for updated education for health professionals about addiction and harm reduction. Birth parents felt that doctors who had graduated many decades ago often had harmful views on addiction, viewing addiction as a moral or behaviour issue, rather than a deeply complicated disease. Birth parents also felt at times that they had to advocate for themselves in health care to receive OAT, or that they had to educate health care professionals on best practice in OAT; reflecting a need to have consistent and updated education on the topic of substance use and pregnancy. Reflecting on her experience engaging with doctors who held harmful views on addiction, Phoenix reflected, "And yeah, and just and just for the older school doctors, like, I wish I don't know if it's mandatory for older doctors to take training on new things."

Almost all Indigenous individuals reflected on their experiences of racist treatment in health care settings, and already feeling like they are entering at a disadvantage as a racialized Indigenous person. Phoenix described a lack of cultural access when she was in crisis at the hospital, noting that her ability to pray was a vital part of her wellness, and that the hospital could not provide her this simple necessity:

> So I had a huge breakdown. I called Indigenous Services and I asked them to take me to smudge. That's supposed to be our right. You know, and then, like, 24 hours later, they fucking show up. Like, they - just it was insanity to me. Like, shouldn't I be allowed to pray.

Melissa reflected on the importance of healthcare providers being understanding and taking the time to listen and hear the stories of their patients. When speaking about past experiences and shared stories of people feeling rushed and invalidated during medical appointments, Melissa had a short but strong message to share: "Especially native women."

People feel rushed during their medical appointments with their doctors, but especially native women. People feel fear in disclosing substance use to their doctors, but especially native women. People feel apprehensive in attending to emergency rooms, but especially native women. When speaking about Brian Sinclair, a 45-year-old Indigenous man who was labeled as "intoxicated" by medical staff, and ultimately died in the emergency room waiting for medical care, Phoenix stated: "I feel like there's some sort of some sort of, like, emotional complex that happens when you're constantly seeing people in the news that look like you."

Individuals reflected on being discriminated against for using drugs, for using drugs during their pregnancy, and for being an Indigenous woman using drugs in their pregnancies. The totality of these three pieces created a deep feeling of stigma and distrust for medical systems as a whole.

5. "*I would like to know that something's being done about it.":* Guidance for Future Research

Individuals were asked open and close-ended questions regarding future research engagement and potential research outcomes that should be a priority. All birth parents except for one expressed comfort with the hypothetical of participating in clinical research, noting the need for further research in opioid-affected pregnancies, and wanting to personally contribute to a greater body of knowledge and potential health advancements. Jessica reflected, **"**Now, what would I like to know now? I would like to know that something's being done about it."

Previous experiences of having inadequate information about how to manage their perinatal health informed positive responses to contributing to future research.

Table 2. Considerations when conducting research with pregnant people who use drugs.

Research Considerations	Responses from Birth Parents
Biological Samples (blood, urine, breast/chest milk)	Collecting samples is positive for research Provision of samples is up to each individual Informed consent is required Uncomfortable with collecting samples "Playing God" May lead to stigma and child custody consequences
Knowledge Translation	Social media News (television, paper) Hospital and clinical settings Posters in places of poverty Appointments with doctors Emails from researchers and doctors
Barriers	Potential for content to be retraumatizing Burden of stress and responsibility on parent during pregnancy
Priority Research Topics	Short and long term effects of prescribed opiates (OAT and pain control) of opiates obtained on the streets
Preferred Terminology	Birth giver Gestational parent Special adult, special person Mother Mom Parent

Biological samples for research purposes. Over half of individuals felt generally positive about providing biological samples, such as blood, milk or urine for research purposes if it meant understanding the impacts of opioid use on their baby, and as long as informed consent was given by those giving samples (Figure 4; Table 2). As one individual shared, "So I think for me taking the samples is very, okay. Because it can be helpful somewhere. When you experiencing problems like they can, like, determine the amount of the substance that is in my system."

Other birth parents also highlighted the need for a trusting relationship dynamic between the researcher taking and using any biological samples and participant; ensuring that participants felt their privacy and vulnerability was respected. Falon reflected on context:

I think it depends on what context because sometimes that can be seen as incredibly invasive. But like, if I feel comfortable with the person and they're telling me what they're doing and why they're doing it, yeah, I would feel apt to giving them such personal samples.

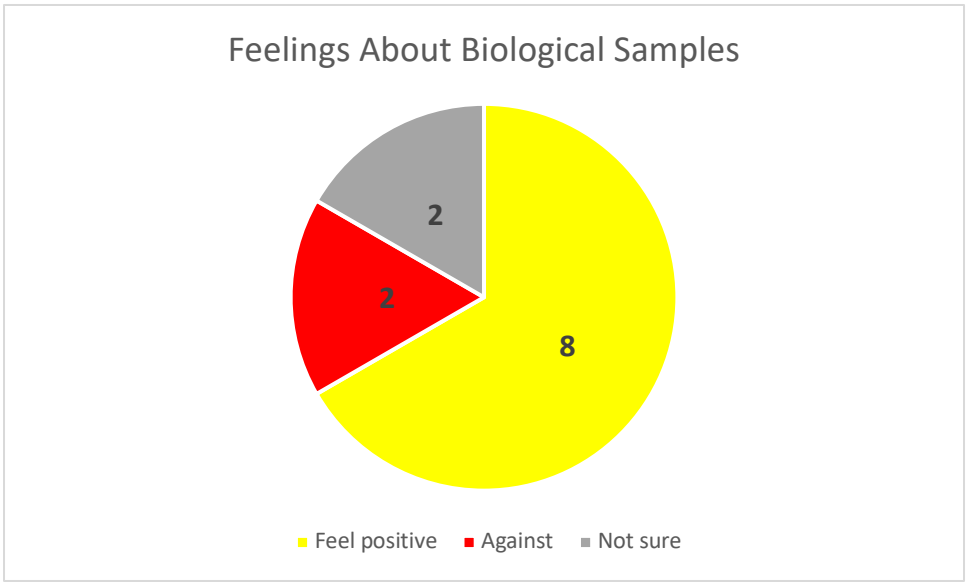

Figure 4. General summary of individuals' feelings around the collection of biological samples (breast/chest milk, blood, urine).

Reciprocity was also a key component of feeling safe and comfortable with sample-giving and research participation generally. Birth parents expressed discomfort in participating in research if it was meant to only further the career of a researcher, and not bring about any positive change in the lives of those with substance-involved pregnancies. Individual autonomy was a key theme in comfort with taking samples such as blood or breast/chest milk (Table 2). One participant stated:

I think everybody can do whatever they want. As long as they have consent. From the other person, because it's their body. Whatever people want to do with their own bodies. Yeah, their own business as long as they're given consent.

