Exploring the reproductive health and social care needs of women who use drugs: A qualitative study.

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Abstract

Background and Aim

Women who use illicit drugs are at higher risk of contracting sexual transmitted infection or disease, have poor contraceptive use, higher rates of unplanned pregnancy and are more likely to experience child removal. This research aims to explore the experiences and understanding women who use drugs have in relation to their reproductive health and sexual wellbeing.

Methodology and Methods

A systematic review of qualitative literature explored the lived experience of pregnancy among women who use drugs. Semi-structured, one to one interviews were conducted with women who use drugs and professionals who support them to explore their perspectives on reproductive health and sexual wellbeing.

Findings

Women who use drugs regard sexual and reproductive health as protection from disease and prevention of pregnancy. Findings from the qualitative systematic review indicate that pregnancy is often considered to be a window of opportunity for women who use drugs to incite change, however, this is nuanced and challenging for both them and services providing support. Findings from qualitative research demonstrate the lack of autonomy and body sovereignty experienced by women who use drugs have over their sexual and reproductive wellbeing. This was often exacerbated by sexual and physical abuse in their childhood and adult life. Accounts from women involved in my qualitative research suggest that they do attempt to exert agency surrounding their reproductive health, by exercising their right as women, to have children or not. Findings from both the qualitative systematic review and the qualitative research indicate that women who use drugs and experience pregnancy or have children are fearful of child removal which impacts on their access to care.

Discussion

Women are cognisant that access to care will increase their visibility and often results in intensive monitoring and surveillance from health and social care agencies. For this reason, and in order to pursue anonymity, women and mothers who use drugs avoid treatment and care and instead

implement discursive and covert strategies to manage their health and wellbeing. Punitive and adversarial approaches (including drug testing) are a barrier to women's access to care. Trauma informed care across all health and social care services should be implemented to support them better. Women who use drugs have limited autonomy and agency over their reproductive health and wellbeing, which further marginalises and compounds their ability to meet societal expectations. Reproductive health and wellbeing interventions designed specifically for women who use drugs may improve their autonomy and access to care. These interventions should include family planning, informing women of the impact of drug use on their fertility and the promotion of healthy intimate partner relationships. Further research is necessary to support the implementation of these interventions and should be undertaken alongside women who use drugs so they can inform the development of interventions that will best meet their needs.

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Dedication

This thesis is dedicated to my sister Elizabeth (Libby) Mary Dean. Your strength, determination and support has inspired and encouraged me to keep going. The loss of your baby Amelia Rose in 2020 and your resilience and determination to keep her memory alive is a testament to the person you are. I am very proud to be your sister (and Irish twin).

List of abbreviations

ARC- Applied Research Council

ACMD- Advisory Council for the Misuse of Drugs

HRA- Health Research Authority

IRAS- Integrated Research Application System

NIHR- National Institute for Health and Care Research

NICE- National Institute for Health and Care Excellence

PHE- Public Health England

QSR- Qualitative Systematic Review

QR- Qualitative Research

UK- United Kingdom

USA- United States of America

WHO-World Health Organisation

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Chapter 1: Background

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1.1 Chapter introduction

This thesis explores the reproductive health and social care needs of women who use drugs, including pregnancy and motherhood. This chapter presents the background to and the justification for the research presented in this thesis. The chapter begins by describing the current use of drugs among women, and their access to treatment. The next section explores previous research into the reproductive health of women who use drugs including contraceptive care, family planning and contemporary family planning interventions for women who use drugs. Pregnancy and motherhood is then presented, after which, barriers to care and gaps in research is then discussed. The chapter concludes with an overview of the thesis.

1.2 Women who use drugs

Drug misuse is a complex and major public health concern which impacts the individuals who use them, their families, friends, and the surrounding communities. Drug misuse refers to a psychoactive drug or substance that when taken or administered into one's system, affect mental processes of perception, consciousness, cognition or mood and emotions (UNODC, 1971). Substances that are misused or abused can be categorized onto two forms: illicit and legal substances (UNODC, 1971). Illicit drugs are commonly understood to be those which are unlawful to use, possess or distribute for example: cannabis[2], cocaine, heroin, amphetamines, ecstasy and ketamine. This also includes the diversion of prescribed medication. Legal substances include alcohol and nicotine alongside prescribed medications such as cough medicine, pain relief. Both illicit and legal drugs may have a significant effect on the psychological processes such as thinking, perception and emotion and misuse refers to those deliberately taken to produce an altered state of consciousness (e.g. hallucinogens, opioids, inhalants, cannabis and therapeutic agents

[1] Some sections included in this chapter have previously been published in my book chapter 'Smiles, C., McGovern, R., Kaner, E., Rankin, J. (2022). Drug and Alcohol Use in Pregnancy and Early Parenthood. In: Borg Xuereb, R., Jomeen, J. (eds) Perspectives on Midwifery and Parenthood. Springer, Cham. https://doi.org/10.1007/978-3-031-17285-4_9'

[2] The legality of cannabis has changed across the Western world in the last decade with some countries decriminalising the possession of cannabis for personal possession personal possession others legalising its use for recreational purposes. Cannabis is still a regulated substance in the UK.

designed to ameliorate a mental condition). The health risks of illicit drug use increase with frequency, quantity of use and route of administration (UNODC, 2016). Often drug use is referred to under the framework abuse (recreational drug use) and dependence (problematic or dependency), both commonly referred to as substance use disorder.

In 2021, United Nations Department of Crime (UNDOC) estimated that over 296 million people worldwide were using drugs, with 1 in 17 people aged between 15-64 having used drugs in the last 12 months (UNODC, 2021). In 2019, around 2.7million adults used an illicit drug in the UK, with 314,000 reporting heroin and/or crack cocaine use (PHE, 2019; PHE 2020). Around 270 thousand adults were in contact with drug and alcohol treatment services within the same year (PHE, 2019; PHE 2020). Women represent just under one third of all patients accessing drug treatment in the UK, averaging 27.5% of the overall treatment population (PHE, 2019). Problematic drug use is cited by 41% of women on arrival at prison, often as a consequence of funding and maintaining their drug use (PHE, 2019). This indicates that 90% of people who use drugs in the UK, do so without any formal interventions, placing themselves at risk of acute health and social harm.

Health inequality and drug use are inextricably linked, with the most deprived local authorities having the highest prevalence of problematic substance use (PHE, 2020). However, the structure of this relationship is complex and multifaceted. Gender, socioeconomic deprivation, family history of addiction, poor mental health, unemployment and homelessness are considered to be the main factors that contribute to deprivation (Galea *et al.*, 2004). These factors and their interplay are recognised as the biggest challenges faced by individuals with problematic substance use, making this large population one of the most vulnerable in modern society.

Women who use drugs are often confronted with even more barriers to health and social care (both statutory and voluntary sector services) than their male counterparts. Research indicates that exacerbating circumstances such as homelessness, heavy drug use, caring responsibilities, and transient lifestyle, limited some women's use of services, and pregnant women have a higher

dropout rate than other individuals in treatment (Hathazi *et al.*, 2009; Milligan *et al.*, 2011). Low self-regard, traumatic experiences, drug use and its associated implications due to illicit status appear as mutually reinforcing factors that dominate the daily lives of women who use drugs (Edelman *et al.*, 2013). Women who use drugs face greater stigmatisation then men and are judged more harshly (especially if they are mothers), including for their crimes (Lee & Boeri, 2017). A 2011 study by Radcliffe, researching pregnant and postpartum women in South East England hospitals, found that more than half of the women who participated (n=24), had funded their drug use by shop lifting, sex work or pick pocketing and had received custodial sentences, probation or drug treatment rehabilitation orders. This highlights the adverse, difficult and often complex lives that women who use drugs must manage and attend to.

For this thesis, the definition of drug use will include any illicit substance use or the misuse of prescription drug use that has the potential to cause physical, emotional or psychological harm to the individual consuming it. These definitions will be used across this thesis and where applicable, distinctions will be made in accordance with type of drug use, variation in legislation for cannabis regulation for qualitative systematic review.

1.3 Reproductive health among women who use drugs

The World Health Organisation (WHO) define reproductive health and healthcare as:

> *"…a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity, in all matters relating to the reproductive system and to its functions and processes. Reproductive health implies that people are able to have a satisfying and safe sex life and that they have the capability to reproduce and the freedom to decide if, when and how often to do so.*
>
> *Reproductive healthcare is defined as the constellation of methods, techniques and services that contribute to reproductive health and well-being by preventing and solving reproductive health problems. It also includes sexual health, the purpose of which is the enhancement of life and personal relations,*

and not merely counselling and care related to reproduction and sexually transmitted diseases."

Women's reproductive health begins from puberty to menopause and beyond, with changing needs throughout their life course. Reproductive health extends beyond pregnancy and childbirth and shapes not only the wellbeing of women, but also their families, communities and wider society (PHE, 2021). According to Mann and Stephenson (2018), a three-pronged approach to reproductive health consists of: 1) pregnancy related (contraception, preconception, abortion, unintended pregnancy, pregnancy planning; 2) sexual health related (sexual pleasure, violence and coercion, FGM, prevention of infective reproductive sequelae e.g. infertility and cervical cancer); 3) non- pregnancy related (period poverty, menstrual difficulties, menopause, incontinence, inequalities). The World Health Organisation definitions and Mann and Stephenson (2018) three-pronged approach of reproductive health and wellbeing will be used to guide the interpretation of both the qualitative systematic review findings and empirical research outlined in this thesis.

Around one third of women who use drugs are of childbearing age (WHO, 2002; 2006). Women who use illicit drugs often have poor reproductive health, poor contraception use and general health impairment (Black *et al.*, 2012). Women who use drugs are considered to be at high risk of contracting sexually transmitted infections (STIs) and at an increased risk of sexual violence and trauma (Vanthuyne, *et al.*, 2016). A 2002 study by Tyndall *et al.*, researching risky sexual behaviours of injecting drug users with Human Immunodeficiency Virus (HIV), found that women who participated in the study had over 100 lifetime partners and were more likely to have contracted a Sexually Transmitted Disease (STD) than men who use drugs.

People who use drugs often have lower health literacy due to poor physical and mental health and deprivation (Rolova et al, 2021). According to Gollub *et al.*, (2013) women who use drugs and experience vulnerability and lack 'basic body knowledge' in relation to their reproductive and sexual health. The authors reported that women who participated in their study had a poor understanding of contraception, anatomy, HIV/STI transmission and cancer screening, which

placed them at risk of adverse health outcomes (Gollub *et al.*, 2013). Gollub et al., (2013) postulate that there is an education exigency among women who use drugs regarding their basic body knowledge and their findings encouraged the use of female-initiated contraceptive methods, like female condoms, reporting these could give women autonomy over their reproductive health and decrease the risk of STI/STD and unwanted pregnancies. Although improving health literacy and educating women about their sexual and reproductive health is important, it is unlikely this will improve outcomes without consideration of the wider health determinants of this population and the availability of, and their access to, sexual and reproductive health services (Rolova *et al.*, 2021).

According to Public Health England, all women should have the opportunity to enjoy their lives without being affected by reproductive symptoms or lack of choice, however, we also need to do better to ensure the needs of all women, this includes extending the universal reach of service provision for reproductive health (PHE, 2021). This should be informed by a strategic and comprehensive understanding of the health and social factors that might make reproductive issues more onerous for some women than others (PHE, 2021).

1.3.1 Fertility

Illicit drug and alcohol use can impact on women's fertility and ovulation (NHS, 2020). Many studies have found that women who use drugs have irregular periods or none at all, with many believing they are infertile (Olsen *et al.*, 2014; Lewis *et al.*, 1995; Black *et al.*, 2011). Other research suggests that women who use drugs can have a misperception of their fertility and because of this, they use contraception sporadically (Oliva *et al.*, 1999). Having irregular menstruations or believing their substance use (including prescribed methadone) makes them incapable of conceiving, places women who are sexually active and who use drugs at the highest risk of unplanned pregnancy, as well as STIs/STDs (Olsen *et al.*, 2014: Lewis *et al.*, 1995). This misperception of fertility underscores the urgent need to address the myths that surround fertility for individuals that use drugs.

1.3.2 Contraceptive care

There are many forms of contraceptives available, however, little qualitative research has been undertaken to establish the uptake and attitudes women who use drugs have towards them. Research which has explored this found that the most common method of contraception for women who use drugs is the male condom (Clergue-Duval *et al.*, 2017; Black *et al.*, 2012; Sharma *et al.*, 2017). A 2001 study by Sherman and Latkin, found that partners who live together will be less likely to use condoms consistently compared with partners who do not live together. According to this research, trust and financial interdependence also played a role in condom use, with consistent condom use inversely linked with financial dependency and relationship security (Sherman & Latkin, 2001). Similar research indicates that women who engage in sex work are 80% more likely to use condoms with paying partners/ clients then casual or regular partners (Tyndall *et al.*, 2002). Often men had less favourable attitudes than women toward using condoms; however, maintaining sexual relationships and obtaining drugs were higher priorities for women than protection against HIV or pregnancy (Gutierres & Barr, 2003). These studies demonstrate that while women who use drugs hold the responsibility of pregnancy and childbearing, however, many rely on male contraceptives to manage their fertility and often their sexual and reproductive health is dominated by their partners attitude and preference of contraception.

Research into family planning provision in rural Britain found that women attending contraceptive and counselling services had high rates of drug and alcohol use, and those who used substances daily attended these services more frequently than other patients (Tolland *et al.*, 2003; Hall *et al.*, 2006). A UK survey study (n= 77) researching sexual risk taking and health-seeking behaviours among substance using women, found that 53% of their respondents were sexually active in the four weeks prior to taking part and 66% of those engaged in unprotected sex (Edelman *et al.*, 2014)**.** A similar survey from Australia (n=116), found that although the majority of their participants were not actively planning to get pregnant, over a third reported no contraceptive use (Black *et al.*, 2012). Of the 55% (n=64) of women who used contraceptives to prevent unplanned pregnancy, 37.5% (n=24) used long-acting reversible contraceptives

(LARCs) or had been sterilised (Black *et al.*, 2012). LARCs such as intrauterine devices (IUD), implants and injectables, could give women who use drugs the best chance of avoiding pregnancy with the least maintenance. Gutierres and Barr (2003) advise that dual birth contraceptive methods such as birth control pills for unplanned pregnancy, alongside condom use for disease protections, should be encouraged by practitioners offering sexual and reproductive healthcare, education and advice.

1.3.3 Family planning

It is estimated that 45% of all pregnancies in the UK are unplanned, with one third of births being unwanted, mistimed, and ambivalent (Heil *et al.*, 2011; Nordenfors & Hojer, 2017). Factors strongly associated with unplanned pregnancy include first sexual intercourse before 16 years of age, current smoking, or drug use (other than cannabis) and lower educational attainment (Wellings *et al.*, 2013). There are many risk factors and implications in unplanned pregnancy which include adverse maternal and neonatal risk, particularly in relation to parental substance use (Lui, et al, 2008).

Data from a large study in the US researching maternal opioid treatment enrolment (n=946) found that 9/10 of their sample reported the current pregnancy was unintended (Heil *et al.*, 2011). According to authors, this inferred that percentage of women reporting an unwanted pregnancy in their study was nearly three times higher than in the general population (Heil *et al.*, 2011). Wellings *et al.*,(2013) report that unplanned pregnancy is more prevalent among women who have two or more children or no children, compared to those with one child.

Half of all unplanned pregnancies in the UK end in a termination, however there is no data available that relates specifically to women who use drugs (Finer & Henshaw, 2006; Black *et al.*, 2016). Some research has postulated that while some women who use drugs "plan pregnancies", they also "practice abortion de facto" (Black *et al.*, 2016:30; Sun, 2014; Clergue- Duval *et al.*, 2017: 4). Pregnancy among women who use drugs is often only detected after the first trimester, where the mother feels foetal movement or other physical changes (Boyd, 1999). For women who choose to have an abortion, late identification of pregnancy can impact and limit women's

access to, and the availability of, termination services (Boyd, 1999). Women who choose to have an abortion, particularly where this recurrent, may be less likely to receive prenatal care in a future pregnancy (Coleman et al, 2005).

1.4 Family planning interventions

The Hidden Harm Report, produced by the Advisory Council on the Misuse of Drugs (ACMD) in 2003 (over 20 years ago), recommended the establishment of sexual health services in drug treatment, but over 20 years after this recommendation, it remains unclear as to whether reproductive healthcare is a priority in the commissioning of drug and alcohol services. Research undertaken ten years after ACMD also recommended that all patients in drug and alcohol treatment are screened for sexual risk taking and STI, indicating that this was still a priority yet to be addressed (Edelman, 2013). While there has been research conducted elsewhere on this topic (USA, Australia and France), there was been little focus on sexual and reproductive health for women in drug treatment in the UK (Olsen *et al.*, 2014; Black *et al.*, 2012; Clergue-Duval *et al.*, 2017). Alongside this, within the research in the UK and the ACMD (2003) recommendations, there was a distinct absence or consideration for the exploration of pregnancy risk and reproductive healthcare with women who use drugs.

Clergue-Duval *et al.*, (2017) recommend that during standard care for substance use dependency, contraception and the desire to be a parent should be discussed with patients and they should be empowered to make their own choices. Successful sexual, reproductive health and family planning provision should allow individuals to make educated and informed decisions and "exercise their sexual and reproductive right" (Gehbreyesus & Kanem., 2018:2584). As demonstrated above, it is unclear if this is standard practice in drug and alcohol services in the UK and this requires more research to ascertain the availability, accessibility and engagement women who use drugs have in relation to their reproductive health care. Keen (2001) suggests that for women who use drugs, the optimal time for intervention is at the inception of methadone maintenance programmes.

Outside of treatment settings, interventions to reduce intrauterine drug exposure are under-researched with a wide variation in practice and service provision. At present, there is no best practice model or gold standard approach to care for women who use drugs. There are two dichotomies when it comes to improving outcomes for women who use drugs and experience pregnancy: 'help women avoid alcohol and drugs or help them avoid becoming pregnant' (Grant *et al.*, 2005: 483).