Individuals reflected that providing biological samples was ultimately to the discretion of those participating in research, and that informed consent was a key component of this. Two individuals felt hesitant or opposed to providing biological samples for research purposes. One birth parent described fear of being stigmatized and losing her license or child if opioids were found in her system. Another individual described discomfort from a philosophical perspective and concern for effects on the child: "Everything is the way that it is for certain reason. And that's playing God. By going in and digging around with pregnant like that, dangerous to the child."

"Speaking two languages," knowledge translation needs. Birth parents were supportive of many different types of knowledge translation, including in social media, hospital websites, in written and televised news, perinatal health clinics, individual doctor appointments, posters and brochures in shelters, and through distribution of academic literature (Table 2). Accessibility of information was a key priority; noting that new findings should be widely available and composed in a way that is easy to understand. The key message in knowledge translation was that it is important to get vital health information out to the public by any and all means necessary.

One individual mentioned "speaking two languages," referring to academic language and slang or popular terminology. The ability to speak both languages was viewed as positive in building a connection and trust with the intended audience. Another birth parent noted the importance of distributing important health care findings in area where poverty exists,

"Advertisements in the hospital. You know, like, advertisements in women's centers. Advertisements in shelters. Like, where – I think to put it where the more you know, where there's poverty you know."

"It can also be retraumatizing": **barriers to research.** Some individuals commented on not being in the right head space during their pregnancies to meaningfully or willingly participate in research. One individual suggested postnatal research would be optimal to allow time for settling into a new routine with the baby.

The potential to feel retraumatized by involvement in research was an important note for some participants, noting that many Black, Indigenous and People of Colour (BIPOC) have been exploited in research involvement in the past, and that providing such sensitive and personal information without a reciprocal value would cause a further traumatizing experience on top of daily experiences of discrimination and racism (Table 2). As one individual shared,

> And it can also be retraumatizing in a way, especially if someone is so dismissive after they've shared so much. And it's like, well, great. Now I'm just once again a number to this person I am once again, just a story to this person. I am once again here as a person of color, giving my labor to someone who was once again using it for academic purposes.

"I wish I would have known" **priority research topics.** Birth parents were asked about what they would like to see researched in the future, and what they wish they had more information on in the past. A key theme was short and long-term side effects of all forms of opioid use (OAT, prescription, street-acquired) on both the birth giver and the child (Table 2). As one birth parent expressed,

> I would wish to see, do these drugs have effect on the baby? Like the moment you prescribe such a drug to a pregnant woman? What are the side effects to the baby? Let

alone the mother. The baby here is like not really the main problem, the mother's in pain, but what about the baby; will the baby affected? Will it have like a problem in future let alone now that the baby is in the womb? What about in future when they're growing up? What will happen? What are the side effects of these drugs? You know, these are the things we see when we need to see the long-term side effects rather than the short term.

Birth parents felt that they did not have adequate information on how opioids would impact their children's health and felt immense regret and shame for their substance use. Individuals felt that if they had more widely available information when they were using opioids during pregnancy, they would have moderated their habits so as not to cause harm to their children. One birth parent shared, "I wish I would have known… I didn't know that they would be suffering after."

Individuals also reflected on their own excruciating experiences of detoxification from opioids, and wondered what this experience would have been like for a fetus.

I would like to know… they say low birth weight, early birth, or premature birth and then the baby also can be if you're withdrawing, you know, but I think these girls may need to be more aware of like how much it can affect your baby.

One individual reflected on the use of methadone and pondered how the methadone transfer to her baby through blood and eventually breastmilk would effect their cognitive development:

I still want to know how methadone affects the brain. You know, especially in children, how much did it affect? Also, how much did it affect the genetic growth of their brain, their nervous system, their emotions? Does it affect their emotional development? And their cognitive development? And just everything, like how does it affect the way that they

think, the way that their body moves, their mannerisms? Their personality? Their eye color, their hair colour?

Preferred terminology and research practices. Most individuals did not have any preference in terminology referring to their role as a parent, and felt comfortable with common binary words like “mommy” or “mother.” Inclusive and informal language was brought up as a priority for some birth parents, noting the importance of reflecting all gender identities that may be able to give birth with words like “birth giver” and “gestational parent,” and suggesting ambiguous terminology so as not to assume the gender or identity of a participant (Table 2).

Another birth parent reflected on the diversity of family systems outside of the stereotypical “parent” role, noting that many children grow up with caregivers that are not their biological parents. Phrases like “special person” or “special adult” were suggested as terminology to refer to caregivers in a non-assumptive way.

It was important to individuals that researchers approached their projects and relationships with participants with gentleness, understanding, humility, and a strong adherence to privacy and confidentiality. Birth parents noted that their comfort with a researcher and the level of information of samples they shared would grow through relationship building, trust, and reciprocity. One birth parent brought up the necessity of research after-care; describing immense feelings of vulnerability after sharing personal information and wanting to communication with the researcher to remain open after initial research involvement:

> It's weird in that regard, because it's like you want. And it can also be retraumatizing in a way, especially if someone is so dismissive after they've shared so much. And it's like, well, great. Now I'm just once again a number to this person I am once again, just a story

to this person. I am once again here as a person of color, giving my labor to someone who was once again using it for academic purposes.

The notion of personal, professional, financial, and academic gain from researchers collecting vulnerable stories and information from research participants was identified as a hesitancy in participating in future research, especially for individuals with systemically oppressed identities, highlighting the importance of authentic reciprocity and community gain in research.

Two individuals also noted the positivity of having people with lived-experience of addiction or "street-involved" experience on the research team, noting that this would help foster a connection and sense of trust. When I asked what researchers and healthcare professionals should know when conducting research on opioid use and pregnancy, she stated, "Someone who has probably been more street-involved"

Healthcare professionals and researchers who have lived experience relating to opioid use and pregnancy have an intrinsic ability to understand the complicated dynamics and experiences of their patients and participants. The value of speaking with someone who can understand the experience of birth parents was an important step in feeling safe and supported in their perinatal care.

Birth parents reflected on their experiences with empathy for other individuals who may also be experiencing addiction in pregnancy. This compassionate foundation set the foundation of positivity for future research that respected the autonomy of birth parents' experiences and feelings in research participation. Personal experiences of a lack of adequate information about the effects of opioid use in pregnancy contributed to a desire for future research focusing on short- and long-term effects of opioid use in pregnancy. Experiences of inadequate information

about opioids and pregnancy also informed a strong desire to improve knowledge translation that was accessible to PPWUD. Birth parents whose lived experience incorporated diverse identities and family dynamics, such as gender and community parenting, suggested a need for inclusive terminology when referring to perinatal health. The requirement for reciprocity and trauma-informed approaches was routinely highlighted for any future research on opioid use and pregnancy.