1.4.1. Southwark Pilot

In 2011 in Southwark, London, a pilot study explored the uptake and effectiveness of family planning services in drug treatment (Vanthuyne *et al.*, 2016). Support from the local authority allowed researchers to operate a sexual and reproductive health clinic parallel to a drug and alcohol service and to measure the outcomes. The primary objective of this study was: "the prevention of unplanned pregnancies and the preservation of fertility to help women to have their pregnancies when it was right for them and when they had optimised their chance of a healthy pregnancy with a child that could remain with them" (Vanthuyne, *et al.*, 2016: 153). After establishing the clinic, they incentivised attendance for STI/ blood borne virus (BBV) screening, cervical screening and LARC insertion such as intrauterine devices (IUD) (Vanthuyne *et al.*, 2016). Seventy seven percent (n=108) of patients attending the clinic said that contraceptive care was relevant to them and 71% (n=80) wanted services to be available in treatment centres (Vanthuyne, *et al.*, 2016). The pilot was a deemed a "huge success" and evidenced the effectiveness of integrated sexual and reproductive healthcare provision in drug treatment, however, currently, this is only available within the 'Healthy Young Peoples' service (up to the age of 25) and not for all women who use drugs (Southwark., 2021).

1.4.2. Pause

Pause, a UK based charity, offer an intensive programme of support for women who have been involved in repetitive care proceedings, many of whom have complex backgrounds, including drug and alcohol dependency, domestic abuse and involvement with the criminal justice system. When engaging with *Pause,* women are required to take the most effective form of contraceptive appropriate to them in order to take a break from pregnancy. An evaluation of *Pause* by McCracken *et al.*, (2017) found that of the 108 women who completed their 'Client Monitoring Form' section on

"children", a total of 368 children were removed from the care of their mothers prior to engagement. Almost 50% of the women who took part in this evaluation were aged between 24-34 years (McCracken *et al.*, 2017). This highlights the importance of psychosocial intervention and preconception care for vulnerable populations, particularly women who use drugs and alcohol. Although the benefits of contraceptive services in drug treatment centres are clear, its unknown whether they are routinely offered and "work is still needed to determine an array of acceptable and effective models." (Black *et al.*, 2016: 32).

1.4.3. Project Prevention

Since the 1980s, the USA has increased criminal sanctions for "deviant" mothers under the guise of the 'foetal protectionism movement' (Fentimen, 2009; Stone., 2015). The rationale of the programme is that people who use alcohol and other drugs are both incapable of making appropriate decisions about their fertility and caring for children. They describe themselves as global social enterprise based in the US called *Project Prevention* aims to "…reduce the burden of this social problem on taxpayers, trim down social worker caseloads, and alleviate from our clients the burden of having children that will potentially be taken away" (Project Prevention., 2011). The distinction between *Pause* and *Project Prevention* is that the latter offer sterilisation for people who use drugs incentivised by a cash payment (Project Prevention., 2011). The British Medical Association rejected proposals to financially incentivise sterilisation to drug users in the UK, however, Project Prevention do offer contingency management in the form of cash payments in return for the use of long-term birth control (Project Prevention., 2011). On this premise, *Project Prevention* offers reproductive control to people who use drugs, however, this is without the necessary consideration for their wider health, social and emotional needs (Olsen *et al.*, 2014). Academics have expressed concern that that offering incredibly vulnerable individuals' cash in exchange for their fertility is unethical, stigmatising and harmful (Stone., 2015; Olsen *et al.*, 2011). One review of *Project Prevention* by Olsen *et al.*, (2011) evidenced that women who use drugs do not need to be paid to limit or end their fertility and demonstrated that women who inject drugs are capable of organising permanent, long-acting and reversible contraception on their own accord. Women who took part in their study valued motherhood and wanted to retain care of their children (Olsen *et al.*, 2011). It has been suggested that programmes w

hich aim to reduce the barriers women who use drugs face to achieve good reproductive healthcare would benefit this population more than those that promote sterilisation (Olsen *et al.*, 2011; Stone., 2015).

All three projects (Southwark Pilot, *Pause, Project Prevention*) have different approaches and varying interventions and outcomes, but all have the objective of reducing drug and alcohol exposed births. Models which facilitate access to appropriate specialist support and encourage early and preventative interventions, including education, choice over contraceptive method and family planning, can provide women who use drugs with the ability to make informed choices over their reproductive health.

1.5 Pregnancy and motherhood

1.5.1 Pregnancy

In the UK, it is estimated that women who access treatment for drug and alcohol use will average 3.2 episodes of pregnancy (Edelman *et al.*, 2014). A longitudinal study by Hathazi *et al.*, (2009) researching pregnancy and sexual heath among women who were homeless street injecting drug users in the USA, found that pregnancy was a fairly common occurrence. The majority of women who experienced pregnancy also reported sexual trauma such as sexual abuse during childhood, sexual exploitation, sexual assault and rape, including gang rape resulting in their current pregnancy (Hathazi *et al.*, 2009). Among their research cohort (n=41), there were a total of 14 pregnancy events, eight births, four miscarriages, one termination and one current pregnancy (Hathazi *et al.*, 2009). Of the eight women who gave birth, five had care of their children, while the other three had relinquished the care of their children to state authorities or family members (Hathazi *et al.*, 2009). Interestingly, the most common outcome of pregnancy for women was birth, whereas men who participated in the study reported termination of pregnancy (Hathazi *et al.*, 2009). The study suggests that there was poor reproductive healthcare access among homeless drug using women prior to pregnancy, however, some women reported that during their pregnancy they accessed a range of antenatal and medical services (Hathazi *et al.*, 2009). It was difficult to ascertain why women chose to actively engage with women's healthcare providers during pregnancy and if this continued post-partum (Hathazi *et al.*, 2009). Although

precarious to translate into a UK context due to polarising healthcare systems, a meta-analysis by Milligan *et al.*, (2011) supported the hypothesis that women who participated in integrated treatment programmes had better birth outcomes: including infants with higher birth weights, larger head circumferences, fewer birth complications, and fewer positive infant toxicology screens.

The 2010 NICE guidelines for pregnancy care reflects on social factors, including a model for service provision for pregnant women with complex social factors. Within these guidelines, there are specific NICE guidelines for women who use drugs (1.2) and stipulate that women who use drugs "…need supportive and coordinated care during pregnancy" (NICE, 2010). Specific reference is given on practice (1.21) and how they can best support women who use drugs. This includes the integration of care and the need to ensure that the attitudes of professionals does not prevent women who use drugs from attending services. The guidelines also reflect on the fears women have in relation to children's social care and that this can be addressed by providing information which is tailored to their needs. This includes that pregnant women who use drugs may have feelings of guilt and the potential effects drug use may have on their babies.

Pregnancy is commonly referred to as a "unique opportunity" or a "window of opportunity" for intervention and change (Black *et al.*, 2012; Milligan *et al.*, 2011; Chou *et al.*, 2018). Pregnancy among women who use drugs is often used as an opportunity to stabilise or reduce drug use and address other complex issues such as trauma, housing and mental health. Drug and alcohol services often encourage women to utilise this "unique opportunity" by connecting them with psychosocial and clinical intervention and peer support networks, to help them maintain recovery from substance use. This engagement with health and social care services relies on the early detection of pregnancy, women's willingness to engage with support and the service provision and support available to them (Chou *et al.*, 2018).

Substance-exposed pregnancies and delayed antenatal care can cause physical and psychological impairments for both mother and child. Antenatal care is a key factor in determinants of birth

outcomes, such as maternal nutrition and physical health, indicating integrated services improve the health of the mother and baby (Milligan *et al.*, 2011; Hall *et al.*, 2006). The National Institute for Health and Care Excellence (NICE) guidelines recommend that women be offered at least four antenatal care appointments during pregnancy (NICE., 2008). Late identification of pregnancy impacts on antenatal care, meaning some women may not receive this recommended level of care.

1.5.2 Motherhood

Research indicates that many women who use drugs value motherhood (Olsen *et al.*, 2011; Lewis *et al.*, 1995). A study by Lewis *et al.*, which explored illicit drug users' experience of pregnancy, found that women were "resigned, happy or even excited about the prospect of having a baby" and all of the women involved in their study intended to keep their child (Lewis *et al.*, 1995: 223). A study by Holt & French (2019) found that all the women who participated in their research wanted to become mothers and all of the women reported that they loved their children, and all felt they had a maternal nature. Women whose children were no longer in their care reported that the loss of their children facilitated higher drug use and a sense of a loss of purpose (Holt & French, 2019; Hathazi *et al.*, 2009). Pregnancy and motherhood often place women who use drugs in an arduous position, often faced with the grave ultimatum of keeping their children or continue using drugs.

Mothers who use drugs and alcohol typically experience shame and stigma having "…been constructed as deviant and dangerous" (Holt & French 2019: 297). To avoid the stigmatised figure of "drug addict" many parents attempt to manage their identity, often creating and managing a lifestyle aimed at avoiding detection as drug users, and juggle parental responsibilities in parallel to this (Radcliffe, 2011; Klee, 1998). It has been suggested that in society, "… women are generally held differentially responsible for the outcome of their children's health and wellbeing in a process through which mothers are to blame for their own circumstances, be they the breakdown of relationships, or poverty" (Radcliffe, 2011: 935). Women who use drugs often fall short of what is considered "good motherhood" and regularly face "serious moral disapprobation" (Broadhurst et. al., 2013:295). Policy and practice partners and indeed the wider public, focus on the failings of women who use drugs to prevent pregnancy, to stop their drug

use for the sake of their (unborn) child/ children and the irresponsibility of continuing to use substances that may harm them (Broadhurst *et al.*, 2013; 2020; Lee & Boeri, 2017; ACMD, 2003). This agenda continues to generate narratives of stigma and shame, reinforces the agenda that women who use drugs are undeserving of motherhood and discounts the love and care many women who use drugs have towards their children.

1.6 Vulnerable families

Women who use drugs and go on to have children often experience vulnerabilities, as do their children. In 2018, 46,109 children in the UK were recorded as having a parent in substance use treatment (GOV.UK, 2019). Eight percent of those children were on a child protection plan and five percent were recorded as "looked after" children who were placed in local authority care (GOV.UK, 2019). Women who have multiple children and engage with substance use services have been referred to as "prolific parents", often resulting in state intervention to safeguard the child/children and considered to be at risk of "rapid repeat pregnancy" within the first three years (Bedston et al, 2019:10; Broadhurst *et al.*, 2015: 2252-2254).

A recent study undertaken in Scotland, found that mothers were six times more likely to experience child removal then men, and women who were younger, with drug and mental health issues were at the highest risk of child removal (Russell *et al.*, 2022). Mothers are far more likely to re-partner and give birth to a new child, placing them at risk of repeat care proceedings (Bedston *et al.*, 2019). Research suggests that the family justice system "recycles" a sizeable percentage of women through repeat episodes of a care order (as defined by section 31 of the Children Act) placing a child in the care of a designated local authority (Bedston *et al.*, 2019; Broadhurst *et al.*, 2015; McCracken *et al.*, 2017). One in every four of these women are likely to reappear at subsequent child proceedings within seven years, whereby there is a tendency to intervene very early in infant life if there is a history of proceedings (Broadhurst *et al.*, 2015). Despite the prevalence of repeat care proceedings, and what appears for some women to be a revolving door, more research is necessary to understand the lived experience of the mothers whose children have been removed, the impact this has had on their identity, subsequent relationships and reproductive choices (Broadhurst & Mason, 2013).

There is little support for women whose children are removed from their care, with no mandates via the local authority or the courts to support women's rehabilitation (Broadhurst *et al.*, 2015; 2020). The grief, stigma and impact on housing, employment and welfare benefits associated with removal of children have repercussions on their life trajectories, but also, the likelihood of caring for any children they may have subsequent to proceedings (Broadhurst & Mason, 2020).

Most of the parents involved in child protection services and care proceedings have experienced various forms of disadvantage in their own childhood (Broadhurst & Mason, 2020). Many drug using parents have been exposed to acute childhood trauma and poor parenting themselves, meaning they may lack good models for parenting their own children (Keen., 2001). Parents perception of risk, children's capacity and the psychoactive effect of drugs could jeopardise children's health and wellbeing (Klee., 1998). Parental drug use often limits their ability to care for children, it also increases the likelihood that their own children will use drugs and these children are likely to become young carers (HM Government, 2017; McGovern et al, 2018). In contrast to this, Tolland *et al.*, postulate that there is an "inaccurate and non-established view that substance misusing parents are lacking in parenting skills" (Tolland et al, 2003: 201). Although there is conjecture about the parental capacity of substance using parents, it is clear that the impact to each new generation of 'exposed and affected children' is profound (Grant *et al.*, 2005: 486).

1.7 Barriers to care

The most discernible barrier to reproductive health and social care for women who use drugs are stigma and shame. Women who use drugs and have children are often resistant to engage in treatment due to shame, denial and family responsibilities (Jackson and Shannon, 2012). A meta-summary by Renberger *et al.*, (2020) found that pregnant and postpartum women who use drugs and who engaged with healthcare professionals found that encounters were frequently perceived as adverse, unhelpful and detrimental to their health or wellbeing and were difficult with often contentious interactions. Vulnerable birth mothers, including those who use substances, reported they were poorly understood by practitioners which compounded their

sense of isolation and despair (Broadhurst & Mason; 2013). This in conjunction with perceived judgemental attitudes, was the single biggest "…deterrent for parents seeking help" (Klee, 1998:447). Additional barriers to care for substance using women included: misperception of fertility, intimate partner violence (IPV) with reproductive coercion, fear of losing custody of children, and denial or embarrassment regarding their substance use (Black *et al.*, 2016).

Studies into practitioners' attitudes to reproductive health of women who attend substance use treatment services, suggest that their beliefs could be a significant barrier to addressing reproductive health with women who use drugs (Black *et al.*, 2016; He *et al.*, 2014). A study by Klee (1998:439) found that some health care professionals and social services did stereotype and held judgemental views of drug using women referring to them as: 'selfish and uncaring'; 'irresponsible'; 'distracted'; 'neglectful'; 'intolerant'; 'irritable and aggressive'; 'no-child centred activity'; 'puts drugs before child'. This language not only validates women's "perceived" experience of judgement and bias, but it also evidences the systemic prejudice some women who use drugs experience when engaging with healthcare professionals. A study by He *et al.*, (2014), who interviewed drug and alcohol practitioners found they were less likely to believe that parents who use drugs could provide effective parenting. Practitioners involved in the study were also more likely to believe that abstinence was a criterion for reunification where the child had been taken into care and more likely to agree that parents should receive jail time as a consequence for noncompliance with a family court order (He et al, 2014). Cook *et al.*, (2010), stated that healthcare practitioners who treat their patients through these bias stereotypes are not contributing to "…their mental or social wellbeing, or therefore their health". The attitudes and bias perceptions some healthcare workers have towards women who use drugs is a legitimate barrier to why women may not access their service, it is also likely to contribute to high STI and unintended pregnancy, increasing their risk and vulnerability even further.

1.8 Gaps in existing guidelines and research

Previous research has postulated that drug and alcohol treatment failed to meet the sexual and reproductive health needs of female patients, because they were designed for men and that addiction care needed to consider the life course of women, particularly when they transition to parenthood (Clergue-Duval *et al.*, 2017; Grant *et al.*, 2005; Sun *et al.*, 2004). Grant *et al.*, (2005)

recommended that treatment designed to support the needs of women who used drugs would be an attributable factor for successful outcomes. Sixteen goals by 2030 for the UK Faculty for Reproductive and Sexual Health "Hatfield Vision" aim to address inequalities for reproductive healthcare with recommendations for specific populations (FRSH, 2024). However, within this manifesto, guidelines relating to women who use drugs are non-existent. While Public Health England have acknowledged that more needs to be done to destigmatise reproductive health and social care and NICE guidelines supported the coordination of care for women who use drugs during pregnancy, a more joined up approach from all agencies is necessary to prioritise and address the health and social care inequalities of women who use drugs. As previous research (outlined above) has demonstrated, shame and judgement are inherent barriers to care and while gender specific services may benefit some women and improve their engagement with services, more research is necessary to understand the views women who use drugs have towards women only services and if this would be helpful to removing barriers to care. Acknowledging the challenges health and social care inequalities pose alongside the incorporation of how stigma and shame can impact upon access to care within policy and practice guidelines may begin to address the unmet need presented in this chapter of women who use drugs

The most frequent recommendation from studies researching women of childbearing age who use drugs, is that a more integrative approach to sexual and reproductive health and substance use treatment is necessary (Black *et al.*, 2011; Robinowitz *et al.*, 2016; Clergue- Duval *et al.*, 2017; Terplan *et al.*, 2015; Keen, 20012; Catalao *et al.*, 2019 Tolland *et al.*, 2003). Stone (2015), proposed that the most effective way to improve service provision for women who use drugs was to incorporate women's voices into shaping the care and treatment they receive. Studies which explored participants views on an integrated sexual and reproductive healthcare and substance use treatment found that female clients are open to using contraception and receiving family planning education and intervention at the same location they receive drug and treatment (Robinowitz *et al.*, 2016; Vanthuyne *et al.*, 2016). While the combined results from these studies is relatively small, therefore with low generalisability, it does suggest that more research is necessary to determine effective and appropriate models of care for this population (Black *et al.*, 2016).

A systematic review of literature by Terplan *et al.*, (2015:30) into contraceptive use and method choice among substance using women, concluded that 'providing family planning services, including promotion of more effective methods of contraception as part of the drug and alcohol treatment offer, has the potential to improve reproductive health'. They also surmised that providing family planning services may also help to address unintended pregnancy in this vulnerable population (Terplan *et al.*, 2015). As evidenced in the Southwark Pilot, this has the potential to improve access to sexual and reproductive care however, we must caveat this with the fact that not all women who use drugs (particularly mothers), access drug and alcohol treatment services, meaning their needs would continue to be overlooked.

Cergue-Duval *et al.* (2017), recommended that during standard care for drug and alcohol dependency, contraception and desire to be a parent should be discussed and patients empowered to make their own choices and should aim to help women plan pregnancies though the use of well-suited and effective contraceptive methods (Finer & Henshaw, 2006). Offering targeted and supportive preconception care to this population would also allow for health and social risk factors to be addressed before there is explicit intention to conceive (Catalao *et al.*, 2019). The results of a meta-analysis found that integrated programmes for women with substance use issues and their children are associated with significant reduction in substance use (Milligan *et al.*, 2010). While integrating services is said to have positive outcomes, these outcomes presented are for those engaging with services, meaning those who avoid care, usually because of fear and stigma are further marginalised. Introducing the concept of family planning to women who use drugs may give women the knowledge and ability to plan pregnancies at a time that is best for them and may be a more effective and inclusive approach to improving outcomes for women and their families, however, more research is necessary to ascertain if this is an appropriate approach for women who use drugs.

Reproductive healthcare, contraceptive availability and family planning are integral to the health and social care outcomes for women who use drugs. The ability to choose whether and when to bear children is a fundamental aspect of reproductive health but the unmet reproductive

healthcare needs of women who use drugs is unambiguous (Finer & Henshaw, 2006). The real challenge for this population is to ensure that health and social care provision is accessible without the barriers or constraints of stigma and shame. More research is necessary to determine how current barriers to care can be addressed before the integration of health and social care provision or gender specific services are prioritised as the solution to contemporary access to care. Women who use drugs have the same reproductive health rights as the rest of the population and must be given the agency and autonomy to exercise these rights at a time that is best for them.

1.9 Aim and Objectives

The aim of this study was to explore and understand the reproductive health and social care needs of women who use drugs. The study aimed to address the following four objectives:

1. To understand the lived experience of pregnancy among women who use illicit drugs;
2. To explore the perspectives, attitudes and understanding women who use illicit drugs have regarding their reproductive health and sexual wellbeing;
3. To explore the perceptions women who use illicit drugs have of motherhood;
4. To understand service providers attitudes and understanding of reproductive health and social care needs of women who use drugs.

1.10 Structure of thesis

This thesis includes seven chapters consisting of two studies: a qualitative systematic review and an empirical qualitative study. This opening chapter gives context to contemporary literature and provides an understanding and justification for the research included in this thesis. An overview of subsequent chapters can be found below:

Chapter 2 outlines the theoretical and conceptual framework adopted throughout this thesis. Within this chapter, there is a focus on the constructs and rhetoric regarding reproductive agency, pregnancy and motherhood and an exploration of surveillance and governance theory and its application in practice. The chapter concludes with reflexive account of my own family history and lived experience, which have influenced and shaped my approach to this research.

Chapter 3 demonstrates the methodology and methods undertaken for the qualitative systematic review. The aim of this systematic review was to synthesise the findings of all existing published qualitative literature which explored the lived experience of pregnancy among women who use illicit drugs. Within this chapter, and in the interest of transparency required in systematic reviews, a comprehensive and methodical outline of methods undertaken is outlined.

Chapter 4 presents the findings from qualitative systematic literature review. Findings are presented thematically, synthesising all findings from included studies which related to the pregnancy experiences of women who use illicit drugs.

Chapter 5 lays out the methodological approach and methods used to undertake empirical qualitative research which explored the reproductive health and social care needs of women who use drugs.

Chapter 6 presents the findings from qualitative interviews with women who have lived/living experience of using drugs and professionals who support them. Findings are explored thematically, and illustrative quotes are incorporated throughout.

Chapter 7 draws on the findings from both studies to discuss the implications of this research, including an exploration of the strengths and limitations of this work. The thesis concludes with implications for policy and practice and recommendations for improving care for women who use drugs.

Chapter 2: Theoretical, Conceptual and Philosophical approach

2.1 Chapter introduction

The aim of this chapter is to explore and outline the theoretical and philosophical framework which underpins this research. According to Grix (2002:177) exploring theoretical and philosophical approaches is integral as "all research starts from how a person views the world". Examining and critically engaging with both theory and conceptual arguments in the context of this research, offers the readers an insight into the positionality embedded throughout this thesis. The chapter begins with an exploration of reproductive agency and autonomy under the notion of choice rhetoric and expectations of women. The next section of this chapter outlines the intersectionality between social desirability, performativity, and the presentation of self as a response to societal expectations. Section three of this chapter explores the philosophical and theoretical approaches to governance and surveillance, followed by a critical reflection on the Hidden Harm report (ACMD, 2003), detailing how women and their families are represented within it, and how this perpetuates and reinforces the theoretical and conceptual epistemologies outlined in this chapter. I conclude the chapter with a section on reflexivity and my own positionality and lived experiences when researching women's reproductive health.

2.2 Reproductive agency, pregnancy and motherhood

For over a century, social expectations of women's work and family roles, have been rationalised by the biological fact that women can bear children (Weber, 1998: 19). Women's reproductive agency and autonomy is set within the boundaries of childlessness, infertility, pregnancy, childbirth and menopause (Murtagh & Hepworth, 2003; Woollett & Boyle, 2000). This is alongside other intersectional factors such as women's relationships with their families, partners and employment (Woollett & Boyle, 2000).

Petchesky (1984:685) introduced the 'right to choose' discourse- the assumption that women make their own reproductive choices and act to achieve them- however, this hypothesis did not consider societal conditions, access to care and their ability to exercise agency and autonomy (Ramazanoglu & Howard, 2002). The "choice rhetoric" arose seemingly as a compromise to satisfy the inherent idea that the woman is a "free agent" who exercises her rational capacity to make an autonomous decision- as long as that decision is one which manages the risks of

pregnancy and safeguards the health of the foetus (Haakar, 2021: 5). Here, the "choice rhetoric" presents a paradoxical version of agency. In this context, women are given "freedom" to exercise agency, however, this is not without explicit conditions. Through their engagement with health and social care services women's rights and responsibilities are "contractualized" (Rose,1997:165). Some of these conditions and 'contractual obligations' include meeting the expectations of statutory and health and social care agencies, consenting to interventions and demonstrating engagement and progress to them and others. Foucault (1975) presents this as "subjective agency", whereby a person's freedom is subject to social implications. Social implications include, social exclusion, or becoming a social pariah. For women, "… social exclusion remains a determining factor of women's access to healthcare and therefore the reproductive "choices" that are available to them" (Hakaar, 2021: 6). Pollitt (1998) further argues that no government or healthcare service offers the support needed to make it possible for women to abide by this extensive (unwritten) list of societal expectations, citing examples related to this thesis, such as, drug treatment programmes rejecting pregnant women who use drugs.

2.2.1 Pregnancy: medicalisation and responsibilization

Pregnant bodies are ambiguous in their blurring of boundaries between self and other (Lupton, 2012). Pregnancy produces a polarised response whereby women have an opportunity to negotiate more power. There are two aspects to the power of the pregnant body: the first, is through the medicalisation of pregnancy and the second is 'responsibilization' of women as foetal vessels (Ruhl, 1999). Both the medicalisation and 'responsibilization' of the pregnant body can only been seen as 'powerful' when women conform to what is prescribed as appropriate and self-sacrificial (Hakaar, 2021). Although both of these aspects of power constructs can be seen as distinct and separate, the reality is, that there is interplay between both that mutually reinforces the other. They are also influenced and impacted by the narrow paths and health systems that are available to women, while also being scrutinised by external agencies (professionals) as well as those closer to home (partners, family and friends).

The maternal body is represented as dangerously permeable, open to medical view and intervention (Lupton, 2012), whereby the pregnant body is constructed as a 'condition' for which

women need to prepare for by taking care of themselves (Young, 1984: 4; Haakar, 2021). Women are expected to access antenatal care, optimise their health and wellbeing through vitamin intake, avoid particular foods and physical activity. In effect this can be viewed through the Foucauldian lens of self-regulation, conforming to the prescribed norms and expectations of pregnancy for women (Foucault, 1975). This self-regulation is weighted in expert knowledge about the impact of the pregnant women's lifestyle upon the future health and wellbeing of her children (Bertin, 1995).

At this time in history in western societies, pregnant women and their foetuses are potent focal points for regulation and control, whereby pregnant women are expected to "create a shield of safety" around the foetus (Lupton, 2012:330). The pregnant woman is expected to exert her ethical responsibility by rationally seeking out expert medical advice on how best to protect the foetus (Lupton, 2012). This includes preventing any "polluting" substance from coming into contact with the foetus. She is also expected to manage or discard any pre-existing conditions to reduce risk and optimise the health of her baby. This discourse of risk, prevention and reduction, and the cooperation of women within this, produces what society views as a 'responsible' pregnant woman (Ruhl, 1999). The 'responsible' pregnant woman fits "well into the unique social, political, and historical contexts in which they live", meaning those deemed 'irresponsible' risk exclusion (Hakaar, 2021:9). Ruhl (1999:97) describes how "the responsibilization of prenatal care simultaneously casts the pregnant woman as an authority and an agent in the care of herself and her foetus" whereas, the 'irresponsible' pregnant woman- those who do not fit neatly into the paradigm of optimising the health and wellbeing of their baby over their own needs- are viewed as risky and dangerous.

The expectation that pregnant women are to avoid risk behaviours to ensure the health and development of their foetus, is often unattainable, particularly for women who use drugs and alcohol and this further compound their access to care and reinforces stigma they experience (Radcliffe *et al.*, 2009; Lupton, 2012). This discourse also underpins the narrative that women/mothers are the most significant risk factor in their children's lives, thus reinforcing the

ideology of ‘responsibilization’ and compelling them to self-monitor and self-regulate during pregnancy (Ruhl, 1999; Lupton, 2012; Flacks, 2023).

2.2.2 Motherhood

The family unit emerged as particularly fundamental to the governance of the population during the 18th century when the problem of children, including their survival and moral development, became a key governing mentality (Foucault, 1991; Flacks, 2019). In the 21st century, children are represented as precious, vulnerable, and requiring constant monitoring and protection (Lupton, 2012). For this reason, and as many commentators within public health discourse have demonstrated, women are positioned as specifically responsible for the health and wellbeing of their children from preconception, pregnancy and through to childhood through careful risk management of their own health practices, regardless of their own health and wellbeing (Rose, 1999; Ruhl, 1999; Lee *et al.*, 2010; Lupton, 2012; Parker & Pause, 2019; Warin *et al.*, 2019). They are also, responsible for producing healthy, responsible, and well-adjusted social citizens (Rose, 1999). In contrast to this, a recent systematic review (Salonon *et al.*, 2023) found that being a father required them to prioritise their wellbeing in the family over their own immediate interests.

Motherhood promotes desistance from anti-social behaviour, whereby, mothering is constructed as responsible for caring, protecting and rearing children. More importantly, 'good’ motherhood is viewed as self-sacrificing, self discipling and morally consummate (Salmon, 2011). Women who use illicit drugs do not fit the prevailing societal hegemonic model of a ‘good mother’ because they are viewed through the cultural ideology that they fail to protect their children by engaging in risky behaviour (Banwell & Bammer, 2006). This could also include their failure to intervene or moderate fathers’ behaviours. Deviations from these expectations often result in punitive actions in the form of stigma, driven by the intent to motivate a change in maternal behaviour. These anxieties coupled with hegemonic notions of good mothering position women who use drugs, and particularly those who use them during pregnancy, as ‘unfit’ or ‘bad’ mothers, posing simultaneous threats to their children, their communities, and the institutions of the State (Gomez 1997, Boyd 1999, Humphries1999, Campbell 2000). Sharpe *et al.*, (2015)

describes this as 'precarious maternal identities' as the State will intervene in 'bad mothering'. Despite women who use drugs often being framed as bad mothers, children may offer a tangible source of meaning for them, and motherhood is often one of the few roles in which women who use drugs and alcohol 'feel recognised' while other avenues for gaining social esteem and personal satisfaction appear vague and tenuous (Sharpe, 2015; Mason *et al.*, 2020).

2.3 Social desirability and presentation of self

Social desirability is the tendency to underreport socially unacceptable attitudes and behaviours and to over report more desirable attributes, often fabricating identities to appease those to whom we are presenting ourselves to (Rose, 1999). According to Paulhus (1984), there are two components to social desirability: 1) impression management, which is the purposeful presentation of self to fit into a social situation or please an audience; 2) self-deception, which may be unconscious, and is based on the motivation to maintain a positive self (Paulhus, 1984). Women often reconcile multiple and conflicting interpretations of social desirability which are rooted in their identities as a woman, mother, wife, and partner whilst also being dependent on one's simultaneous location in the race, class, gender and sexuality hierarchies (Weber, 1998). As outlined above, paradoxical, and conflicting identities are often outward facing and an attempt to manage and mitigate the risk of them being viewed as "bad", but also to avoid the stigma associated with being an undesirable woman, and potentially, mother.

In order to negotiate one's positioning and social desirability, individuals take on the role of "performer" and "audience" to navigate the presentation of self in everyday life. Goffman (1959) postulates that individuals will enact differently to different audiences at different times. This is regarded by Goffman as performativity (Goffman, 1959). Radcliffe (2011) makes the case that this performativity work entails the representation of lived practices as well as the presentation of self. For women who use drugs, the presentation of self is of paramount importance, particularly as they are aware of the surveillance, scrutiny and consequences they face. Women who use drugs employ "impression management" strategies to avoid this (Goffman, 1959). In doing so, they often present two mutually exclusive worlds, one of chaotic drug use and another of ordered family life (Radcliffe, 2011). Neale *et al.*, (2010) have argued, it is in the interests of

drug users and their children (both born and unborn) for there to be symmetry between the performance of their identities and their lived practices (Neale, *et al.*, 2010). According to Neale *et al.*, for individuals who use drugs, symmetry between identities is important, whereby there is a precarious balancing act of presenting an authentic self, alongside a socially acceptable self (Neale *et al.*, 2010). Whilst "poor performances are inevitable, but usually rectifiable", this is more difficult for women who face child removal and the fear and the permanency of this if enforced (Neale *et al.*, 2010:7).

According to Neale *et al.*,(2010) identity is a process which is open to modification. Individuals are dependent on their identity being endorsed and reinforced by professionals and in the context of this research, midwives, nurses, GPs, social workers, and drug workers, all of which have the power either to make the label stick or to endorse new identities (Kunitz, 2008; Valentine & Sporton, 2009). In every new encounter, there is an opportunity for women to be thoughtful, considerate and minimise previous identity damage done and project a more positive self (Neale, 2010). For women who use drugs, reporting their behaviours honestly opens them to societal stigma and into a network of drug treatment and safeguarding procedures, however, if they deny their behaviours, their reputation as dishonest deviants is confirmed (Radcliffe, 2011; Wolf, 2007).

2.4 Governance and Surveillance: philosophical and theoretical understanding

Women who use drugs are under surveillance in almost every aspect of their life, particularly if they are pregnant or parents. The theorisation of surveillance, surveillance techniques and governance began in the 18th century with Jeremy Bentham. Bentham (2010) conceptualised the panopticon as an architectural 'strategy of space' for prison and reform settings. In essence, the panopticon was for optimising surveillance through structural design and architecture, creating an 'all seeing' eye' whereby prison guards held a centralised view of all surrounding corridors, giving them the ability to 'see' all prison cells. Bentham's panopticon created an illusion of constant surveillance whereby prisoners were not constantly watched, but believed they were. This version of the panopticon created the impression that surveillance was intense and all prevailing and was a purposeful and necessary measure to reform deviant individuals. The aim

of Bentham's panopticon was to reform and train prisoners to comply, using surveillance as a tool of compliance. If this could be achieved, all 'deviants' would be reformed, and they could successfully build a utopia. This way of thinking has relevance for other areas of social practice.

Many years later, philosopher and theorist Michel Foucault's seminal work, 'Discipline and Punish' (1975) presented and dissected the structures of hegemonic power, focusing on the surveillance of citizens. For Foucault, akin to Bentham's original concept, hegemonic ideologies reinforce beliefs about what is right and proper, which reflect the dominant groups stance and pervade society (Weber, 1998). In "Discipline and Punish", Foucault (1975) describes the panoptic principle of the unequal distribution of seeing and being seen as a core mechanism by which modern societies provide discipline. Foucault shifted the focus of the panopticon from the goal of governing to the mode of governing. The key differentiation between Bentham's and Foucault's perspective and theorisation of the power of the panopticon was a structural and biopolitical structure. Foucault's 'panoptic' refers to 'seeing everything, everyone, all the time', however, this was extended beyond the walls of prison reform and into wider society as a way to monitor and control citizen's behaviour (Foucault, 2002). Foucault evolved Bentham's ideology of the panopticon and proposed that it was ubiquitous and powerful, a "paradigmatic idea that can be adapted and used in a variety of social spaces and for different purposes" (Galic et al, 2017:11).

In Foucault's philosophical positioning on governance and surveillance, all individuals in society are susceptible to surveillance and therefore, many will self-regulate to conform, thus being viewed as good citizens. However, this is not universal and depends upon "… the way in which the individual establishes his relation to the rule and recognises himself as obliged to put into practice" (Foucault, 1992:27). Foucault (1992) coined the terms 'governmentality' and 'docile bodies' and used' them to describe how power was applied and received by both the ruler and the citizens. Like Bentham, Foucault's panoptic structures function as architectures of power, however, this understanding developed beyond direct power and evolved into the (self-) discipling of watched subjects (Galic et al, 2017). Foucault (1975) hypothesised that through

bureaucratic methods and sequences, docile bodies (self-disciplining or self-regulating) are created and reinforced (Galic *et al.*, 2017). Foucault's theorisation of "docile bodies", premised that individuals are no longer governed as actors or players, but as units of information that can be interpretated and moulded (Foucault, 1991b). Surveillance is central here, because this moulding and re-shaping (reforming) individuals, is only possible because of their visibility.

Haggerty (2006) outlines that a disproportionate level of surveillance is orientated around the underclass, the poor and the marginalised. Foucault's theory of power offers an explanation of how transitory relations of power are the foundation for the emergence of structures of social domination (Bignall, 2008). Weber (1998) further postulates that race, class, gender and sexuality are conceptualised as systems of oppression, however they are never static and fixed, but constantly undergo change as a part of new economic, political and ideological processes, trends and events. In this way, Foucault contributes to critical theories that seek to explain how individuals can be complicit with the forces that repress them (Bignall, 2008).

In the 21st century, the subject of surveillance is being watched with a certain purpose, which can be controlling and disciplining the subject into certain behaviour or a set of norms but also- possibly at the same time- protecting and caring for the subject (Galic *et al.*, 2017; Lyon, 2001; 2002). Foucault and others demonstrated how knowledge and related practices are spread and maintained by "governmental" or "biopolitical" techniques of subjectification, through techniques of governing the self (Baumgarten *et al.*, 2012; Rose, 1999). The family is a key site for social governing which is centred on sexuality and reproduction (Rose, 1999). This is particularly pertinent in the context of pregnancy and motherhood. Under contemporary neoliberal governments, citizens are expected to take responsibility for their own actions and welfare, and for women, this includes taking care of their children. Under these regimes, individuals are expected to be productive and self-regulate (Foucault 1991a,b; 2002; Lupton, 2012). These regimes have evolved beyond government and statutory agencies and now include digital methods of surveillance via social media, whereby we are surveilled by 'followers' (family, friends and strangers) and algorithms which monitor and track our location, likes and follows

(Ruckenstein & Granroth, 2018). This modern surveillance can often be perverse and unknown to digital users (for example, through faceless accounts, from followers who don't interact or though the tracking of content through web browsers). Digital surveillance adds complexity and concern for many, but reinforces and modernises Bentham's panopticonism without the purpose he had intended.