Discussion

As participants shared, the link between trauma and addiction was strong. It is common for people with diagnosed substance use disorders to have past traumatic experiences, especially in the form of adverse childhood experiences (Hand et al., 2021; Nichols et al., 2023) encompassing physical, sexual, verbal and emotional abuse and neglect. A person living with an addiction is more likely to have experienced past trauma (Nichols et al., 2023). Many individuals I spoke with expressed that their addictions stemmed from attempts to numb the pain of past trauma, and trauma occurring in their daily life, such as intimate partner violence. Hubberstrey et al. (2022) noted the association between addiction and experiences of trauma, abuse, domestic violence, mental health struggles, child welfare involvement and poor physical health; all of which can be exacerbated when co-occurring with poverty and systemic racism. In Winnipeg, the present-day effects of colonization and presence of systemic racism in healthcare and social support systems automatically places Black, Indigenous and People of Colour (BIPOC) at a systemic disadvantage when navigating healthcare systems or seeking addictions support. This same racialized stigma is apparent in other jurisdictions (Frew, 2023). BIPOC are disproportionately more likely to experience poverty and poor health outcomes, creating a disproportional impact of the weight of addiction, trauma, and poverty (Castro-Ramirez et al., 2021). Addressing these social determinants of health, namely food and housing insecurity, would foster equity and accessibility for BIPOC individuals seeking health and/or addictions care. Understandably, an individual that is struggling with an addiction and struggling with stable housing will have a more challenging time managing their addiction than someone who is stably housed. Removing barriers and potential crisis-triggers such as unstable housing provides

an integrated, wrap-around support model in assisting individuals with addiction (Altman et al., 2021; Blair et al., 2021; Collard et al., 2014).

Stigma, both internalized and from external forces, continued to be a key theme in individual's experiences accessing healthcare systems. Stigma contributed to massive feelings of shame and guilt that manifested as self-doubt, self-blame, and individual isolation. Especially as it related to addiction, stigma, shame and guilt created large barriers for people wishing to access addictions treatment (Kim et al., 2022; Paris et al., 2020; Proulx & Fantasia, 2021; Recto et al., 2020; Reese et al., 2021). Only two of twelve individuals I spoke with had accessed addictions treatment at the time they were pregnant. Stigma and shame contributed to isolation such that ten individuals were unaware of treatment options such as OAT at the time they were pregnant. Fear of stigmatized treatment in healthcare systems, as well as stigma for using OAT medications, continues to be a contributor to why individuals with addictions avoid or delay seeking addictions treatment (Altman et al., 2021; Boeri et al., 2021). Stigmatization of drug use, especially while pregnant, is weaved into the fabric of social services, healthcare, and justice systems (Ahlbach et al., 2020; Choi et al., 2022) exemplifying an urgent need to create strong and evidence-based policy and education practices that abolish stigmatized narratives of drug use.

Trauma from the historic and ongoing effects of colonization was interwoven into the stories of all Indigenous individuals I spoke with. This included experiences of poverty, child apprehension, growing up in the child welfare system, sexual assault, the loss of loved ones to homicide, racist treatment in systems and community, and experiences of addictions themselves. Intergenerational trauma does not present as one specific ailment, but rather presents across multiple psychosocial, spiritual and physical health domains (Heberle et al., 2020). Manitoba is

home to the largest Indigenous population in Canada (Nejad et al., 2019), and so these systemically enforced discrepancies of health become extremely relevant when addressing issues of addiction and pregnancy. Phoenix spoke to the lack of in-hospital culturally relevant care in her time of crisis, and others described the tension they experienced in deciding to seek care as an Indigenous woman. Creating spaces in healthcare and social systems that are rooted in anti-racism, culturally appropriate and trauma-informed care, and wholistic perspectives of health is critical to support all individuals with addictions in pregnancy.

Access to non-judgemental care that approached perinatal health with a harm reduction lens was a critical turning point for the two participants able to access it in their pregnancies. This care included physicians who were up to date on evidence-based approaches to addiction in pregnancy, the provision of OAT, and housing supports. Across North America, physicians, social service providers, and individuals experiencing addiction while pregnant, all acknowledge the need for wrap around support systems that prioritize an individual's basic needs and accommodate for multiple psychosocial health factors such as trauma, poverty, culture, and the necessity to include families (Altman et al., 2021; Blair et al., 2021; Cochran et al., 2019; Hubberstey et al., 2022; McKinney et al., 2022; Nichols et al., 2023; Proulx & Fantasia, 2021; Recto et al., 2020; Rose-Jacobs et al., 2019; Urbanoski et al., 2018). Evidence shows that when multiple systems work together, namely perinatal care, addictions support, psychiatry, child welfare services, and community support, there are significant positive outcomes for infant and birthing parent health, as well as reduced child apprehension (Hubberstey et al., 2022). The individuals involved in this study described facing crises in multiple domains in their lives that deepened their vulnerability to addiction, such as lack of familial support, poverty, and intimate partner violence. Siloed systems with complicated navigation pathways create unnecessary

barriers that impede not only the ability for individuals to access treatment, but also the ability of physicians and social service providers to effectively support individuals with addictions in pregnancy (Altman et al., 2021; Hubberstey et al., 2022; Huhn & Dunn, 2020; Joshi et al., 2021). The multiple and often conflicting demands experienced by PPWUD highlights the need for researchers to remain flexible and understanding in their approach and engagement with PPWUD. Methods to reduce any additional barriers or stress in a research context could include providing cash honorariums available immediately to the research participants, planning for transportation and childcare accommodations, inclusion of cultural supports such as Elders, plans to follow up with participants after emotionally taxing conversations, flexible member checking procedures, coordinating with local resources in the community for potential referral, and planning for disruptions of communication devices and use of common communication platforms such as Facebook Messenger. Researchers should inquire with participants about potential barriers that they anticipate and make every effort to address and eliminate these barriers.

Fear of child and family services intervention and ultimately, child apprehension, is well-reported to be the primary barrier to individuals with substance-affected pregnancies accessing perinatal and addictions care (Altman et al., 2021; Blair et al., 2021; Boeri et al., 2021; Howard, 2016; Kim et al., 2022; Leiner et al., 2021; O'Rourke-Suchoff et al., 2020; Paris et al., 2020; Proulx & Fantasia, 2021). Only recently in Manitoba were Birth Alerts, the standard of an automatic notification to child and family services for a pregnant person who used drugs, abolished (Wall-Wieler et al., 2019). The distrust and fear of CFS involvement was evident throughout the conversations I had with individuals in this study; especially for those who have had children previously apprehended or grew up involved themselves in CFS. This fear was

layered by racialized discrimination and the overrepresentation of Indigenous children in care for Indigenous individuals. The impact of child apprehension pushed individuals into greater pain and further addiction in this study. Huhn & Dunn (2020) reported that child apprehension for pregnant people who use drugs increases the risk of both fatal and non-fatal toxic drug poisoning, demonstrating the emotional complex and pain child apprehension has for individuals who are already struggling.