2.5 Surveillance in practice: The Hidden Harm

It's been over 20 years since the publication of the "Hidden Harm: Responding to the Needs of Children of Problem Drug Users" (ACMD, 2003). The report aimed to shine a light on the needs of children whose parents use drugs. The Hidden Harm report delivered a powerful message about the harmful effects of parental drug use on children and the failure of professionals to adequately govern the "problem" (Whittaker, 2020:173). The report incited a number of significant changes in both policy and practice, which included increased monitoring and surveillance of families of people who use drugs. Critically, the Hidden Harm report makes the case for greater child protection intervention in the lives of people who use drugs. Later in 2003, the 'Every Child Matters' (HM Treasury) Green Paper was published, outlining governmental proposals for reform. Within this Green Paper, clear expectations of parents were outlined, which included punitive approaches to intervention in the private sphere of family (HM Treasury, 2003; Gillies, 2005; Whittaker, 2020). These included the disciplining of parents, particularly mothers, who were deemed to be neglecting parental obligations because of their drug use, which in turn, had public consequences (HM Treasury, 2003; Gillies, 2005; Whittaker, 2020). The recommendations from both Hidden Harm Report and the 2003 Green Paper related to the governing of parents and responsibility of professionals to enforce this governing (Flacks, 2019; Whittaker, 2020). Both reports placed obligations on "experts" (professionals), whereby mothers involved in safeguarding of their children needed to be educated by health visitors, doctors and social workers and their skills as a mother needed to be monitored and reported accordingly (Rose, 1999).

The Hidden Harm report disproportionally targeted women and mothers under the guise of failure to care for their children. Whittaker calls this the "splitting of needs" whereby we move

away from family assistance and support and divide the family, where the needs of children are separate and independent from caregivers (Whittaker, 2020:180). Of the 48 recommendations within the Hidden Harm report (ACMD, 2003), nine relate specifically to mothers and none to fathers (Flacks, 2019). Furthermore, two recommendations relate to contraceptive services, both of which are directed as the responsibility of women/ mothers (Flacks, 2019). The Hidden Harm report documents the stigma faced by mothers but further marginalises them by exposing the strategies they employ to minimise drug related harm and safeguard their children's welfare, presenting them as deceitful.

An indirect consequence of the Hidden Harm report is that it has weaponised vulnerability and caring responsibilities and encourages the increase in the surveillance of women who use drugs. It does so divisively, by positioning mothers under the rhetoric of risk and threat to their children and the responsibility of professionals to enact and implement safeguarding measures. Reinforced by the emergence of 'working together to safeguard children' (HM Government, 2018), the responsibility for surveillance is placed upon the many, exposing women who use drugs to greater regulation. The dispersal of surveillance across institutions outside of the state (for e.g. schools, families, within neighbourhoods) has intensified the scrutiny, while valorising adversarial and divisive "support" (Rose, 1999). The Hidden Harm Report infers that the risk and failures of protecting children is beyond women and the family unit and is also the responsibility of statutory and third sector services via safeguarding protocols and procedures. However, this is not about balancing responsibility between mothers and the state, the focus of this was to increase vigilance, and impose intervention and marginalise these women and their children. The legacy of the Hidden Harm report is difficult to present without considerable research, however, it is worth noting that the surveillance of women and mothers has increased and since then, child removal cases have increased threefold nationally, with an increase of 77% in the North East of England (North East ADC, 2021).

The governing of women and mothers perpetuates stereotypes and gendered identities wherein women are considered to be responsible for reproduction and fertility and critically, to rear

children, without considering the role of fathers (Salonen *et al.*, 2023). This was further demonstrated in a recent study by Flacks (2023), which found that women who use drugs and alcohol are described by professionals as inherently vulnerable and due to their 'weakness', they "pose greater threat to their children" (Flacks, 2023: 484). Flacks described how mothers carried risk because of the amount of time they spend with their children, thus they are subject to greater surveillance because of gender-based inequalities of care (Flacks, 2023).

2.6 Reflexivity- considerations and personal exploration

Finlay & Cook (1991) defined the "…reflexive process as a means of analysing how one particular researcher left their imprint on the research findings". Reflexivity within research demands the exploration of the complex relationship between epistemology (the production of knowledge); methodology (the process of knowledge production) and ontology (the involvement and impact of knowledge production) (Wilson *et al.*, 2022). To address the complex relationships described above, researchers must begin first by consciously outlining their positionality. In order to do so, researchers must "examine their own identity to assess the effect of their personal characteristics and perspectives in relation to the study population" (Wilson *et al.*, 2022: 44). Leatherby (2007:109) further contextualises this by stating: "…it is important to acknowledge that our sex, age, skin colour, accent and so on are likely to have an effect on how we are seen by respondents, and this will subsequently affect the data we collect" (Leatherby, 2007: 109).

Throughout my PhD I have been challenged and encouraged by my supervisory team to reflect on my tendency to 'advocate for' the women and my emotional closeness to the research. Although this has evolved over time with the aid of reflexive practice and self-monitoring, I feel it is important to outline my lived experiences and family history which may have impacted on my approach and epistemological understanding of this research. For context, I am a 36-year-old, white, heterosexual female, married with two children (one birth child and one stepchild). I come from a working-class background in Dublin, Ireland. Given the focus of this research is women's health, it is acknowledged that my gender will have had an impact on data collection within this study.

Given my identity as an Irish woman, the infringement and erosion of women's reproductive health and social care rights is all too familiar, as it has had profound impact on the last three generations of women in my family. Ireland has a long and well documented, contentious history in restricting and intervening in women's reproductive choices and access to care. An example of state and church intervention in women's reproductive rights in Ireland is the Magdalene Laundries. In short, Magdalene laundries were workhouses for pregnant, unmarried mothers and women identified as having sex outside of marriage. These women were referred to as "fallen women". Often these women were removed by clergy men and women from their family home and taken to laundries to reform their ways. On "admission" to laundries, women were given new identities, often their head was shaved as a mark of shame, and they were to remain there for an indefinite time. For women who were pregnant, when their baby was born, many were removed from their care and some women never saw their children again. My great aunt was one of those women removed from her family home as a pregnant teenager and placed in a laundry. She subsequently died there in the early 1990s, locked away and institutionalised for a lifetime.

Access to contraception and family planning has been another unequivocal issue in Ireland. Universal access to contraception only became available in 1992. Again, this had impacted directly on women in my family. My grandmother had a chronic heart condition which was exacerbated during pregnancy and childbirth. After having many children consecutively, my grandmother approached the local priest for permission to avail of the contraceptive pill due to the impact on her health. The priest vehemently denied her request. She had a heart attack that day in the church and died a few years later at a young age.

Access to abortion only became legally available to women in Ireland in 2018. Prior to this, abortion was a criminal offence and woman had to either continue with their pregnancy or many would fly to the UK to avail of termination services there. Throughout the referendum campaign I was a pro-choice and openly supported the availability and access to abortion for women in Ireland, believing women had the right to choose what is best for them, but also, they have a

right to safe and legal termination services. These experiences and family history have shaped my awareness and understanding of the importance of women's reproductive health and social care rights and the impact infringement can have.

This research was primarily influenced by women I had met during my time in practice. Prior to this PhD I worked in the drug and alcohol services for many years. I was 'Women's Lead' when working in a London Service. During my time in practice I met and worked with women experiencing very difficult circumstances, such as domestic abuse and violence, severe and complex mental ill health, survival sex and women who had experienced child removal. One woman I met had experienced eleven children removed from her care consecutively. Although not her key worker at the time, I remember when her last child was removed because days earlier her urine sample had tested positive for drugs. I remember her screaming in despair and rage that this had happened again and her opportunity to take care of her child was over. Years later, I recounted that experience to myself and wondered did we as a service ever discuss family planning or contraceptive with her. Regrettably, I do not remember this being a priority with drug and alcohol services while I was in practice.

Throughout this research I have kept a reflexive journal where I reflect on my positionality in research, considering my identity as a researcher consciously challenging any presuppositions I may have about this research and findings. I have also had extensive and abundant conversations with my Expert Advisory Group (EAG), and other women with lived and living experience of drug use. Alongside this, I have also discussed this research and emerging findings with practice, policy, academics and key stakeholders. A reflexive journal and comprehensive discussions supported me to gain "insight and crucial scrutiny of the research process" but also allowed me to reflect on my positionality and presence within the research (Fonow & Cook, 1991; Ramzanoglu & Holland, 2002; Liamputtong, 2019: 11).

These experiences and family history hold great sentiment, but also have shaped my perception, view and ultimately my understanding of the world and the way in which it is constructed. Liamputtong (2019) describes how researchers have an 'emotional closeness' to the research and

reflection on this is often required for authenticity and integrity. Reconciling the experiences of women in my family and my practice experience with those of women involved in this study is both a strength and a limitation. Having the ability to be able to approach participants with empathy increased the depth of exploration within interviews and in turn, the richness of the data. Presenting my background, positionality, and reflections on this gives transparency to readers and according to Gomm (2008:240): "Researchers making themselves accountable to readers are also researchers making themselves accountable to themselves".

2.7 The role of theory in this thesis

Theoretical, conceptual and philosophical approaches to research are important to give context to the operating principles and preconceptions of the research presented (Collins and Stockton, 2018). The theory and positionality outlined within this chapter were used to 'structure, scaffold or frame' the analytical approach to both the qualitative systematic review and interview data in empirical research. Exploring existing knowledge and philosophical understandings of the expectation, surveillance and governance of women and motherhood, alongside my own positionality and epistemological dispositions, guided and informed the interpretation of empirical data, in turn offering a conceptual explanation of findings and emerging themes. Incorporating theory further enabled me to make implicit assumptions explicit (Collins and Stockton, 2018). The role of theory within this thesis added a valuable lens to construct coherence and depth to the findings and discussion of this research.

2.8 Chapter Summary

This chapter outlined the philosophical and theoretical approach to the research within this thesis. The chapter began with an exploration of the reproductive agency, pregnancy and motherhood using theoretical constructs and rhetoric of each. Section two of the chapter presented the understandings of social desirability and the presentation of self, exploring performativity in the context of women who use drugs. After this an overview of surveillance and governance theory from inception to its modern-day application, drawing on the work of Bentham and Foucault. I then explored of surveillance in practice using the Hidden Harm report

(2003) to critically demonstrate the monitoring and state intervention experienced by women who use drugs. The chapter concluded with a reflexive account of my background, family history and time in practice to give transparency to the reader.

Chapter 3: Qualitative Systematic Review Methodology and Methods

3.1 Chapter introduction

The aim of this chapter is to present the methodology and methodological approach to the qualitative systematic review included in this thesis. The chapter begins with the aim and objectives justifying the motivation for undertaking a systemic review of literature which explored the lived experiences of pregnancy among women who use illicit drugs. The methodology includes details of the rationale and justification for each systematic step included in the review. The second aspect of the chapter rigorously outlines the methods employed to identify, extract, appraise and synthesise the findings of primary studies included in this review.

3.2 Aim and Objectives

This systematic review aims to explore the lived experience of pregnancy among women who use illicit drugs, using the following objectives:

- To systematically identify, collate and appraise published qualitative literature which explored the experience of pregnancy among women who use illicit drugs.
- To synthesise the relevant literature using thematic analysis and extract narrative summaries.
- To operationalise the findings from the review to inform the qualitative research protocol and later, be used to draw comparisons between existing literature and the findings from qualitative research (Chapter 8).

3.3 Rationale for adopting the systematic review methodology

Systematic reviews are considered to be the 'gold standard' method of identifying, synthesising and evaluating all the existing research on a specific topic (Munn *et al.*, 2019). Systematic reviews are often used as the seminal point for developing and influencing clinical practice and guidelines (Moher et al, 2009). A high-quality systematic review draws together research evidence to inform policy and improve practice and can also illustrate where knowledge is lacking (Seers, 2015; Gopalakrishan & Ganeshkumar, 2013). Undertaking a systematic review and appraising all the relevant literature available on the research topic can offer rich insights into depth and breadth of research and according to Gopalakrishan & Ganeshkumar (2013), "… they increase the precision of the results".

According to the Cochrane handbook for systematic reviews of interventions (Higgins *et al.*, 2019:4)., systematic reviews "…collate all the empirical evidence that fits a pre-specified eligibility criteria in order to answer a specific research question". Systematic reviews aim to minimise bias by using pre-specified methods to make the systematic review replicable to other independent researchers (MacKenzie et al, 2012: 33). They do so by detailing systematically, the steps undertaken, what was found, and the clarity of the reporting (Moher *et al.*, 3009). The strict scientific design, integrity and rigour in which systematic reviews are conducted, with predefined and reproducible methods, make them important tools for policy and practice (Gopalakrishan & Ganeshkumar, 2013). Researchers undertaking systematic reviews are encouraged, and often a requirement of publication, to detail their steps using PRISMA (Preferred Reporting in Systematic Review and Meta- Analyses) flowchart. The PRISMA flowchart is a "living document" which details the steps used to search, include and exclude primary studies for synthesis, providing transparency, in turn, evidencing the rigour of the review (Moher *et al.*, 2009:3). For this reason, and given the context of this research, a systematic review was chosen to gain comprehensive understanding of available research on the topic, synthesise the findings from primary research and build on existing research.

3.3.1 Rationale for qualitative systematic review methodology

A qualitative systematic review of literature offers an opportunity to comprehensively explore topics focused on lived experience and understand the breadth of available studies and identify any paucities in research. Qualitative systematic review's collate research on a predefined topic, systematically searching for research evidence from primary qualitative studies, unifying their findings to identify commonalities and complexities of available research (Seers, 2015). Exploring and synthesising the findings from a range of qualitative studies with diverse samples allows researchers to identify clear gaps, while also addressing heterogeneity. Undertaking a qualitative systematic review and appraising all the relevant literature available on the research topic offer rich insights into depth and breadth of research (Gopalakrishan & Ganeshkumar, 2013). Consequently, qualitative systematic reviews can illustrate where knowledge is lacking and uncover new and detailed understandings of phenomena (Gopalakrishan & Ganeshkumar, 2013).

Collating and systematically searching for all available literature on a pre-defined topic can posit new understandings and contribute to theory development which may benefit patients, health professionals and planners (Seers, 2015; Dixon Woods *et al.*, 2001). While quantitative reviews aim to test or confirm existing hypotheses, qualitative reviews attempt to answer open-ended research questions whereby the aim is often of understanding experiences. The aim of understanding experiences is of particular importance for my systematic review, where the intersectionality of pregnancy and drug use will be explored. Exploring lived experience can give rich insight into how we can provide support and care to better meet the needs of the population we are researching (Seers, 2015).

3.3.2 Quality appraisal methodology

Quality appraisal is an integral method of systematic reviews which supports the readers to make a judgement about the credibility, dependability, transferability, and confirmability of the research (Tong *et al.*, 2012: 6). Quality appraisal is used to demonstrate the author has considered positionality, rigour and quality of the studies included in the review. Critical appraisal of qualitative research can also offer policy and practice decision makers confidence in qualitative evidence (Long et al, 2020). MacKenzie *et al.*, (2012) recommend that reviewers used a structural critical appraisal checklist with a range of frameworks available for qualitative systematic reviews. One framework commonly used by qualitative systematic reviewers and endorsed by the Cochrane Qualitative and Implementation Methods Group (CQIMG) is the CASP (Critical Appraisal Skills Programme) tool (Higgins *et al.*, 2019; Long et al, 2020). The CASP tool is used to assess the methodological strengths and limitation of qualitative studies. According to Pearson *et al.*, (2011) the CASP tool "…elicits an extensive amount of additional information related to how the criteria on rigour and relevance of an original research report should be interpreted".

Assessing quality of potentially unreliable results prevents them from influencing the review findings (Thomas & Harden, 2008). Traditionally, methodological detail is essential for the critical appraisal of any research and lack of detail can mean a study is ejected from the review. However, as demonstrated by Long *et al.*, (2020) the absence of detail in a published primary study is not an indicator of poorer quality but perhaps due to limitations of depth and journal requirements.

For this reason and like Hawker et al, outlined in their review, and with the application of the CASP tool, papers of limited methodological detail will not be rejected, they will be marked as 'satisfactory' for methodological rigour (Hawker *et al.*, 2002). The CASP tool could be considered to be a scale or continuum and in itself, requires reviewers to reflect on their own potential bias. However, the risk of bias is mitigated by the systematic review process of having many experienced reviewers involved (Long *et al.*, 2020). For the purpose of this review, supported by the considerations outlined above, the CASP tool was deemed both appropriate and sufficient to appraise methodological rigour in all primary studies included in this systematic review.

3.3.3 Data analysis and synthesis methodology

The synthesis of studies is an iterative process resulting in the integration of findings associated with the pre-defined aim and objectives (Barnett-Page *et al.*, 2009). Meta-synthesis is used in qualitative research to combine findings such as themes found across many different sites and studies (Florczak, 2019). Thomas and Harden developed an approach to qualitative systematic review analysis termed "thematic synthesis" (Barnett- Page *et al.*, 2009). This method amalgamates and modifies approaches used in meta-ethnography and grounded theory, whereby it utilises the translation from descriptive to analytical (used in meta-ethnography) and combines it with the 'inductive' approach of constant comparison (used in grounded theory) (Barnett-Page *et al.*, 2009). Thematic synthesis includes iteration, particularly at the synthesis stage. Thematic synthesis seeks to move beyond the data of the primary studies and perform a "fresh interpretation of the phenomena under review" (Barnett- Page *et al.*, 2009:8).

3.3.4 ENTREQ

Enhancing transparency in reporting the synthesis of qualitative research (ENTREQ) statement contains 21 items covered in five overarching domains: introduction, methods and methodology, literature search and selection, appraisal, and synthesis of findings (Tong, 2012). According to Tong *et al.*, (2012:6):

> "For readers to make an assessment about the transferability of the findings to their own setting, a description of the study characteristics, screening process and reasons for excluding studies is needed".

The ENTREQ statement has been used in this review to ensure the qualitative evidence synthesis of the systematic review is precise and replicable (Tong *et al.*, 2012).

3.4 Methods

3.4.1 Aim and Objectives

This review aimed to explore the lived experience of women who used illicit drugs during pregnancy. The focus of the review was qualitative studies which narratively reported the views and perspectives of pregnancy among women who use illicit drugs. Previous systematic reviews have explored alcohol use during pregnancy (Henderson *et al.*, 2007; Skagerstrom *et al.*, 2011; Lyall *et al.*, 2021) and were deemed sufficient to have addressed and explicated the implications for policy and practice, thus alcohol use was not the focus of this review. This review aimed to draw on all available literature on illicit drug use, to synthesise findings and to understand the implications for policy and practice and also, to inform the qualitative research outlined in Chapters 5 and 6 of this thesis.

The review considered the following questions:

- What is the lived experience of pregnancy for women who use illicit drugs?
- What perceptions do women who use illicit drugs have of motherhood?
- Does pregnancy have any impact on women's substance use?
- What experience did women have of the services they accessed during pregnancy?

3.4.2 Review question and inclusion criteria

The review began with a scoping of the literature with the aim of understanding the breadth of published literature on the topic. I identified five key texts and used these to glean an understanding of contemporary research into the topic area and to develop the qualitative systematic review protocol. A comprehensive search of PROSPERO (International Prospective Register of Systematic Reviews) was also undertaken for reviews of similar or related interest and to ensure the review protocol was sufficient and niche. A protocol was co-designed in consultation with my supervisory team and was registered with PROSPERO (CRD42020198884) and published on their website in September 2020.

The SPIDER (Sample, Phenomenon of Interest, Design, Evaluation, Research type), model is commonly used for public health intervention analysis. The SPIDER model was devised by Cooke *et al.*, (2012) and was an adaptation to PICO (Population, Intervention, Comparison, Outcome) and SPICE (Setting Perspective Intervention Comparison Evaluation) that was specifically designed for qualitative research. The SPIDER model (table 1) was used within this review to inform the development of a robust inclusion and exclusion criteria.

Table 1: SPIDER model

Sample	Women who use illicit drugs.
Phenomenon of Interest	Pregnancy.
Design	Interview, focus group, case study, observations, questionnaire/ survey with open ended questions.
Evaluation	Lived experience, attitudes, perspectives, view.
Research type	Qualitative and mixed methods which include qualitative research.

Studies were defined as eligible for inclusion if they met the following criteria: 1) women who use or have used illicit drugs (defined as substances which are unlawful to use, possess or distribute for example: cannabis, cocaine, heroin, amphetamines, ecstasy and ketamine) during pregnancy/ pregnancies; 2) qualitative studies including ethnographies, one to one interview, focus groups and surveys which offered open ended responses. Mixed method studies were included if they had qualitative research which met the above criteria; 3) studies published from database inception to January 2023. As this review was focussed on lived experience of pregnancy, any papers which reflected on women's lived experience of pregnancy (current, postnatal or historic) were included in the screening. No language restrictions were applied. In order to capture emerging evidence, recent dissertations (2015 onwards) were included.

Qualitative studies were excluded if 1) they only explored alcohol use with no other drug use; 2) if the focus of the study was women who use illicit drugs but did not narrate experiences of

pregnancy; or 3) women who began using drugs post-partum. As this was an international review, it was acknowledged that some drugs (for example cannabis may be legal/ regulated in some countries). Papers which referenced psychoactive substances where they were legal or regulated within the country/ state in which the research was undertaken, where therefore excluded from the review on the basis they were not illicit drugs. Grey Literature was excluded from the study was excluded from the review because of the difficulty in assessing the quality.

While the inclusion and exclusion criteria were designed to aid the identification of appropriate studies, there are implications to the application of these. Firstly, given the heterogeneity of including any illicit drug use (as opposed to one substance in particular, for example, crack cocaine) during pregnancy mean that the review is broad in scope. This means that while the review is inclusive of experiences of substance use and considerate of polydrug use, focus on a particular substance may have been more informative for policy and practice. The second implication is the incorporation of lived experience of pregnancy, whereby studies were included if they had presented findings from women who were currently pregnant, postnatal or had historic experience of pregnancy. Due to variation in reporting across studies, it was often difficult to ascertain when pregnancy had occurred and if this was current, recent or historic. This may also have impacted participants accounts and views in relation to drug use during pregnancy. For example, those were pregnant at time of data collection may have been hesitant to report drug use due to concern they had for themselves and their unborn child. Lastly, not including grey literature means that some reports (such as government papers, charity reports) which may contain important findings were not included for synthesis. The implication of this being that some perspectives and views were not included in the synthesis, which may have altered the findings of the review.

3.4.3 Search strategy

The following electronic databases were searched: Applied Social Sciences Index Abstract (ASSIA), CINAHL (Cumulative Index to Nursing and Allied Health Literature), MEDLINE (OVID), EMBASE (OVID), PsychINFO (OVID), Scopus and Web of Science. During my first year Annual Progression Review, the panel suggested that including searches of the electronic database CINAHL

(Cumulative Index to Nursing and Allied Health Literature) would strengthen the review. After discussion with the wider team and the recommendation of the importance of CINAHL by experienced systematic review academics who considered CINAHL to be a "... good sources of primary studies with the potential to yield unique studies", a search of CINAHL was undertaken using the same parameters defined above and with a date restriction that reflected the searches conducted in all other electronic databases (Booth, 2016). The PROSPERO protocol was amended in March 2021, to include a search of the CINAHL database.

A robust search strategy was carefully crafted in consultation with my supervisory team who have extensive experience of undertaking qualitative systematic reviews. The search strategy was successfully piloted on MEDLINE to test for sensitivity, specificity, and rigour. Previous research has found that the SPIDER model has shown the greatest specificity (smaller number of hits generated) however, it is lower in sensitivity (may not retrieve all of the relevant studies for review) (Methley *et al.*, 2014). Given the breadth of databases searched, it is anticipated that this may have mitigated the perceived lack of sensitivity to database searching using the SPIDER model.

Due to the absence of 'standardisation' across electronic resources, search strategies were developed, revised and translated according to database specifications using Medical Subject Headings (MESH) terms and appropriate Boolean operators (Hawker *et al.*, 2002). A sample of this can be found in Table 2 (page 60). In the interest of transparency and to ensure our searches are reproducible, a copy of the Master Search Strategy (refined and translated across databases) can be found in the Appendix A. Searches ended when databases became exhaustive using the following criterion: same references appearing repeatedly; bibliographies not yielding new articles; adequate saturation had been reached (Hawker *et al.*, 2002). Database searches concluded in January 2023.

Searches of all seven databases identified 4541 studies. All 4541 studies were exported to referencing management software, EndNote, for deduplication (I reviewed each paper and also

used the software within Endnote to identify duplications). An additional paper was found subsequent to database searches, within a reference list of included studies. This study did not mention pregnancy within the title, abstract or keywords, which offered an explanation as to why it had not been identified during database searches. After deduplication in EndNote, the search yielded 3285 studies for screening.

3.4.4 Screening

Title and abstract screening were undertaken independently by two reviewers using Rayyan (CS and EA[3]). The Rayyan online software gives reviewers the opportunity to export Endnote literature directly into an accessible platform for screening. Rayyan gives reviewers the ability to collaborate on the same review and screen titles and abstracts (Ouzzani *et al.*, 2016). Rayyan features the ability to blind and unblind the review process. As reviewers screen titles and abstracts, they can include or exclude (with reason), undecided and conflict (with other reviewers).

In total 3285 studies were exported from EndNote to Rayyan where two researchers (CS, EA) double blind screened all titles and abstracts for inclusion/ exclusion. All studies excluded at title and abstract screening were done so with reasons outlined in the exclusion criteria or if they were duplication or wrong publication. Any conflicts between reviewer's decision making were resolved together and agreement was reached resulting in 3178 papers being excluded as they did not meet the inclusion criteria.

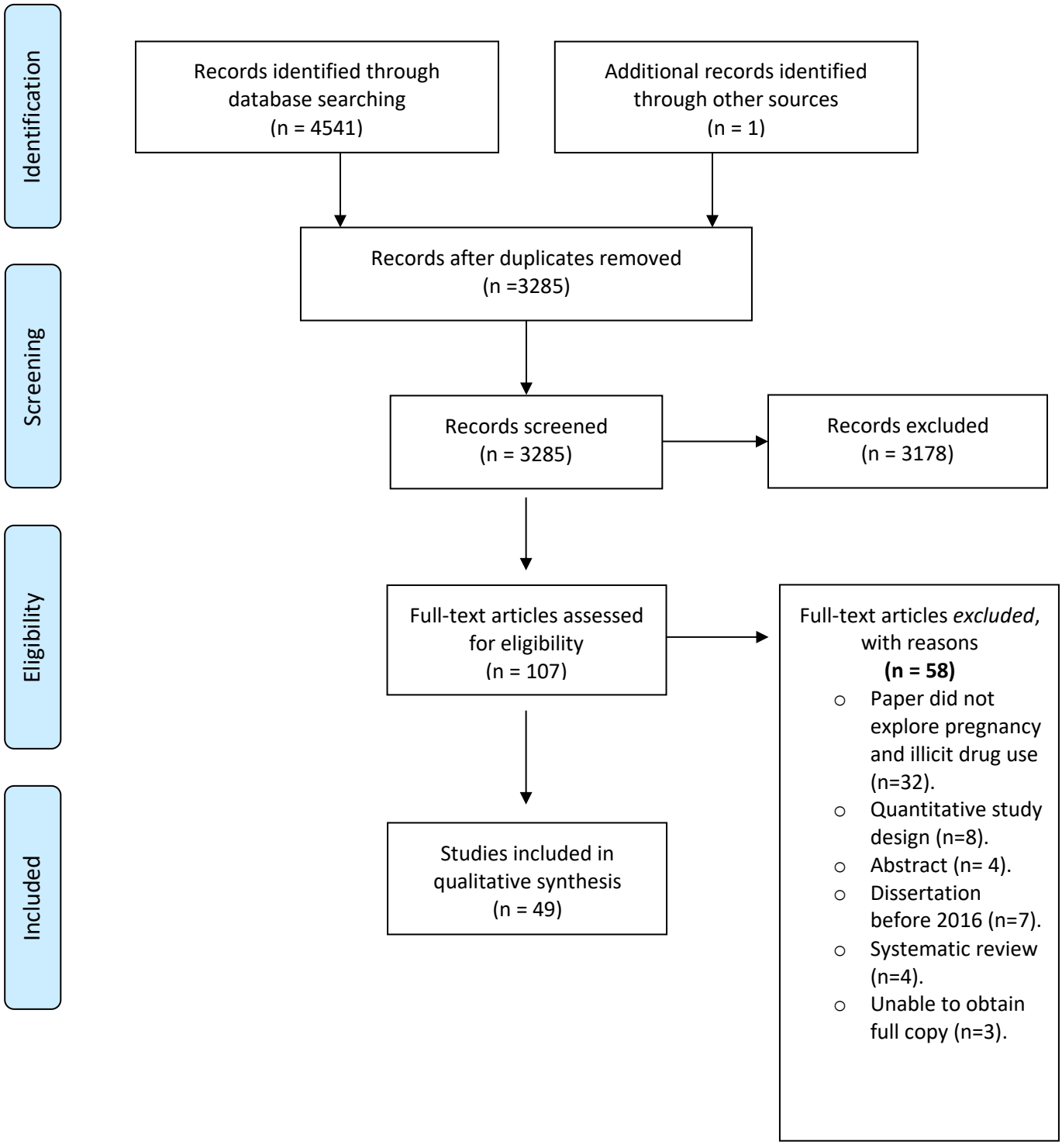
Full text screening of 107 studies was undertaken independently by the same reviewers (CS, EA). After full text screening, 58 studies were excluded with exclusion criteria outlined in the PRISMA Flow chart (Figure 1, page 61). Forty-nine primary studies were included in the systematic review for synthesis.

[3] EA- Emma Adams, Pre-Doctoral Fellow, Population Health Sciences Institute, Newcastle University.

Table 2: MEDLINE Search Strategy

SPIDER:	**Keywords:**
Sample	Pregnancy OR pregnan$ OR unintended pregnancy OR unplanned pregnancy OR planned pregnancy OR pregnancy planning OR pregnant women OR pregnancy intention OR intention OR pregnant women OR substance-exposed pregnancy OR childbearing OR fertility OR family planning OR family intention OR family planning service provision OR reprod0uctive health OR reproducti$ OR female healt$ OR contraception OR contraceptive OR Child OR infant OR prenatal OR parenting OR birth outcomes OR miscarriage OR mother OR motherhood
Phenomenon of Interest	Drug OR drugs OR drug user OR drug dependenc$ OR drug abuse OR drug misuse OR substance user OR substance abus$ OR substance dependenc$ OR substance misuse OR substance disorder OR drug addict$ OR illicit drug user OR illicit substance OR addiction OR recreational OR recreational drug user OR recreational substance user OR recreational drug abus$ OR injecting drug OR injection drug OR opioid opiate OR heroin OR crack OR cocaine OR stimulant OR opioid drug OR amphetamine OR cannabis
Design	Interview OR grounded theory OR ethnography OR interpretative phenomenological analysis OR phenomenology OR focus group OR content analysis OR thematic analysis OR constant comparative OR participant observation
Evaluation	perceive OR perception OR perspective OR view OR experience OR attitude OR belief OR opinion OR feel OR know OR understand
Research type	Qualitative OR qualitative analysis OR qualitative research OR mixed methods

Figure 1. *Prisma flowchart of included studies 2023*



3.4.5 Data extraction and quality appraisal

Data extraction is not linear but repetitious process and "…often, it involves moving backwards and forwards between review stages" (Higgins *et al.*, 2019: 534). For the purpose of this review and in the interest of clarity, data extraction of all primary studies included in this review is presented here in three stages.

Stage 1: Paper summary, including sample characteristics.

All 49 primary studies included in the review were read and re-read to gain familiarity and to support data extraction. A comprehensive and bespoke data extraction form was built in Microsoft Excel to support stage 1 of the extraction to ensure critical information about each study was recorded. Author, publication year, country, study title, aims and objectives, participant characteristics (age, gender, illicit drug use, socioeconomic background, pregnancy/ pregnancies, parental outcomes), data collection method, methodology, findings, themes, recommendations, and references were extracted from each study and placed in table format. This gave the lead reviewer (CS) the opportunity to reflect on each study individually, but also provided a comparative overview of all studies included in the review. Critically, stage 1 and stage 2 of the systematic review allowed for reflection and consideration of the heterogeneity and variability of the primary studies included in this review.

Stage 2: Quality appraisal using the Critical Appraisal Skills Programme (CASP) tool.

The CASP qualitative checklist tool was completed in conjunction with the data extraction of contextual details. The CASP checklist can be broken into three sections (10 questions), which encourage reviewers to critically engage with each primary study and consider the methodological strengths and limitations of each as well as appraising the criteria, rigour and relevance of the primary studies included in the review (Pearson *et al.*, 2011; Higgins *et al.*, 2019). The checklist included narrative summary key quality issues of concern (if any). Each paper was then evaluated into Key paper A (most relevant and conceptually rich/ no or few issues with quality); Key Paper B (relevant but with limited themes and data/ few issues with quality) and Key Paper C (satisfactory) (less relevant to review with few or major issues with quality/ relevant but major issues with quality).

A table summarising all of the included primary studies and the quality appraisal of each is presented at the end of this chapter (Table 3, page 65).

Stage 3: Qualitative data extraction.

Qualitative data extraction was undertaken using an inductive approach. The lead reviewer (CS) extracted all of the 'findings' from each of the primary studies included in the review into a Microsoft Word document in preparation for synthesis. According to Sandelowski & Barrosa, (2002) qualitative findings may take the form of quotations from participants, subthemes and themes identified by the study's authors, explanations, hypotheses, new theory, or observational excerpts, author interpretations of the data and recommendations. For qualitative synthesis, Thomas & Harden (2008) recommend taking all text labelled as results or findings, including findings in the abstract. Regardless of detail, all of the included studies' findings (all reported themes and quotes) and discussion were extracted for review and synthesis.

As this review contained studies with many qualitative methodologies, meta-aggregation was used to identify and categorise findings for synthesis (Florczak, 2019). As posited by Florczak (2019) meta-aggregation is not linear, but iterative and interpretative, producing statements that are useful for action, particularly evidence-based practice.

3.4.6 Data synthesis and interpretation

When all three stages of data extraction were completed, thematic synthesis of primary studies began. In order to undertake thematic synthesis, all included primary studies (n=49) were exported to NVivo (version 1.2) for analysis and synthesis. The principles of grounded theory were used to understand the context in which the theme was constructed (Thomas & Harden, 2008). Grounded theory, whereby "grounding a text in the context in which it was constructed" was used to support the development of descriptive and analytical themes (Thomas & Harden, 2008). Thomas & Harden's approach to thematic synthesis was used in the following three stages: coding, developing 'descriptive themes', generation of 'analytical themes' (Thomas & Harden, 2008). As outlined by Higgins *et al.*, (2019) the qualitative evidence that was extracted contained both 'rich' and 'poor' conceptual detail, alongside,

'thick' and 'thin' contextual detail. Synthesis began with papers that ranked highly during quality appraisal (Key papers A).

Stage 1 & 2: Line by line coding- used to develop descriptive themes.

Line by line coding, one of the key tasks in the synthesis of qualitative research, was undertaken (by CS) on the 'findings' of each study using NVivo (version 1.2) (Thomas & Harden, 2008). Analysis began with the coding of statements and quotations in each primary study. Every sentence had at least one code, with some having many. Line-by-line coding was used to build a book of 59 codes. These codes were descriptive in nature, with some having many statements and quotations referenced in them from many studies (for example "preparation for motherhood" was coded 131 times across 29 primary studies in comparison to "stillbirth", which was coded four times across two studies).

Line-by-line coding was an important aspect of this review which allowed engagement with descriptive themes, close to the primary studies themes. I then explored similarities and differences across all studies included in the review, interpretating data within and between primary studies. Each of the 'free' codes was collated to form a weighted library of codes and build a hierarchy of codes. Before finalising synthesis, the review team examined the library of codes (and hierarchy) to check for consistency and interpretation.

Stage 3: **Generating analytical themes.**

In order to address the aim and objectives of this review, it was integral to explore and generate analytical themes (Thomas & Harden, 2008). Analytical themes are those that generate new interpretive constructs, explanations, or hypotheses and is guided by the inductive analysis of descriptive themes, exploring these in depth to answer the review questions. Generating analytical themes goes beyond the original content of the studies included in the review and requires objectivity, reflexivity, and an understanding the context (or grounding) in which the study was undertaken. Descriptive themes (derived from line-by-line coding) were then collated to develop themes and sub-themes. Through comprehensive and iterative discussions with my supervisory team, analytical themes emerged. Appendix B details the analysis process with exemplary statements/ quotations to illustrate how descriptive and analytical themes emerged.

3.5 Chapter summary

Within this chapter the methodology and methodological approach to my qualitative systematic review were outlined in detail. The chapter began with the aims and objectives for undertaking a systematic review, followed by a detailed rationale for adopting a qualitative systematic review and the predefined approaches applied to quality appraisal and synthesis of included primary studies. The second section of this chapter demonstrated the methods used to undertake this systematic review. This included a detailed account of each step undertaken in the review including supporting documentation (Search strategy, PRISMA flowchart, summary of included studies). This chapter gives background and context for the next chapter, whereby the findings of the qualitative systematic review will be presented.