The legacy of Child & Family Services in Winnipeg is one of fear, distrust, and disdain. Individuals with personal experience and indirect experience interacting with Child & Family Services are often left in a place of choosing to access care that may be beneficial, while balancing the very real possibility of losing custody of their children. Although some changes to CFS have been implemented to increase support services and reduce apprehension, community views on CFS have remained unchanged. Birth parents described needing more support to meet the demands of caring for their children, managing their addiction, and seeking healthcare, among multiple other traumatic life circumstances they were juggling. Policy makers should critically view and update the mandates of child welfare services to address the legacy of fear and distrust of community, and prioritize an increased focus on supporting birth parents with addictions to retain custody of their child while also seeking addictions treatment if they wish. An extensive review of the structuralized racism and stigma within CFS must be undertaken to ensure that BIPOC families are not subject to unnecessary scrutiny in their interactions healthcare and social services.

Pregnancy is a particularly unique time in a pregnant person who uses drugs life and can act as a window of opportunity where motivation to access addictions services and treatment is strong (Boeri et al., 2021; Goodman et al., 2020; Proulx & Fantasia, 2021). Researchers may

acknowledge these motivations by connecting participants with perinatal and addictions care programs and understanding that many individuals are not aware of the resources available to them in terms of harm reduction and specialized perinatal support. Any research inquiry into addictions and perinatal care must understand the vulnerability that accompanies pregnancy for PPWUD, and utilize any interaction from a place of compassion and responsibility to assist in the connection to appropriate resources.

Individuals in this study shared the sentiment that retaining custody of their children would have motivated them to address their addictions and may have enabled them to seek support earlier. Perinatal addictions researchers could work proactively with an individual's healthcare team to assist in sharing knowledge about perinatal health and CFS policies to the patient. From a policy and public services perspective, these vulnerable moments for PPWUD seeking care and treatment should be responded to from a place of non-judgement and empathetic consideration and be treated as an opportunity to engage individuals in perinatal and addictions care to address addictions concerns, family health, and reduce the likelihood of child apprehension. It must be a priority that PPWUD are able to access evidence-based and compassionate care from the moment they may disclose their substance use, without the imminent fear of child apprehension.

Over the past decade, PPWUD have described the stigma and discrimination they have experienced in healthcare settings (Blair et al., 2021; Choi et al., 2022; Recto et al., 2020; Syvertsen et al., 2021), and recent studies engaging healthcare providers have confirmed this implicit bias against PPWUD (Blair et al., 2021; Bukowski & Combellick, 2022; Nichols et al., 2023; Radcliffe, 2011; Reese et al., 2021). Community pharmacists, nurses, midwives, and doctors have described frustration with PPWUD and perceived lack of motivation and

engagement in care; a disproportionate emphasis on infant health rather than that of the birthing person; and high scrutiny on any deviances from treatment plans (Alhusein et al., 2021; Nichols et al., 2023; Radcliffe, 2011). Implicit bias in healthcare can start to be addressed with comprehensive education on the impact of trauma on addiction, and a strong understanding of best-practice and harm reduction practices in healthcare provision (Altman et al., 2021; Byrne et al., 2018; El Helou et al., 2022). Recto et al. (2020) suggest incorporating the ACTS (Acknowledge – Create Circumstance for Reflection – Teach – Support) framework (Marcellus & Poag, 2016) into healthcare education to address stigma and provide actionable communication frameworks for reflection and learning. Participants in this study emphasized the need for trusting, non-judgemental and person-centred relationships with healthcare providers as a first step to provide safety and support in their perinatal care. Physicians also must incorporate a level of flexibility in their work, understanding the multiple and at times conflicting obligations and responsibilities for PPWUD (Byrne et al. 2018). Other recommendations from PPWUD include providing elaborate and comprehensive information on what to expect with child welfare involvement, hospital protocols, social service roles, pain management in birth, and potential for NAS or neonatal intensive care unit (NICU) care (Altman et al., 2021; Blair et al., 2021).

Perinatal and addictions care needs to understand and incorporate the important role of partners, family members, and close supports of PPWUD given the influential role supports play in treatment and healthcare engagement (Asta et al., 2021; Banks et al., 2023; Boeri et al., 2021; Jones et al., 2011). Individuals in this study described the detrimental impact of partners with a lack of understanding on OAT and the increase in stress that this caused. Indeed, familial views on OAT and understanding of addictions can be a strong barrier to treatment access for PPWUD (Banks et al. 2023). Partners of PPWUD who are still using themselves can create tension and

confliction for birthing people to engage in addictions treatment (Boeri et al., 2021; Goodman et al., 2020; Jones et al., 2011).

Clinical Research Recommendations

The comfort level of individuals in engaging in clinical research was informed by traumatic experiences in the healthcare system; contributing both to positive and negative perspectives of desires to engage in research. The potential for research involvement to empower individuals and contribute to further knowledge and reduced harms for future generations was highlighted, while fear of being further stigmatized due to research involvement was a barrier.

In terms of researchers collecting biological samples, such as breast/chest milk, blood, and urine, the overall message was that comprehensive informed consent and a trusting relationship with the researcher was required as a foundation for such clinical work. The importance of genuine reciprocity between researcher and participants was noted as a key importance to research involvement, noting the traumatizing impacts of sharing vulnerable studies or samples only to further the career of a researcher. Participants expected that their contribution to research should ultimately result in further knowledge that would benefit their communities.

Participants cited many forms of knowledge translation including news outlets, social media, clinical interactions, and community settings. The key message highlighted the importance of authentic knowledge translation that was widely shared with PPWUD.

Individuals in this study wanted to see research that focused on short and long-term effects of opioid use on infants and children; both unprescribed opioid use and the use of OAT. Participants felt that they did not have enough information on consequential effects of opioid use to their children, and that having this information early may have mitigated their use. All

participants supported further research on clinical effects of opioid use in pregnancy, and others wanted to know about the psychosocial impact of dehumanizing and stigmatizing treatment in healthcare and child welfare involvement.

Preferred terminology for individual's role as a parent reflected each individual's identity in terms of gender and community role. Participants who identified as a woman described gendered words such as "mom" or "mother" were most affirming and descriptive of their role as a parent, while gender non-conforming participants preferred more inclusive terms like "birth giver" or "gestational parent." One participant reflected on the diverse family dynamics that can exist when children are not parented by their biological parents, and encouraged using inclusive terminology like "special adult." Although majority of participants in this study identified as women and preferred female-centric terminology to describe their parenting role, it is important to note that inclusive terminology is key to ensure that all people are included and reflected in research and healthcare. Researchers and healthcare providers can use both terms such as "mother" and "gestational parent" in communication, knowledge dissemination, and recruitment to ensure that all experiences and identities are captured in future work.