Table 3: Summary of all included primary studies and quality appraisal

First Author (Year), Country	Sample size (Female), Ages	Illicit drug use during pregnancy	Data collection, Recruitment and Analysis	Summary of main findings	Quality Appraisal
Abdul-Khabir (2014), USA	N=30, 18-45 years	Methamphetamine	Semi- structured interviews; addiction treatment centres, community; thematic analysis.	Most women involved in this study reported they continued methamphetamine use during at least one pregnancy. Some women (n=5, 17%) identified pregnancy as a motivation to quit or reduce use, suggesting an opportunity for intervention. Though most women knew about free and low-cost reproductive health services, few accessed them, with 33% citing aspects of methamphetamine use itself as a barrier. Just over one third (45/133) of reported pregnancies were terminated by abortion. Most women (67%) began using before age 18, suggesting need for screening and intervention among adolescents.	Concerns about positionality of researchers (no context or background of researchers). The themes in the paper directly relate to the three topics they wanted to explore. Interviews were very short for qualitative research 15-20 min. Many women were in recovery so this could have influenced responses. Interviews were not audio recorded but transcribed during interview meaning it was up to the interviewer to write down responses verbatim during a very short time frame. **Key Paper B**
Baker (1999), USA	N=17, 20-41 years	Crack cocaine and crystal methamphetamine- n=14; alcohol- n=2; painkillers- n=1.	Semi-structured interviews; residential substance treatment programme; content analysis.	The findings of the study are classified into two categories: "Bad mothering practices"; "Good mothering practices".	It is difficult to ascertain if the original aim of the research was to explore mothering practices or if this was something that emerged and became the focus of the study. **Key Paper B**

Benoit (2015), Canada	N= 34 (26F), mean 29 years	Cannabis- n=15; cocaine- n=9.	Semi structured interviews; health and social care settings; thematic analysis.	The results of this study outline how that many mothers and fathers hold abstinence as the ideal during pregnancy and early parenting, they simultaneously recognize the autonomy of women to judge substance use risk for themselves. Participants also call attention to social structural factors that increase/decrease harms associated with such substance use and present an embodied knowledge of substance use based on their tacit knowledge of wellness and what causes harm.	Although this paper performed well for methodological appraisal there is clear duplication between this and the Stengel paper, also included in this review. Data was extracted alongside to see if this was duplicated or the methods. After extraction, it was agreed that this study was a separate/ follow up study to Stengel paper. **Key Paper B**
Chandler (2013), UK	N= 19 (14F), 23-29 years.	Heroin n=5, benzodiazepines	Semi- structured interview; healthcare settings; narrative and comparative analysis.	Participants' accounts of drug treatment were clearly oriented towards demonstrating that they were doing 'the best thing' for their baby. For some, OST was framed as a route to what was seen as a 'normal' family life; for others, OST was a barrier to such normality. Challenges related to the physiological effects of opioid dependence; structural constraints associated with treatment regimens; and the impact of negative societal views about drug-using parents.	A robust study with minimal concerns related to the methods, ethics and analysis. A little more clarity around who the researchers were and how they worked with gatekeepers etc would have made this an exemplary paper. **Key Paper A**
Chang (2019), USA	N= 25, 19-36 years.	Marijuana	Semi- structured interview; healthcare setting; thematic analysis	This study found that participants reported using higher amounts of marijuana use prior to pregnancy and attempted to reduce use once they realized they were pregnant; they	There were no real methodological concerns. Narratives and themes relate directly to this SR but provide nuance in the context of marijuana. Questions around the purpose of urine screening

				used marijuana to help with nausea during pregnancy or to improve mood; they described marijuana as "natural" and "safe" compared to other substances; they had conflicting opinions regarding whether marijuana was addictive; and they were uncertain but concerned about potential risks of prenatal marijuana use.	by researchers and whether this was necessary. **Key Paper B**
Cleveland (2016), USA	N= 15, 22-40 years.	Prescription opioids, heroin, cocaine.	Semi- structured interviews; thematic analysis	Findings included five primary themes: 1) facing the reality of pregnancy complicated by substance use, trauma and loss; 2) finding a higher meaning; 3) dealing with the consequences; 4) managing details of daily life; and 5) looking toward the future with my children.	This is a good paper that performed well using the CASP tool. However, there is little data that relates specifically to pregnancy as the focus was mothering. **Key Paper B**
Courvette (2016), Canada	N=38, 21-54 years.	Stimulants, illicit prescription drugs (opioids).	Interviews, no recruitment information, thematic analysis	Thematic data analysis identified three significant events that weaken maternal identity for these women: pregnancy, loss of custody, and incarceration.	There is conflict within the paper. The methods section (under procedure) states that n=25 women were incarcerated in provincial prison however in the section on participants, the authors state the data (at the time of the interview) that all women had been in trouble with the law during the past five years. More information about the recruitment process is necessary. Were the women interviewed whilst in prison or were some retrospective accounts. **Key Paper C**

Da Costa (2015), Brazil	N=13, over 18.	Crack cocaine, marijuana.	Narrative interviews, homeless outreach service, content analysis.	The analysis was conducted through the thematic grouping of excerpts of narratives, and the following four main categories were identified: life on the street; care and pregnancy; future projects; and public services.	There were no real methodological concerns with this study, however it is important to consider that as this was translated from Portuguese to English, some context may have been lost in translation. **Key Paper B**
De Souza Ramiro (2018), Brazil	N=12, mean 29.5 years.	Crack cocaine.	Semi- structured interviews, NGO and women's organisations, content analysis/ thematic analysis	The data included in this study demonstrates that some women who use crack cocaine are unaware of the risk and harms associated with this type of drug use during pregnancy.	Within this paper, there is no clear statement of findings. No definitive concerns about methodological rigor however, the "measurements" section does not follow into the results/ themes. **Key Paper B**
Diez (2020), Argentina	N=62, 18-29 years	Cocaine and cannabis.	Semi-structured interviews (qualitative)/ (quantitative); multi centre hospitals; content analysis/ Statistical Analysis for the Social Sciences.	This study explored the concerns and worries women (in Argentina) who use drugs have in relation to pregnancy, particularly the consequences to their unborn child (physical health, premature baby etc). It should be noted that some of the interviewees referred to pleasure, mentioning the sensation of calm and relaxation that substances give them and the attention they receive from their relatives as a result of consuming.	There was little primary data presented within this study and often it was presented with with little context. Despite this, authors presented some interesting concepts. **Key Paper C**
Frazer (2019), USA	N=22, 22-38 years.	Heroin and prescribed opioids.	Interviews; specialist addiction and pregnancy centre; thematic and	Three major categories were highlighted through interviews: (1) major motivators to seek SUD treatment, included : seeking daily structure, concern for the health of the baby, homelessness, and desire	A quality paper. This paper would have been improved with more transparency about the interviewer and two coders could have been used to prevent risk of bias. A reflexive statement about positionality and no affiliation between

			descriptive analysis.	to retain custody of the baby and other children; (2) hesitation to seek treatment because of: not wanting to leave children or a partner at home, fear of punitive measures or loss of custody and lack of information about available treatment options; and (3) logistical barriers to treatment including lack of childcare and transportation and limited availability on the housing unit.	researcher and setting, alongside rich data improved the appraisal of this study. **Key Paper A**
Goodman (2020), USA	N=10, mean age 28 years.	All had a diagnosis OUD. No further break down of drug use.	Semi- structured interviews; substance use treatment provider; grounded theory.	This study demonstrated that despite multiple barriers, pregnancy was a change point from which they were able to develop self-efficacy and exercise agency in seeking care.	During appraisal, ther were concerns about the positionality of the PI who was known to all participants, however, authors detailed how they would reduce bias in the analysis stage. The barriers/ facilitators codes were established in advance of coding, however there wasn't a clear statement of these in the results. **Key Paper B**
Gordon (2019), UK	N=11, 18-40 years.	Heroin and cocaine n=8.	Semi- structured interviews; hostel; thematic analysis.	The following three themes were reported within this study: 1) unstable family and childhood trauma; 2) wanting the best for baby versus fear of child loss; 3) biomedically competent, emotionally unsupportive care. Further themes were being seen to do 'the best for the baby'; pregnancy-enabled access to necessary holistic biopsychosocial care; and lack of postnatal support for CLSS or parenting.	Appraisal of this study found both depth and rigour. This study contains rich data and Themes 2 and 3 directly relate to this review. The authors reflect on the strengths and limitations of the research which was reflexive and well considered. **Key Paper B**

Hall (2006), UK	N=12, 19-36 years.	Heroin and crack cocaine use.	Questionnaire and semi- structured interviews; specialist antenatal clinic; content analysis.	Findings of this study indicated that women preferred the multidisciplinary clinic (one-stop shop) to traditional prenatal care centred within General Practice. The relationships of the clients to the range of Clinic professionals and in hospital were explored as well as attitudes to Clinic care. The study participants attributed success in reducing their drug use to the combination of different aspects of care of the multi-agency clinic, especially the 'high level' prenatal support. It is this arrangement of all aspects of care together that seem to produce better outcomes for mother and child than single care elements delivered separately. Some women within this study reported that their pregnancy encouraged them to rapidly detoxify due to the guilt experienced. The most important aspects of the clinical care were found to be non-judgemental attitude of staff, consistent staff, high level of support, reliable information and multi-agency integrated care.	This is a good paper with rich data. The authors make the paper accessible using tables, quotes verbatim and the topic guide which evidence their robust approach to research. They reflect on the limitations of the study in the context of ethical approval. A good paper that is both methodologically sound, with rich data. **Key Paper A**
Hathazi (2009), USA	N=41 (20F), 16- 28 years.	Cannabis, Inhalants, Cocaine, Mushrooms, Heroin, Methamphetamine,	Interviews and ethnography; Non clinical locations (parks and street	This study was focussed on homelessness and pregnancy experienced by women who use illicit drugs. Despite this, pregnancy history and recent events was explored;	The main concerns related to the methods of this study was that authors were vague about interview, consent, confidentiality etc methods . This study has a large sample with lots of

		Ecstasy, Ketamine, Crack and other drugs.	settings); thematic analysis.	alongside contraception use and access and use of prenatal care. Authors also evidenced that within this population, there was a unique opportunity to encourage positive health behaviours in a high-risk population seldom seen, especially those seldom seen in a clinical setting.	interesting findings. The tangible failure of the study was its failure to reflect on the vulnerability of participants. In all, there was missed opportunities within this study to capture data related to-multiple pregnancies, children post-partum which were not explored. **Key Paper B**
Jessup (2003), USA.	N=36, mean age 30.2 years	Cocaine/crack cocaine n=16; heroin n=6; methamphetamine n=5; cocaine/ marijuana cigarettes n=2; psychedelics.	Semi- structured life history interviews; residential substance abuse programme; life history analysis.	Results from this study indicated that the majority of participants (n=34) sought prenatal care but identified that they feared punitive actions from helping institutions and individuals as a major barrier. Other extrinsic barriers included substance abuse treatment programme barriers, partners, the status of opiate dependency, and the status of pregnancy. Biological, socio-cultural, and psychosocial dimensions of participants' care-seeking experiences were also identified. The turning point for women included in this study, was pregnancy, and they responded to this by making adaptations to their lifestyle which included preserving the family, managing fear, and manifesting faith. Findings describe the transformation of the therapeutic alliance and the gendered impact of two decades of the War on Drugs in the United	Researchers collected comprehensive information on the backgrounds and characteristics of participants. The data included in the findings is rich (though limited). This paper is almost 20 years old and in comparison, to others from this time and later, it appears progressive in both the language used to describe women who use drugs, the themes that emerged and the recommendations it produced. **Key Paper B**

				States. Participants' coping strategies suggest that the desire for child custody and concern for foetal and child well-being was a priority and motivated care seeking despite extrinsic barriers perceived to be threatening to the woman's safety and autonomy.	
Kearney (1994), USA	N=100, 18-58 years.	Crack cocaine and cannabis.	Interviews; word of mouth; grounded theory.	The following five themes emerged from data analysis: Reappraising; Limiting (control), limiting sex on crack; Settling for less; Perspectives on sex, babies and fertility.	This is a brilliant qualitative study with rich descriptions and was progressive for its time in terms of the language used, the methodological and theoretical approach and how many participants were recruited- which are all presented with clarity. However, given the overlap with Jessup *et al.*, 2003) more information is needed to understand how all the studies relate. Authors were contacted to in relation to both studies but no response was received despite follow-up emails. Key Paper B
Latuskie (2019), Canada	N= 11, 25-42 years.	Heroin, cannabis.	Focus groups; early intervention specialist programme; thematic analysis.	Women within this study identified that external and internal stressors, feelings of guilt and low-self efficacy, and a lack of understanding of the scientific and medical consequences of substance use contributed to their continued substance use. Conversely, women highlighted the importance of high self-efficacy and the quality of relationships when trying to make	Within this paper, there were no real concerns with the methods, ethics and analysis and the paper performed well in critical appraisal. Data within the paper was deemed useful for this SR. The discussion section considered central themes and self-efficacy well. The strengths and Limitations section was reflexive**.** **Key Paper A**

				positive changes to their substance use during pregnancy.	
Leppo (2012), Finland	N=14, not collected.	Polydrug use and illicit Subutex.	Ethnographic semi structured interviews, specialist maternity programme; thematic analysis.	The interviewees' expressions of worries, fears and anxieties linked to prenatal drug use are divided into the following three subsections: risks to the foetus or child, risky encounters with professionals and risks related to abstaining from drug use.	Qualitative appraisal found this to be a good paper with rich data that pertains to SR. The study was vague information in relation to ethical approval, ethical considerations and recruitment strategies/ sites used. **Key Paper B**
Lewis (1995), UK	N=30, 18-31 years.	n=23 illicit drugs (not defined); reported n=20 prescribed methadone at time of interview.	Semi- structured interviews; recruited via drug workers, midwives and drug using field contacts; content and thematic analysis.	The themes covered in interviews within this study included: women's past, present and future drug use; their feelings about their pregnancy, and experience of antenatal care and perceived professional's attitudes to their drug use.	Within this study there are minimal flaws in relation to transparency of ethics and recruitment. This is a good piece of qualitative research with rich data with demonstrable key findings. **Key Paper A**
Mattocks (2017), USA	N= 14, 23-36 years.	Illicit drug use referred to in findings.	Focus groups; methadone treatment clinic; thematic analysis using grounded theory.	Five emergent themes were derived from the data: 1) guilt and fear of negative outcomes for their infant, dictates women's OST treatment decisions; 2) challenge of finding experienced obstetricians to treat women using methadone; 3) methadone clinic physicians are key to supporting women find the right dose of methadone during pregnancy; 4) some women had strong preferences for methadone over buprenorphine; 5) women faced substantial challenges after delivery.	In accordance to the sections of the CASP tool- this is a well-considered paper, however, there are agreeable concerns about the lack of ethical approval and transparency about how the site was chosen. Although the study focus was OST the women involved (data) reflect on drug use during pregnancy (highlighted in paper). Themes about barriers and challenges to OST and stigma and shame. **Key Paper B**

Mburu (2020), Kenya	N= 45, 19-49 years.	Heroin, cocaine and other polydrug use including rohypnol, khat, solvents and cannabis.	Semi structured interviews (n=24) and three focus groups (n=21); community-based harm reduction services; inductive thematic analysis.	There were four key themes that emerged when outlining determinants of drug use during pregnancy: 1) the stress of unexpected pregnancy influenced drug use during pregnancy; 2) drug use continued during pregnancy to manage withdrawal; 3) the interplay between the drug use and pregnancy as both a facilitator and a moderator; and; 4) the role of male intimate partner in influencing women's drug use during pregnancy.	This is an excellent piece of research which complements and uses relevant key texts (some included in this SR) to demonstrate their findings. This paper includes rich data. **Key Paper A**
Mejak (2016), Slovenia	N=15, 24-34 years.	Heroin, cocaine and poly drug use.	Interviews; psychiatric hospital; thematic analysis.	The findings of this paper consider both the physical and psychological harms associated with drug use in pregnancy. All women in this study used opioids and most women had experience of unplanned pregnancy When the mothers became aware they were pregnant, they began to follow various harm reduction strategies that they believed would benefit their child, such as discontinuing illicit drug use and taking part in an agonist opioid maintenance treatment. The involvement of supportive partners and other relatives, as well as the comprehensive management of pregnancy and drug use, demonstrated positive effects on prenatal care. However, prejudice	This is a good study with rich data. Grey areas around recruitment and analysis reduce the quality of this paper. In saying this, the data within the papers relates to pregnancy, childbirth and lived experience of women who use drugs in Slovenia. **Key Paper B**

				and various stereotypes prevented individuals from applying effective strategies.	
Miller (1995), USA	N=2, 30-32 years.	Crack cocaine (n=1).	Interviews; not known; comparative analysis?	The findings of this study demonstrate the success of treatment engagement in reducing or abstaining from drug use during pregnancy. The study also indicated that it often takes the removal of these women's children from their custody to enter treatment.	This is a descriptive study, profiling two women and is not representative in nature. Overall, the data in the study is rich. There was no discussion about the case studies, only a short conclusion. **Key Paper C**
Morris (2012), Australia	N=20, 18-35 years.	Heroin, cocaine, marijuana, methamphetamine	Interviews (2 preceding birth, 1 post-partum); specialist antenatal clinic, grounded theory.	This paper focuses on women's perception of the degree to which the treatment centre met their needs. The paper contains in depth contextual information including: background demographics; factors influencing drug use and impact on pregnancy; stage of recovery at time of interview and the impact this may have had on their perspectives of care.	This research is valuable given the many methods used to collect data. However, it is unclear why the authors undertook three interviews with each participant. A large amount of the word count is dedicated to explaining how the theory related to the study. A more robust discussion linking it to previous research/ practice, along with strengths and limitations would have given the paper more rigor. K**ey Paper B**
Myra Mrete (2016), Norway	N= 8, 17-44 years.	All women diagnosed with SUD.	In- depth qualitative interviews; two closed units for pregnant women who use drugs; phenomenological analysis.	The main findings show how involuntary detention enabled safety for pregnant women and improved their connection with the unborn child. This study found that the most significant barrier to care for women who use drugs and experience pregnancy was their own relational experiences and developmental histories which impacts on their	This study was vague in the context of methodological rigour. No critical reflections on that the women were effectively incarcerated and how they mitigated this from an ethical perspective. Lack of transparency about recruitment. The paper does offer rich data but under the unique setting of compulsory treatment and the effects