Challenges & Recommendations

Throughout the research process and drawing from my research proposal, I humbly learned how important it is to keep research methods flexible and relatively immediately available. Initially, I had planned to gather interested participants, host an opening ceremony, and then conduct focus groups and individual interviews. I had hoped for this opening ceremony to be an opportunity to provide information about the study, answer any questions, and schedule focus groups and interviews. Unfortunately, what resulted from this planning was a delay in conducting interviews with some eligible participants, and then losing contact with some people

while I waited for the opening ceremony. I realized the importance of being available to speak to people as they reached out, not only to respect the multiple demands and busy schedules that parents have, but also to catch people while they are interested. The structure and timeline I had imagined as relational had ultimately resulted in lost participants. There were four individuals who had reached out initially that I could not regain contact with to schedule an interview.

I faced some difficulty in getting Carey Sinclair's honorarium to her in a timely manner. This was due to administrative processes and delays that lead to multiple emails back and forth between the funding agency and our administrative assistant, and a long period of waiting for the cheque to be sent out. I felt that this impacted the way I was able to work with Carey, as it was important to me that she be compensated for the work that she did in a timely manner. I learned that this could avoided in the future through early planning, requesting of funds, and processing. I would suggest to anyone offering honorarium payments to Elders, Knowledge Keepers, and community members to request these funds early, so that they can be distributed immediately after the service provided.

Strengths and Limitations

This study was limited to Winnipeg to understand the specific set of circumstances that impact people using opioids in pregnancy in this city. Access to evidence-based perinatal care for people using opioids in pregnancy is extremely limited in rural, remote, and First Nation communities that already experience staff and health resource crises. Further research should focus on rural, remote, and First Nation communities to hear from individuals who have used opioids and other substances in pregnancy and to determine actionable steps to improve access to critical services.

This study was open to people who have used opioids in pregnancy, regardless of race, ethnicity, gender identity and sexual and romantic orientation. However, this study was almost exclusively composed of racialized (Black, Afro-Indigenous, and Indigenous) participants. Although social determinants of health such as racism disproportionately impact BIPOC people, addiction in pregnancy is not exclusive to racialized communities. It would have been worthwhile to hear from White individuals to examine any differential experiences and treatment in healthcare. This study heard from a number of members of the 2SLGBTQIA+ community and one gender non-conforming individual. Although this study was open to trans men who had been pregnant while using opioids, recruitment efforts did not reach this population. It is important that all gender identities are represented in perinatal health research, especially given the added impact of transphobia and cisheteronormativity in health care.

Implications for Policy, Research, and Healthcare

Addressing structural and institutionalized stigma against PPWUD is key to reducing the harms experienced for individuals accessing healthcare. Although genuinely deconstructing deeply embedded stigmatizing and racist narratives held by individuals in the healthcare system is challenging without voluntary and meaningful participation, early medical school education can and should require anti-oppressive training. Policy addressing both stigma and racism with healthcare and CFS must move beyond individual training and look at a systems-wide approach to dismantling documented barriers for PPWUD. Meaningful action to eliminate racism and stigma provides benefits both to families, in terms of positive health outcomes, reduced relapse and fatal toxic drug poisoning, and increased retention of child custody, and to community health by addressing root causes of addiction and poor mental health.

There is currently inadequate resources available for PPWUD, and inadequate public education about the resources that do exist and how to access them. Wrap-around support systems are a necessary and evidence-based response to addressing the multi-faceted challenged that PPWUD face when navigating parenting, healthcare, and addictions. The province of Manitoba desperately needs wholistic wrap-around support services that address social determinants of health that PPWUD experience, including inclusion of culture, therapy, housing supports, education supports, parenting education, and inclusion of familial and social support. Appropriate implementation of evidence-based support is shown to decrease the burden on healthcare and child welfare systems, by reducing adverse health outcomes for parents and infants, and increasing parental retention of child custody.

There is an urgent need to address structural stigma and racism in healthcare. Physicians must be mandated to continually take on new education that addresses harm reduction, impact of trauma, cultural humility, and destigmatizing of drug use. These principles must be embedded in medical curriculum for new physicians in a meaningful way that goes beyond a single day training session, and is instead incorporated into all aspects of health and learning.

Researchers in addictions and perinatal health should prioritize the voices and experiences of PPWUD by including community advisory boards made up of people with the specific lived experience of substance use and pregnancy. Researchers should be well-versed on the impact of trauma, racism, medical discrimination, and colonization when engaging with PPWUD and incorporate flexible and tangible methods to reduce barriers to motivated participants to engage in research projects. Future clinical research should focus on short- and long-term effects of opioid use in pregnancy, and meaningfully disseminate findings to community settings where PPWUD can access this knowledge.

Conclusion

Pregnant people who use drugs experience immense stigma, shaming and trauma when accessing medical and social service systems. Racialized people experience an even greater burden of stigma when seeking help. Fear of child apprehension and traumatic past experiences with Child and Family Services continues to be the primary barrier to pregnant people who use drugs in feeling safe and supported to seek medical and addictions assistance. There is inconsistent and inadequate information available for pregnant people who use drugs when seeking care, harm reduction support, opioid agonist treatment, and supports for other social determinants of health. There is ample evidence to support wrap-around approaches to care for perinatal substance use and the use of harm reduction approaches. Health policy makers, physicians, social workers, and researchers alike must collaborate to ensure that adequate and appropriate support is available to individuals seeking care immediately. Pregnant people who use drugs are keen to understand more about the short- and long-term effects of substance use in pregnancy, but require a baseline of trust and reciprocity in the collaborative relationship with the research team.

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Appendix A: Focus Group/ Interview Questions

1. Can you tell me (as little or as much) about your experience using opioids while pregnant?
    - What year/ how old you were
    - opioid(s) used
    - any supports you accessed (medical/ social/ anything)
    - what was helpful/ not helpful (broad or specific)
2. Have you ever participated in research related to opioid use in pregnancy?
    - If yes, what was your experience like? Both positive and negative
    - If no, what hesitancies would you have had? Would there have been any motivators that would have caused you to want to participate?
3. There is a lot of ongoing research focusing on clinical outcomes for individuals and families, and recently more research on social aspects of opioid use in pregnancy. Is there anything that you would like to know now, or wish you would have known previously related to opioid use in pregnancy?
    - Ie social supports available, medical interventions, etc

    What do you want researchers to know when conducting clinical/ social studies on opioid use in pregnancy?
    - Ie social/ cultural safety
    - Accessibility
    - Use of language (gendered/ stigmatizing etc)
    - Confidentiality/ privacy/ legal concerns
    - Where to approach (ie at doctor's office, at social service agency, through social media, etc)
4. How would you like researchers to share the results of their studies with you?
    - via email, community event, sharing circle, social media, etc
5. What is the most important thing you've told me today?