				ability to bond with the expected child.	this has on how women relate to their pregnancy and children. **Key Paper B**
Nordenfors (2017), Sweden	N=17, 21-40 years.	No data available regarding specific drug use.	Semi- structured questionnaire; specialist antenatal and child welfare support service; content analysis categorisation.	The main findings of this study were that women felt ambivalence towards pregnancy and were concerned about the support they received during this time, specifically the judgment they experiences from healthcare practitioners.	Brief statement on ethics which could have been more detailed. More detail about who conducted the interviews and who analysed the data. The main concern when appraising this paper was published in 2017 however, research was conducted between 2009- 2010. The methods of this research was also published in 2012 paper. **Key Paper B**
O'Connor (2020), Australia	N=20, 18-45 years.	Methamphetamine and polysubstance use including illicit benzodiazepine and cannabis.	Semi- structured interviews; hospital; thematic analysis.	This study identified the following five themes: 1) patterns of drug use and pregnancy; 2) mental health and MA use; 3) Family and domestic violence; 4) child protection and family support; 5) support services and assistance.	This is of good methodological quality and the paper performed well at quality appraisal. There is little data relating to pregnancy, despite this being the focus of the study. **Key Paper B**
Olsen (2014), Australia	N=90, 17-42 years.	Heroin, amphetamine, benzodiazepine, and other opioid injection.	In depth semi-structured interviews; community organisations; thematic analysis.	This study presented three main findings: 1) contraception, sterilisation, long-acting methods, easily reversible methods; 2) Non-use of contraception; 3) Pregnancy and Motherhood.	This is an excellent paper however, there is only a short section on pregnancy and motherhood (pages 5-6). **Key Paper B**
Ovens (2018), South Africa	N= 102, mean age 28.7 years	Methamphetamine, heroin, Wunga (form of black tar heroin and cannabis), Mandrax (methaqualone); cannabis, illicit	Semi- structured interviews; recruitment not outlined; thematic analysis.	Findings were presented under the following socioecological themes: 1) substance use within the domestic environment; 2) pre-natal care issues; 3) self-reporting of substance abuse; 4) treatment for substance use; (5) termination of drug use; 6) access to	This paper did not perform well under quality appraisal with concerns relating to methodological quality. Concerns about the language used (coloured woman used 60 times, substance abuse) in a 2018 published paper. Lots of data but responses seem quite

		prescription medication, cocaine,		treatment; 7) counselling; and 8) effective parenting skills.	abrupt- more like open ended answers akin to a survey response. **Key Paper C**
Paris (2020), USA	N=21, 21-44 years.	Crack cocaine, heroin.	Interviews; word of mouth and flyers sent to drug services; thematic analysis.	Findings showed that participants perceived a clear tension between sharing past or current substance use in order to receive care specific to their needs due to numerous fears and concerns. Four overarching themes were identified in the analysis: 1) fear, shame and guilt; 2) avoidance, manipulation, and lying; 3) reasons for disclosure, including maternal concern for the child, and; 4) ways of disclosing, including informing health care providers and family.	It was difficult to extract illicit drug use from those receiving medication for addiction treatment (MAT). The interpretation of the authors is difficult to follow. **Key Paper B**
Paterno (2019), USA	N=5, 31-56 years.	No data available regarding specific drug use.	Digital story telling workshop and semi-structured interviews; peer recruitment; constructivist grounded theory.	This study explored the role of peer mentors to support recovery among women who used drugs during pregnancy. All of the women involved in this study had lived experience of pregnancy and were now peer mentors supporting women in the community Peer mentoring supported their own recovery, and story sharing was integral to this process.	The methods used in this paper were novel and interesting. There is sufficient data for the paper but given the length of focus groups (data collection), the authors could have presented more of the rich data around lived experience of pregnancy. **Key Paper B**
Phillips (2007), Australia	N=10, 19 years and under.	Heroin, marijuana, amphetamine	Semi- structured interviews; flyers posted in areas of interest; thematic analysis.	Interview transcripts were analysed, and the results revealed six main themes: practice style, assessment of substance use, practice environment and privacy, child protection issues,	Concerns about the lack of transparency around ethical approval. This paper has lots of rich data pertaining to the relationship between midwives and pregnant women who use substances.

				health of the baby, and continuity of care. The findings are discussed in relation to recommendations for best practice in midwifery care when working with pregnant women who use substances.	Although this is a lived experience relating the review, the authors did not consider the settings of the interview, two populations involved and the interplay between these. **Key Paper B**
Roberts (2011), USA	N=38, age of participants not outlined.	Methamphetamine, crack/cocaine.	Semi- structured interviews; staff at three sites recruited women; thematic analysis.	This research explored how and why women who use drugs avoid prenatal care. The study found that women using drugs attend and avoid prenatal care for reasons not connected to their own drug use but out of concern for the health of their baby, social support, and extrinsic barriers such as health insurance and transportation. Women also fear the effects of drug use on their baby's health and fear being reported to Child Protective Services, each of which influence women's prenatal care use.	This is an important piece of research that relates to our review question. The authors have evidenced a robust and ethical approach to research and reported this well. The paper explores the barriers to prenatal care for women who use drugs and explores this adequately. There is a range of qualitative techniques used- interviews, focus groups, case studies. **Key Paper A**
Sadeghi (2021), Iran	N= 13, 21-50 years.	Methamphetamine, heroin and opium.	Interviews; harm reduction and treatment services; thematic analysis.	Six main themes emerged from the analysis: women's understanding, feelings, and actions regarding unplanned pregnancy; violence in public places; social rejection; maintaining femininity through maternal roles within hegemonic masculinity; social exclusion; and addiction as an aggravation of homelessness.	The authors demonstrate qualitative credibility and confidence within the paper and were explicit about their methods. Unfortunately, only a small section of findings explore pregnancy. **Key Paper B**
Sharpe (2001), USA	N=34, 26-47 years.	Crack cocaine.	Not clear if interviews were undertaken/ 8	This paper presented attachment during pregnancy. This included cognitive, affective and altruistic	Concerns around ethics, consent and who conducted the research. The procedures for data collection

			participants took part in a focus group; key informants from previous studies identified and recruited women; grounded theory thematic analysis.	attachment of women to their baby during pregnancy.	(interviews) is not stated, however the author outlines key informants were used to identify participants for the study. **Key Paper C**
Shieh (2002), USA	N=40, 16-37 years.	Marijuana, cocaine and heroin.	Semi- structured interviews; referred by healthcare providers; content analysis.	The following three issues shaped the women's responses to sex-for-crack pregnancies: 1) severity of crack use; 2) religious beliefs, and 3) social organisation patterns within poor Black communities.	Concerns about the lack of transparency around ethical approval and vague around the recruitment strategy. This is a very clinical qualitative study. Some rich data within the tables, although it was difficult to follow how the sub theme headings emerged. **Key Paper B**
Silva (2013), Portugal	N= 24, 25-42 years.	Cocaine, heroin.	Interviews, specialist maternity treatment centre; thematic analysis using grounded theory.	This study aims to show that the everyday risk construction of pregnancy, labour and delivery is compounded significantly by drug use and the stigmatisation associated with this perceived risk-taking behaviour.	The methodological rigor of this paper did not perform well under appraisal (for e.g. the authors allude to best practice but don't demonstrate that they did this). The data presented in this paper is 13 in text quotes in the findings, however many were from the same individuals. **Key Paper C**
Soderstrom (2012), Norway	N=14, 20-39 years.	Amphetamine and poly substance use.	Thematic focus groups; public inpatient clinic for families affected by parental drug use; interpretative	The findings show that recognition of pregnancy was distorted and delayed, and strong feelings of ambivalence and guilt persisted throughout pregnancy, along with hope for change.	"Those with ongoing substance use and/ or psychosis were excluded from participation" may be grounds to exclude? Fair and explicit limitations by the authors. **Key Paper B**

			phenomenological analysis.		
Stengel (2014), Canada	N=13, 17-40 years.	Heroin, methadone, crack/ cocaine, crystal methamphetamine, GHB, marijuana.	1-1 interviews; community organisation providing support to pregnant women; inductive thematic analysis.	This exploratory study aimed to understand the treatment and support needs of women who use drugs in a community-based maternity project. Findings included: healthcare and social care professionals adversarial or allies, risk and stigma.	This is a good paper with a couple of quality issues that may be due to word count of publication. Initially, I was confused about the aim, but this was clarified after reading the notes section. This research was conducted in partial fulfilment of a Masters. Although it was affiliated with a larger study, the author undertook all of the research within the paper. There is some rich data included in the paper including in depth exploration of lived experience of pregnancy (including birth plans). **Key Paper A**
Stone (2015), USA	N=30, 19-41 years.	Illicit opioid and benzodiazepine, marijuana.	Semi- structured interviews; flyers in maternity wards and drug treatment centres; thematic analysis.	This study presented the stories of women who use drugs and the strategies they used to avoid detection as a drug user during pregnancy. Within the findings women described barriers to care and the rationale for avoiding care.	Some concerns about lack of transparency in relation to ethical approval and data analysis. However, there are rich accounts throughout the findings that directly relate to the SR. **Key Paper A**
Torchalla (2014), Canada	N=27, mean age 32	No data available regarding specific drug use.	Semi- structured interviews; posters in services; thematic analysis	Six key themes were found; the themes are as follows: (1) women spoke of adverse and traumatic experiences in early childhood, (2) the continuation of adversities and trauma in adulthood, (3) intimate partner violence, (4) structural violence, (5) transgenerational trauma and (6) their interest in trauma counselling. The results	Within this study there was little reflection on lived experience of pregnancy. A good paper with methodological rigor. **Key Paper B**

				illustrate the complexities of the target population, all of which are important considerations when offering harm reduction services.	
Van Soyoc (2017), USA	N=15, 23-38 years.	Marijuana, methamphetamine, heroin, cocaine and other opiates.	Semi- structured interviews; inpatient substance use treatment centre; constructivist grounded theory.	The qualitative analysis yielded ten themes, clustered under four thematic categories: 1) beliefs about the negative impact on the baby of substance use during pregnancy; 2) seeking information about the consequences of substance use; 3) reducing substance use outside of accessing treatment services, and 4) engaging in healthy behaviours to protect the baby from harm.	This is a good paper with lots of data and themes. The only concern is the positionality of the researcher (statement on reflexivity helped to mitigate this) however, the first author conducted the research, coding and analysis. It was difficult to see how the other authors contributed to the study (assumption is they supervised the student). **Key Paper B**
Varty (2011), UK	N=6, age range not outlined.	Heroin.	In depth semi-structured interviews; substance use midwife; thematic analysis using grounded theory.	A small qualitative study aimed to explore women's experience of taking methadone or buprenorphine. Findings included: experiences of treatment, breastfeeding, and parents. The overarching theme was the experiences of stigma and shame felt by treatment seeking pregnant women.	This is a small qualitative study- while the title and aim suggest it is focussed on OST, the data within the paper was full of illicit substance use experiences. **Key Paper A**
Weber (2023), USA	N=17, 23-42 years.	Methamphetamine, heroin, amphetamine	Semi-structured interviews; substance use services, homeless shelters; grounded theory.	The aim of this study was to understand how rural women who use drugs navigate pregnancy and post-partum. Four analytic categories were developed to address the research questions. The categories were named: 1) onset of use; 2) dynamics of addiction; 3) moods of addiction; and 4) motivating factors.	This is a good thesis with clear statements/ references and findings. **Key Paper B**

Wronski (2016), Brazil	N=3, 24- 36 years	Crack cocaine and marijuana.	Semi- structured interviews; not outlined; interpretive synthesis.	In this study, women reported that the use of the substance had a negative impact on the gestational period. They revealed difficulties they face and the risks associated with obtaining drugs while pregnant. The authors emphasised the importance of a strengthened social support network and treatment alternatives that assist in the recovery process, allowing for continuous monitoring.	A low-quality paper in terms of methodological rigour. There is some data within the paper, but it is difficult to understand how the themes emerged, how content analysis was applied and by whom, who conducted the interviews and what was their positionality. The interviews were semi structured- what topics did they cover? *This paper was translated from Portuguese using Google Translate. **Key Paper C**
Yotebieng (2016), Kenya	N=17, 20-35 years.	Injecting drugs.	In depth semi-structured interviews; known to research assistant from previous study; social ecological systems framework.	This study found the following three interconnected themes across women's stories: 1) the social context of substance use, including gender inequality and social suffering as driving factors of continued use during pregnancy; 2) conflicting sources of information and disjuncture in decision making regarding substance use and its health effects in pregnancy; 3) healthcare interactions biased toward HIV screening over alcohol and drug screening education.	This research presents limited rich data. There was a considerable focus on characteristics. **Key Paper B**
Zsuzsa (2019), Hungary	N=34, 18-43 years.	Amphetamines, 'designer drugs' and heroin.	Participant observation, semi structured interviews, in-depth interviews, and document collection; harm	The aim of the study was to explore the relationship between drug use to pregnancy and motherhood. The following themes emerged which shaped women's experience of pregnancy and motherhood: Financial uncertainty; Separation; Staying at	The author made a concerted effort to outline the processes and theory used in the study. The methodological rigour of the paper was to a high standard with critical reflections and clarification throughout meaning its methodological criteria was high. There is some rich

			reduction service for pregnant women; thematic analysis.	home vs. work; Substance use; Stigmatisation; Time; Supply system; Blaming; Unique; Friendships; Loss; Positive change; Their feelings and thoughts about their children; Relationship with Dad; Acquiring explicit, implicit knowledge about motherhood	data included in the study and a table summary is useful for the SR. The only real concern is this study was undertaken between 2009- 2010 and was only published in 2019 meaning a lot of what was included in the study was out of date (including references used). * This paper was translated from Hungarian using Google translate. **Key Paper B**

Chapter 4: Qualitative Systematic Review Findings

4.1 Chapter introduction

This chapter contains the findings from the qualitative systematic review which explored the lived experience of pregnancy among women who use illicit drugs. The chapter begins with a summary of included studies, describing the number of participants from primary studies, the drugs that were used during pregnancy and where the studies were conducted. Each theme is then explored in detail with sub themes discussed in each. The chapter concludes with critical reflection on the language used to describe women who use drugs by the authors of primary studies included in this review.

4.2 Summary of included studies:

In total, 49 primary studies which met the inclusion criteria and explored the perspectives of women who used illicit drugs during pregnancy were included for synthesis. The studies reported upon a combined sample of 1210 women, whose age ranged between 18-58 years. Women reported using a range of drugs and this often included polydrug use. Heroin, cocaine/crack cocaine and cannabis were the most frequently reported drugs that were used by women during pregnancy. Methamphetamine, amphetamine, psychedelics (magic mushrooms, 3,4- MDMA, Ketamine), solvents and other drugs (benzodiazepine, Khat, Wunga, Mandrax, Rohypnol) were also reported by participants of the studies included in this review. Some studies did not specify the drugs that were used during pregnancy and referred to them in generic terms such as, “illicit drugs” or “drugs” (da Costa *et al.*, 2015; Mattocks *et al.*, 2017; Mrete Myra *et al.*, 2016; Nordenfors & Hojer, 2017; Paterno *et al.*, 2019; Torchalla *et al.*, 2014). Twenty nine of the studies recruited participants through drug treatment centres (including drug rehabilitation facilities and harm reduction services) indicating that most women were engaging in drug treatment at the time of interview (Abdul-Khabir *et al.*, 2014; Baker & Carson, 1999; Benoit *et al.*, 2015; Chandler *et al.*, 2013; Cleveland *et al.*, 2016; Courvette *et al.*, 2016; Frazer *et al.* ,2019; Goodman *et al.*, 2020; Hall *et al.*, 2006; Jessup *et al.*, 2003; Leppo, 2012; Mattocks *et al.*, 2017; Mburu *et al.*, 2020; Mejak & Kastelic, 2016; O’Connor *et al.*, 2020; Olsen *et al.*, 2014; Paterno *et al.*, 2019; Phillips *et al.*, 2007; Roberts & Pies, 2011; Sadeghi *et al.*, 2021; Stengel, 2014; Soderstrom *et al.*, 2012; Torchalla *et al.*, 2014; Van Soyoc *et al.*, 2017; Varty & Alwyn, 2011; Weber, 2023; Wronski *et al.*, 2016; Yotebieng *et al.*, 2016; Zsuza, 2019). Eight studies recruited participants through health services (reported

as antenatal, prenatal, midwifery services) (Chang *et al.*, 2019; De Souza Ramiro *et al.*, 2018); Diez, 2020; Myra Mrete *et al.*, 2016; Morris, 2012; Nordenfors & Hojer, 2017; Sheih & Kravitz, 2002; Silva *et al.*, 2013). Two studies reported they recruited in public spaces (de Souza Ramiro *et al.*, 2018; Gordon *et al.*, 2019) and eleven studies did not specify where they recruited participants from (da Costa *et al.*, 2015; Hathazi *et al.*, 2009; Kearney, 1994; Latuskie *et al.*, 2019; Lewis *et al.*, 1995; Miller *et al.*, 1995; Ovens & Prinsloo, 2018; Paris *et al.*, 2020; Sharpe, 2001; Stone, 2015).

Of the 49 studies included in this review, there was variation in the reporting on whether participants were pregnant at time of interview or postnatal (and length of time since pregnancy). Sixteen studies explicitly outlined that some or all of their participants were pregnant at time of interview with variation in reporting on gestation (Chang *et al.*, 2019; Diez *et al.*, 2020; Frazer *et al.*, 2019; Jessup *et al.*, 2003; Lewis *et al.*, 1995; Mattocks *et al.*, 2017; Morris *et al.*, 2012; Myra Mrete *et al.*, 2016; Olsen *et al.*, 2014; Roberts & Pies, 2011; Sheih & Kravitz, 2002; Stengel *et al.*, 2014; Stone, 2015, Van Soyoc *et al.*, 2017; Weber, 2023; Yotebieng *et al.*, 2016) Others referenced women postnatal (Cleveland *et al.*, 2015; Goodman *et al.*, 2020; Leppo *et al.*, 2012; Mattocks *et al.*,2017; O'Connor *et al.*, 2020; Sharpe, 2001; Silva *et al.*, 2013; Stengel *et al.*, 2014; Van Soyoc *et al.*, 2017). The remaining studies included in this review reported that participants had experienced pregnancy but did not indicate if this was recent or historic (Abdul-Khabir *et al.*,2014 Baker & Carson, 1999; Benoit *et al.*, 2015; Courvette *et al.*,2016; Da Costa *et al.*, 2015; De Souza Ramiro *et al.*, 2018; Gordon *et al.*, 2019; Hathazi *et al.*, 2009; Kearney, 1994; Latuskie *et al.*, 2019; Leppo *et al.*, Mburu *et al.*, Mejak *et al.*, Miller *et al.*, 1995; Nordenfors, O'Connor, 2017; Ovens &Prinsloo, 2018); Paris, 2020; Paterno *et al.*, 2019; Sadeghi *et al.*, 2021; Soderstrom *et al.*, 2012; Torchalla *et al.*, 2014; Varty & Alwyn, 2011; Zsuza, 2019).