Quick Qs:

1. What is your preferred language (if any) related to your experience as a parent? (Parent, birthing parent, gestational parent, mother, etc…)
2. How do you feel about researchers collecting biological samples (breast/chest milk, blood, etc)

Appendix B: Consent Form

Engaging people with lived experience of opioid use in pregnancy to inform future research on opioid exposures in pregnancy in Winnipeg, Manitoba

University of Manitoba | Rady Faculty of Health Sciences

Department of Community Health Sciences
417-753 McDermot Avenue
Winnipeg, MB, R3E 0T6
Phone: [redacted]

PARTICIPANT INFORMATION AND CONSENT FORM
Focus Group and Individual Interview

Title of Study: "Engaging people with lived experience of opioid use in pregnancy to inform future research on opioid exposures in pregnancy in Winnipeg, Manitoba"

Principal Investigator: Danielle Hart, [redacted]
Co-Investigator: Dr. Lauren Kelly, Dr. Andrew Hatala
Sponsor: **N/A**
Funder: **Children's Hospital Research Institute of Manitoba**

You are being asked to participate in a research study involving a focus group or individual interview. Please take your time to review this consent form and discuss any questions you may have with the study staff, your friends, family, or health professional before you make your decision. This consent form may contain words that you do not understand. Please ask the study staff to explain any words or information that you do not clearly understand.

Purpose of this Study

This research study is being conducted to explore research outcomes that are important to individuals with lived experience of opioid use during pregnancy to design future research that is aligned with the needs of the community in Winnipeg, Manitoba.

Participants Selection

You are being asked to participate in this study because as an individual with experience of substance use in pregnancy, you have valuable knowledge and insight into important factors in research on opioid-affected pregnancy. We are recruited individuals who are 18 years of age or older, have experience of substance use in pregnancy and reside in Winnipeg. You do not need to currently be pregnant or accessing addictions treatment to participate in this study. This study is open to any women, Two Spirit, transgender or gender-diverse individual who has directly experienced pregnancy while using opioids. Experience of opioid use in pregnancy can either be through prescription, opioid agonist treatment, or street opioids.

A total of 12 participants will be asked to participate.

Study procedures

- The method of data collection for this study will be focus groups and/or individual interviews. You may choose to participate in either an individual interview or a focus group, but not both. Focus groups are group discussions with people who know something about the topic of interest. Focus groups are ways of finding out people's thoughts and ideas about a specific topic.
- Focus groups will have approximately four participants, the primary investigator, and a Knowledge Keeper.

- Participation in the study will be for one hour if you choose to participate in an individual interview, or two hours if you choose to participate in a focus group. After interviews and focus groups, you will be asked to look over the interpreted results and your direct quotes, which will take approximately one hour.
- In focus groups, there will be a facilitator who will ask questions and facilitate the discussion. Danielle Hart will facilitate discussion, and knowledge keeper Carey Sinclair will co-moderate discussions.
- Danielle Hart will conduct individual interviews.
- The group, or you individually, if you choose to participate in individual interviews, will be asked some questions relating to your experience with research related to opioid use in pregnancy, and which research outcomes are important to you and your family. These questions will help us to better understand which topics are important to you in research, and design better research in the future that reflects your experiences and wishes.
- The sessions will be audio-taped and the audiotapes will be transcribed by Danielle Hart to ensure accurate reporting of the information that you provide.
- Transcribers will sign a form stating that they will not discuss any item on the tape with anyone other than the researchers.
- At the start of the session everyone will be asked to respect the privacy of the other group members. All participants will be asked not to disclose anything said within the context of the discussion, but it is important to understand that other people in the group with you may not keep all information private and confidential.
- No one's name will be asked or revealed during the focus groups or individual interviews. However, should another participant call you by name, the transcriber will be instructed to remove all names from the transcription.
- The audiotapes and transcriptions will be stored in locked files before and after being transcribed. Tapes will be destroyed within five years of completing the transcriptions and the transcriptions will be destroyed five years after the completion of this evaluation.
- Your contact information will be collected so that we can distribute copies of our initial analysis. You will be able to modify, clarify, add, or retract to any of your statements, and detail whether the analysis fits your experience. It can often feel strange or uncomfortable to see your words quoted directly in text. If you wish to have the transcriber adjust for grammar or remove "filler" words, this is an option available to you. You can choose to have this information mailed to you, provided electronically, or to go over this information with the researcher in person, over the phone, or virtually.

Knowledge Sharing

A community feast will be held in Summer 2023 to present and discuss the results of the study with participants, community members, researchers, and community agencies. This gathering will allow for discussion addressing research and policy implications, and community-guided direction on next steps. Details of this event will be shared with you at the contact information you provide. **You are under no obligation to attend. Your attendance at this event is entirely voluntary.**

Risks and Discomforts

Focus group members will be asked to keep the information provided in the groups confidential; however, a potential risk that might exist for some would be that information about you might be discussed outside the group by other participants and be traced back to you. If this is a potential issue for you, you are encouraged to ask for an individual interview with one of the researchers who would then be knowledgeable of and bound by confidentiality.

There are some potential risks to you by participating in this research. It is possible that talking about opioid use in pregnancy might be emotional or stressful for you. You do not have to answer any

question that makes you feel uncomfortable or that you find too upsetting. Staff (Danielle Hart) and knowledge keeper Carey Sinclair will be available if you feel like there is anything that has come up for you during the focus group or individual interview that is upsetting. Should you need any additional help or support we will refer you to Klinic's Crisis Line (1-888-322-3019) or the Indigenous Hope for Wellness Help Line (1-855-242-3310) or help you to find other counseling help.

Benefits

Being a participant of an individual interview or focus group may not help you directly, but information gained may help other people or family members who use substances in pregnancy in the future.

Costs

There is no cost to you to attend the Focus group discussion or individual interview.

Payment for participation

You will be given $25 your participation in this research study. Bus tickets and meals will be provided at focus groups. Child care will also be available for focus groups.

Confidentiality

We will do everything possible to keep your personal information confidential. Your transcript and knowledge provided will be de-identified and assigned a number. A list of names and addresses of participants corresponding to the assigned number will be kept in a separate, secure file so we can send you a summary of the results of the study. If the results of this study are presented in a meeting, or published, nobody will be able to tell that you were in the study. Please note that although you will not be identified as the speaker, your words may be used to highlight a specific point. The collection and access to personal information and if applicable health related information will be in compliance with provincial and federal privacy legislations.

During the focus groups we ask that all participants respect and maintain the confidentially of the discussion; however, it is not possible for the researchers to guarantee that everyone will do so.

All study team members have an obligation to report any reports of harm to a child, harm to another person, or an imminent risk an individual may pose to themselves (i.e., immediate suicidality). In these cases, confidentiality would need to be broken only to report to the appropriate authorities. If this poses a concern to you, you are encouraged to ask questions or voice concerns to the principal investigator.

Audiotapes of the group discussion will be typed and used to prepare a report. The audiotapes and typed notes will be kept for five years in a secure locked file cabinet and office. Only the research staff will have access to them and know your name.

Some people or groups may need to check the study records to make sure all the information is correct. All these people have a professional responsibility to protect your privacy.

These people or groups are:

- The Health Research Ethics Board of the University of Manitoba which is responsible for the protection of people in research and has reviewed this study for ethical acceptability
- Quality assurance staff of the University of Manitoba who ensure the study is being conducted properly

All records will be kept in a locked secure area and only the principal investigator and co-investigators

will have access to these records. If any of your research records need to be copied to any of the above, your name and all identifying information will be removed. No information revealing any personal information such as your name, address or telephone number will leave the University of Manitoba.

Permission to Quote:
We may wish to quote your words directly in reports and publications resulting from this. With regards to being quoted, please check yes or no for each of the following statements:

Researchers may publish documents that contain quotations by me under the following conditions:	
☐ Yes ☐ No	I agree to be quoted directly if my name is not published (I remain anonymous).
☐ Yes ☐ No	I agree to be quoted directly if a made-up name (pseudonym) is used.

Voluntary Participation/Withdrawal from the Study
Your decision to take part in this study is voluntary. You may refuse to participate, or you may withdraw from the study at any time.

Questions
If any questions come up during or after the study contact the principal investigator and the study staff: Danielle Hart, [redacted]

For questions about your rights as a research participant, you may contact The University of Manitoba, Bannatyne Campus Research Ethics Board Office at (204) 789-3389

Consent Signatures:

1. I have read all four pages of the above consent form.
2. I have had a chance to ask questions and have received satisfactory answers to all of my questions.
3. I understand that by signing this consent form I have not waived any of my legal rights as a participant in this study.
4. I understand that my records, which may include identifying information, may be reviewed by the research staff working with the Principal Investigator and the agencies and organizations listed in the Confidentiality section of this document.
5. I understand that I may withdraw from the study at any time and my data may be withdrawn prior to publication.
6. I understand I will be provided with a copy of the consent form for my records.
7. I agree to participate in the study.

Participant signature_____ **Date** _____
(day/month/year)

Participant printed name: _____

I, the undersigned, have fully explained the relevant details of this research study to the participant named above and believe that the participant has understood and has knowingly given their consent

Printed Name: _____ **Date** _____
(day/month/year)

Signature: _____

Role in the study: _____

Relationship (if any) to study team members: _____

COVID-19 Consent Appendix

Research Project Title: "Engaging people with lived experience of opioid use in pregnancy to inform future research on opioid exposures in pregnancy in Winnipeg, Manitoba"

Principal Investigator and contact information: Danielle Hart, [redacted]

Research Supervisor and contact information: Dr. Lauren Kelly, [redacted]

This document contains important information about in-person research during the COVID-19 public health crisis. COVID-19 (also called SARS-CoV2) is an illness caused by the coronavirus. Coronaviruses are most commonly spread from an infected person through a) respiratory droplets when you cough or sneeze; b) close personal contact, such as touching or shaking hands; or c) touching something with the virus on it, then touching your eyes, nose or mouth before washing your hands.

The University of Manitoba is committed to taking measures to protect the health and safety of their campuses and the wider community. Your safety is important to us. The university has suspended most research that cannot be conducted remotely or virtually. This project requires in-person visits. Therefore, it is important to understand that your participation in this study may increase your exposure to COVID-19.

Our project has been approved to proceed by the Research Ethics Board, our Faculty, the COVID Recovery Response Team, the COVID Recovery Steering Committee, and the University Provost. In order to gain approval, we created policies to ensure the safety of the research team and participants. These plans were reviewed and approved by the parties above. These precautions include:

- *Focus groups will occur at 470 Selkirk Avenue, where there is ample room for physical distancing. Individual interviews will occur at an agreed upon location that is quiet and maintains social distancing.*
- *Focus groups will take approximately two hours, and individual interviews will take approximately one hour.*
- *Individual interviews will be offered virtually or by telephone if you do not wish to meet in person.*

- *All study research teams are wearing 3-ply reusable or disposable masks. You are also required to wear a mask.*
- *We also require all our employees to screen themselves for symptoms daily before they come into work, and we'll screen you for symptoms the day of your visit.*
- *We will provide you with a screening questionnaire. Please complete this on the morning of your visit. If you answer yes to any of the questions, please call us to reschedule your visit. You should not attend any visits if you are not feeling well or exhibiting any symptoms of COVID-19, if you have been a close contact with someone with COVID-19 (or awaiting tests results) or have been told by a health official to self-isolate.*
- *We are following meticulous infection control practices, including disinfection, wearing gloves, and hand washing.*
- *We are limiting the number of visitors accompanying people for their study visits and have rearranged and/or removed furniture in our waiting areas to enforce strict physical distancing practices.*
- *We ask that you attend the study alone, with the exception of children (child care will be provided at focus groups). Accommodations can be made if necessary. Please let us know ahead of time if you require someone to attend with you.*
- *We're also being careful about who we ask to come for in-person study visits, and when possible are using telephone or video conferencing to reduce the number of study participants coming to our research areas at the same time.*

COVID-19 is a serious health threat, and the situation is evolving rapidly. If you feel that you are from a group that is more vulnerable to COVID-19 effects (e.g., senior (over the age of 60 years), immuno-compromised), please discuss your participation with the research team before providing your consent. You are under no obligation to participate and can change your mind about participating in the research at any time and without consequence.
The University of Manitoba is closing watching the situation in Manitoba and may restrict in-person research at any time. We will continue to keep you informed as to changes that may occur to this study.

There is a possibility that during your participation in the study you could encounter someone with COVID-19. We are required to collect your personal contact information that we must retain to follow up with you and/or conduct contact tracing if you may have been exposed to COVID-19 in coming to the research site. **We cannot guarantee anonymity as the personal contact information identifies you as a participant and we may be required to disclose this information in the event of a possible exposure.** Your contact information will be kept separately from data collected through the research study to allow for de-identification of the research data. You maintain your right to withdraw from the study at any time, including your research data. If you do withdraw from the study, we will still need to continue to maintain your contact information and will only give it to the University's Environmental Health and Safety (EHS) Office and/or Manitoba Health if required for contact tracing. Please note, Manitoba Health or the University's EHS office will not have access to your research data.

If you have questions regarding this study, measures we are taking to keep all parties safe, or

have any concerns, please do not hesitate to ask. You can contact any of the above named researchers or the Bannatyne Campus Research Ethics Board office at shelly.rempel-rossum@umanitoba.ca

Your signature on this form indicates that you have understood to your satisfaction the information regarding participation and the COVID-19 risk and agree to participate. In no way does this waive your legal rights nor release the researchers, sponsors, or involved institutions from their legal and professional responsibilities. Your continued participation should be as informed as your initial consent, so you should feel free to ask for clarification or new information throughout your participation.

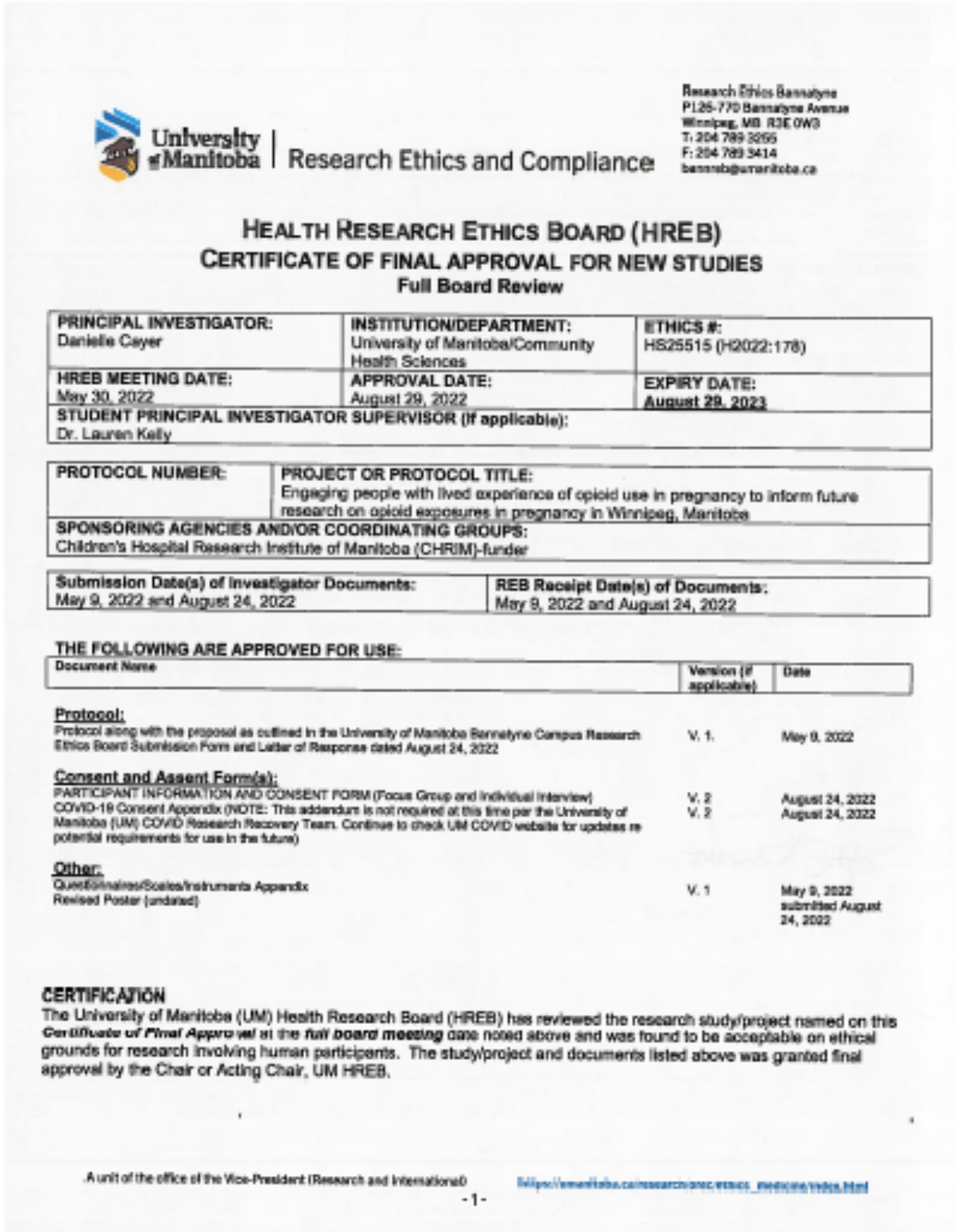
Participant Name _____

Contact Information (phone # or email): _____

Participant's Signature _____ Date: _____

Appendix C: Knowledge Translation Event Poster

Appendix D: Research Ethics Board Approval



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HEALTH RESEARCH ETHICS BOARD (HREB)
CERTIFICATE OF FINAL APPROVAL FOR NEW STUDIES
Full Board Review

PRINCIPAL INVESTIGATOR:	INSTITUTION/DEPARTMENT:	ETHICS #:
Danielle Cayer	University of Manitoba/Community Health Sciences	HS25515 (H2022:178)
HREB MEETING DATE: May 30, 2022	**APPROVAL DATE:** August 29, 2022	**EXPIRY DATE:** August 29, 2023
STUDENT PRINCIPAL INVESTIGATOR SUPERVISOR (If applicable): Dr. Lauren Kelly		

PROTOCOL NUMBER:	PROJECT OR PROTOCOL TITLE:
	Engaging people with lived experience of opioid use in pregnancy to inform future research on opioid exposures in pregnancy in Winnipeg, Manitoba
SPONSORING AGENCIES AND/OR COORDINATING GROUPS: Children's Hospital Research Institute of Manitoba (CHRIM)-funder	

Submission Date(s) of Investigator Documents:	REB Receipt Date(s) of Documents:
May 9, 2022 and August 24, 2022	May 9, 2022 and August 24, 2022

THE FOLLOWING ARE APPROVED FOR USE:

Document Name	Version (if applicable)	Date
Protocol: Protocol along with the proposal as outlined in the University of Manitoba Bannatyne Campus Research Ethics Board Submission Form and Letter of Response dated August 24, 2022	V. 1.	May 9, 2022
Consent and Assent Form(s): PARTICIPANT INFORMATION AND CONSENT FORM (Focus Group and Individual Interview)	V. 2	August 24, 2022
COVID-19 Consent Appendix (NOTE: This addendum is not required at this time per the University of Manitoba (UM) COVID Research Recovery Team. Continue to check UM COVID website for updates re potential requirements for use in the future)	V. 2	August 24, 2022
Other: Questionnaires/Scales/Instruments Appendix	V. 1	May 9, 2022
Revised Poster (undated)		submitted August 24, 2022

CERTIFICATION

The University of Manitoba (UM) Health Research Board (HREB) has reviewed the research study/project named on this ***Certificate of Final Approval*** at the ***full board meeting*** date noted above and was found to be acceptable on ethical grounds for research involving human participants. The study/project and documents listed above was granted final approval by the Chair or Acting Chair, UM HREB.

Appendix E: Recruitment Poster

Participate in Research!

University of Manitoba

Looking to hear from people who've used opioids in pregnancy

Open to

- Women, Two Spirit, nonbinary and transgender individuals who have used opioids in pregnancy
- Adults 18 years and older in Winnipeg
- Opioid use may be prescribed or obtained on the street

Format:

- Individual interviews
- Focus groups

Additional information:

- Meals, bus tickets, childcare and traditional medicines available
- Knowledge keeper co-facilitated
- Honorarium for your time

Future research on opioid exposures should be guided by YOU. What would you like to know more about in terms of you and your family's health? How can research improve? What would you like to see researched?

My name is Danielle Hart (she/her). I am Cree, Ukrainian and French, and a Master's student at the University of Manitoba.

Phone: [redacted]
Email: [redacted]
Messenger: [redacted]

Your voice is important.

Version 3 - November 8, 2022