This synthesis included studies from six continents (Africa, Asia, North America, South America, Europe and Australia). Many of the studies were conducted in the USA (19) (Abdul-Khabir *et al.*, 2014; Baker & Carson, 1999; Chang *et al.*, 2019; Cleveland et al., 2016; Frazer *et al.*, 2019; Goodman *et al.*, 2020; Hathazi *et al.*, 2009; Jessup *et al.*, 2003; Kearney *et al.*, 1994; Mattocks *et al.*, 2017; Miller *et al.*, 1995; Paris *et al.*, 2020; Paterno *et al.*, 2019; Roberts *et al.*,

2011; Sharpe, 2001; Sheih & Kravitz, 2002; Stone, 2015; Van Scoyoc *et al.*, 2017; Weber *et al.*, 2023). Five studies were carried out in both the UK and Canada and four in Australia.

The variation in reporting from primary studies and the unspecified heterogeneity (in terms of both the women in relation to when they were pregnant- currently, recently or long ago- and the nature of their drug use- type, pattern of use) included in this review made it difficult to present participants pregnancy status and drug use during pregnancy. While most of the primary studies reported data collection was undertaken in drug treatment services, which would indicate engagement with these services, alongside the possibility of Opiate Substitute Treatment (OST) for those who used opioids, it is not clear whether they were using illicit substances alongside this. As outlined above, some studies gave characteristics relating to pregnancy (such as gestation, post-partum month), however, most of the included studies information relating to pregnancy was often vague and ambiguous. While systematic reviews rely on the reporting of the authors of primary studies, lack of clarity within primary studies included in this review impacted upon the analysis. Given the lack of consistency in reporting across primary studies, it was not possible to comparatively analyse participants characteristics or experiences. While this qualitative systematic review has an international lens, the transferability of findings is limited given its heterogeneity. Further information about the studies, including the characteristics of participants and critical appraisal, were presented at the end of Chapter 3.

4.3 Themes

The following four overarching themes were identified during thematic evidence synthesis: 1) Surveillance and ambivalence to medication; 2) window of opportunity; 3) Fertility and pregnancy continuation; 4) Self-stigmatisation. Within each theme, several sub themes emerged. Table 4 (below), outlines the themes and associated sub-themes contained within the findings.

Table 4: Theme and Sub-theme overview

Theme	**Sub-theme**
	Surveillance from health and social care professionals

1) Surveillance and ambivalence to medication	Responding to Surveillance
	Ambivalence to prescription medication
2) Window of opportunity	Taking care of baby starts with taking care of self
	Perception of risk to self/ baby
	Isolation and Fear
3) Fertility and pregnancy continuation	Misperception of fertility
	Termination and access to care
4) Self- stigmatisation	Shame and Guilt
	Stigmatisation of women in primary studies

4.4 Theme 1: Surveillance and ambivalence to medication

Women who use drugs were acutely aware that they are under surveillance in many aspects of their lives. This surveillance increases exponentially in pregnancy whereby they are monitored in order to negate/ reduce risk to their baby. The surveillance that women experience comes from health and social care professionals, from family and friends, from their peers who use drugs and the wider community.

4.4.1 Surveillance from health and social care professionals

Within the primary studies included in this review, women who used drugs reported being aware that pregnancy means they will be more visible in the context of health and social care services (Abdul-Khabir *et al.*, 2014; Baker & Carson, 1999; Benoit *et al.*, 2015; Chandler *et al.*, 2013; Chang *et al.*, 2019; Cleveland *et al.*, 2016; Courvette *et al.*, 2016; de Souza Ramiro *et al.*, 2018; Frazer *et al.* ,2019; Goodman *et al.*, 2020; Hall *et al.*, 2006; Hathazi *et al.*, 2009; Howard, 2016; Latuskie *et al.*, 2019; Leppo, 2012; Lewis *et al.*, 1995; Mattocks *et al.*, 2017; Morris *et al.*, 2012; Myra Mrete *et al.*, 2016; Nordenfors & Hojer, 2017; O'Connor *et al.*, 2020;

Olsen *et al.*, 2014; Ovens & Prinsloo, 2018; Paris *et al.*, 2020; Phillips *et al.*, 2007; Roberts & Pies, 2011; Sharpe, 2001; Soderstrom *et al.*, 2012; Stengel, 2014; Stone, 2015; Van Soyoc *et al.*, 2017; Varty & Alwyn, 2011; Weber, 2023; Yotebieng *et al.*, 2016 Zsuza, 2019). Pregnant women in these studies had frequent interactions with health and social care professionals including midwives, criminal justice practitioners and social services/ child protection services. For example, in Frazer *et al.*, (2019) a quarter of participants felt that entering treatment would attract unwanted legal attention and impact on the custody of their children and unborn child. Conversely, many studies found that women engaged in treatment with the view that engagement and visibility from professionals would demonstrate their commitment to make changes to their drug use and increase their chances of retaining their children in their care once born (Benoit *et al.*, 2015; Chandler *et al.*, 2013; Da Costa *et al.*, 2015; Lewis *et al.*, 1995; Weber, 2023). For example, the quote below:

> *"As long as the people at the core group can see that I'm clean hopefully they'll feel more confident about taking her off the [child protection] list."*
> *(Chandler et al., 2013)*

Many women described adverse health and social care interactions during pregnancy (Diez *et al.*, 2020; Mejak & Kastelic, 2016; Lewis *et al.*, 1995; Morris *et al.*, 2012; Paris *et al.*, 2020; Soderstrom *et al.*, 2012). Within these interactions and appointments women reported they were confronted with judgemental attitudes towards them from health and social care practitioners (Goodman *et al.*, 2020; Leppo, 2012; Mejak & Kastelic, 2016; Morris *et al.*, 2012; Nordenfors & Hojer, 2017; Ovens & Prinsloo, 2018; Silva *et al.*, 2012; Stengel, 2014; Stone, 2015; Varty & Alwyn, 2011). One woman from Morris *et al.*, (2012) reported healthcare professionals would approach them differently, something which was always at the forefront of interactions.

> *"You just knew that you were not going to be treated equally and like other pregnant women and accepted for who you were. I mean after all I was at the clinic because of drug problems, and that was never forgotten [by the staff]." (Morris et al., 2012)*

One woman from a Slovenian study described a difficult and upsetting encounter within a maternity hospital which transpired after professionals became aware she had a blood borne

virus (Mejak & Kastelic, 2016). This encounter had a profound impact on her mental health and wellbeing, increasing her vulnerability.

> *They were really mean to me at the maternity hospital. When they realized I had hepatitis C, they wore gloves while holding my baby or bringing me food. This was too much for me, I could not handle this, it was very stressful, two days later I had psychosis and I got postpartum depression." (Mejak & Kastelic, 2016)*

In antenatal settings, women often felt that when they were identified as using drugs (from their physical appearance and then confirmed through drug testing) they reported being treated unfairly (Jessup et al, 2003; Nordenfors & Hojer, 2017; Silva *et al.*, 2012; Stengel, 2014; Stone, 2015). Women in Silva *et al.*, (2012) and Nordenfors & Hojer, (2017) described how they were aware they were treated differently from other pregnant women who attended services.

> *"I'm tired of being discriminated ... from the moment I stepped in the emergencies service, and they knew I was a drug addict, they treated me differently." (Silva et al., 2012)*

> *"At the other antenatal services, they approached me differently—they identified me with my addiction problem—as if my problem was what identified me as a person. I didn't like that." (Nordenfors & Hojer, 2017)*

Being treated differently on the basis of their drug use, often leaves women feeling isolated and open scrutiny from other professionals and patients. Often the confirmation of their drug use was then used as evidence to inform statutory services for intervention and possibly as justification to be treated differently by professionals. This confirmation/ evidence was also the pivotal point at which women came under surveillance from health and social care agencies.

In contrast to this, when women were supported with non-judgemental attitudes during health and social care appointments, many were more likely to engage with services (Hall et *al*., 2006; Hathazi *et al.*, 2009; Howard, 2016; Mattocks, 2017).

"I got care the whole time. I got on methadone and everything. [The healthcare providers] were awesome. They couldn't have treated me better if I'd been the Queen of England." (Hathazi et al., 2009)

Positive interactions with healthcare providers allowed women to feel comfortable in their surroundings and that they were being given the same treatment and support as other patients. This also gave them some anonymity among other patients (as a pregnant woman who used drugs) with one woman directly correlated positive support and care with providers' use of discretion and confidentiality.

"They didn't let anybody else in the ward know why you were there and that you were a drug user...they were discrete..." (Hall et al., 2006)

For women who use drugs, supportive and non-judgemental approaches to care is integral to their engagement with support during pregnancy.

4.4.2 Responding to surveillance.

Throughout the primary studies included in this review, women spoke about their roles, responsibilities and managing daily life, including managing the monitoring of themselves as prospective mothers (Benoit *et al.*, 2015; Chandler *et al.*, 2013; Chang *et al.*, 2019; Cleveland *et al.*, 2016; de Souza Ramiro *et al.*, 2018; Frazer *et al.* ,2019; Goodman *et al.*, 2020; Hall *et al.*, 2006; Hathazi *et al.*, 2009; Latuskie *et al.*, 2019; Leppo, 2012; Mattocks *et al.*, 2017; Mburu *et al.*, 2018; Mejak & Kastelic, 2016; Morris *et al.*, 2012; Nordenfors & Hojer, 2017; O'Connor *et al.*, 2020; Olsen *et al.*, 2014; Ovens & Prinsloo, 2018; Paterno *et al.*, 2019; Roberts & Pies, 2011; Sharpe, 2001; Soderstrom *et al.*, 2012; Stone, 2015; Varty & Alwyn, 2011; Yotebieng *et al.*, 2016). Many women felt pregnancy brought the obligation to conform or be seen to be conforming to the societal expectations of pregnancy and motherhood (Benoit *et al.*, 2015; Chandler *et al.*, 2013; Chang *et al.*, 2019; Cleveland *et al.*, 2016; Da Costa *et al.*, 2015; de Souza Ramiro *et al.*, 2018; Frazer *et al.* ,2019; Goodman *et al.*, 2020; Hall *et al.*, 2006; Howard, 2016; Hathazi *et al.*, 2009; Jessup *et al.*, 2003; Latuskie *et al.*, 2019; Leppo, 2012; Mattocks *et al.*, 2017; Mburu *et al.*, 2018; Mejak & Kastelic, 2016; Morris *et al.*, 2012; Nordenfors & Hojer, 2017; O'Connor *et al.*, 2020; Olsen *et al.*, 2014; Ovens & Prinsloo, 2018; Paterno *et al.*, 2019; Roberts & Pies, 2011; Sharpe, 2001; Soderstrom *et al.*, 2012; Stone, 2015; Varty & Alwyn, 2011; Yotebieng *et al.*, 2016). In a study by Morris *et al.*, (2012), one woman described the

performativity of becoming a 'good' addict, whereby she felt compelled to adhere to the social and pharmaceutical prescribing she was offered.

> *"I got the gist early in the piece. That if I was a 'good addict' the word would get around and I would be treated OK. I was polite and pleasant to them all and told the truth about giving up the 'smack' and sticking to the methadone. I made it work by doing the right thing by them and me" (Morris et al., 2012)*

This performativity to health and social care support services was further demonstrated in Mattocks *et al.*, (2017) whereby one woman presented themselves as managing their drug use to professionals, possibly to mitigate or manage surveillance they expected from them.

> *"My obstetrician encouraged me to get treatment. And then I would lie about it and say I was doing fine because I was thinking I wouldn't do it [use heroin] continuously. I would do it continuously, but at least not every single day. I thought, I got a grip, I can stop, I have control, but in reality I had no control." (Mattocks et al., 2017).*

For some women who use drugs, pregnancy and the associated surveillance, added structure and routine whereby they had to be organised and attend appointments with health and social care professionals (Benoit *et al.*, 2015; Chandler *et al.*, 2013; Cleveland *et al.*, 2016; Courvette *et al.*, 2016; Frazer *et al.* ,2019; Goodman *et al.*, 2020; Hall *et al.*, 2006; Hathazi *et al.*, 2009; Howard, 2016; Latuskie *et al.*, 2019; Leppo, 2012; Mejak & Kastelic, 2016; Nordenfors & Hojer, 2017; Paterno *et al.*, 2019; Roberts & Pies, 2011; Torchalla *et al.*,2014; Varty & Alwyn, 2011; Yotebieng *et al.*, 2016). A participant in the study by Goodman *et al.*, (2020) described how she managed with appointments during this time:

> *It was just like appointment after appointment. My weeks were packed full … I worked two jobs … So, I was a busy girl. I got a big planner. Jotting everything down, oh my God, it's packed full still with her appointments and mine!" (Goodman et al., 2020)*

Other women reported withdrawing from or avoiding care following adverse interactions with practitioners whereby they felt judgement and shame (Frazer *et al.* ,2019; Goodman *et*

al., 2020; Hall *et al.*, 2006; Howard, 2016; Leppo, 2012; Mattocks *et al.*, 2017; Mejak & Kastelic, 2016; Morris *et al.*, 2012; Nordenfors & Hojer, 2017; Ovens & Prinsloo, 2018; Soderstrom *et al.*, 2012). In some instances, women would avoid or delay attending antenatal appointments as they were aware drug testing would be undertaken (Stone, 2015; Jessup et al, 2003).

> *"I wouldn't go to the doctors. I would skip appointments and things and stretch them out. I always went because, again, CPS will get involved if you don't go to the doctors, so you still have to go, but you know, you didn't—you just have to stretch it out or go late or delay it or whatever." (Stone, 2015)*

> *"Knowing that they were gonna test me for drugs, that's what scared me…That's why I didn't go to prenatal care…I didn't want to lose my baby." (Jessup et al., 2003)*

Women's response to surveillance was influenced by what they wanted to 'present' to health and social agencies, often motivated to mitigate adversarial and confrontational interventions.

4.4.3 Ambivalence to prescription medication

Pregnant women who use drugs were concerned that their baby would experience drug withdrawal symptoms when they were born (Abdul- Khabir *et al.*, 2014; Baker & Carson, 1999; Chandler *et al.*, 2013; Cleveland *et al.*, 2016; Courvette *et al.*, 2016; Goodman *et al.*, 2020; Leppo, 2012; Lewis *et al.*, 1995; Mejak & Kastelic, 2016; Sheih & Kravitz, 2002; Stengel *et al.*, 2014; Varty & Alwyn *et al.*, 2011). Women who were accessing drug treatment were apprehensive that their baby would experience neonatal abstinence syndrome (NAS) from prescribed opioids such as methadone.

> *"I never wanted to have a baby while I was on methadone. I, one of the things that was really hard for me was coming to terms with the fact that my baby might be born with withdrawal symptoms just from being on the methadone" (Stengel et al., 2014).*

Women could identify with the physical and psychological effects of withdrawal and expressed concern for their children, having had lived experience of withdrawal themselves.

> *"I don't think that any mother should put anything into her system ... that mother knows what it's like to withdraw, as an adult, so imagine what it's like for a baby." (Varty & Alwyn et al., 2011).*

One woman aimed to reduce the risk of her baby experiencing NAS and did so by reducing her dose below what medical professionals recommended for her (Chandler *et al.*, 2013).

> *"The doctor wanted me to stall at 50 [ml methadone] but I took it to 45 just to make sure because [GP] says it's really unlikely that a baby will withdraw if you're on 50 or less" (Chandler et al., 2013)*

In a study by Stone (2015), women shared ambivalence to OST use during pregnancy, describing methadone as "liquid handcuffs" and a legal way to get high.

> *"I think [Suboxone maintenance] is retarded [laughs]. All it is a legal way for you to get high. Most people abuse it, they don't take it the way they're supposed to. […] You're still getting high, and you're not going through withdrawal. All it is a state-funded way for you to get high. Now the state's paying for your way to get high, and that's the way I feel about methadone." (Stone, 2015)*

As demonstrated above, women lacked confidence in the interventions they were offered and for this reason, they explored alternative ways to manage the risks drug use posed to themselves and their unborn child. Women often used both formal and informal information to develop bespoke harm reduction strategies which would mitigate the risks and meet their needs. Harm reduction strategies included accessing treatment for drug and alcohol use, reducing their drug use or abstaining completely, and switching substances or method of use (Abdul-Khabir *et al.*, 2014; Baker & Carson, 1999; Benoit *et al.*, 2015; Cleveland *et al.*, 2016; de Souza Ramiro *et al.*, 2018; Goodman *et al.*, 2020; Leppo, 2012; Ovens & Prinsloo, 2018; Stone, 2015; Van Soyoc *et al.*, 2017; Varty & Alwyn, 2011; Yotebieng *et al.*, 2016). Examples of this can be found in Leppo *et al.*, (2012) and Mattocks *et al.*, (2017), whereby women

shifted their drug use to illicit (street bought) Subutex to avoid using amphetamines under the guise that Subutex posed less risk to their baby.

> *"I've been told that there is no evidence of any specific harm [from Subutex use]. That's why I felt quite safe using it. It would have been a different story if I had used amphetamines or large amounts of benzodiazepines. I have said no to amphetamines during the pregnancy and that's been easy; I haven't felt like using it. Using one drug less is a positive thing." (Leppo et al., 2012).*

Conversely, some women felt smaller amounts of illicit drug use was less risky than prescribed medication such as methadone (Mattocks *et al.*, 2017; Hall *et al.*, 2006).

> *"I tried to get clean off that on my own by buying it off the street. I mean, I know I probably wasn't using it the right way, but I would just ask them like what their doctor told them to do, and I tried, and it would like get me high still, so I just was like still in that mindset." (Mattocks et al., 2017)*

> *"I was back using heroin but very little, but I thought it was better using very little than going back on methadone" (Hall et al., 2006).*

Women who use drugs often independently acquired information in relation to drug use during pregnancy, sourcing information from peers and web searches. They used this information to develop harm reduction strategies to mitigate risks to themselves and their unborn child. Harm reduction strategies included switching substances, accessing treatment for drug and alcohol use, reducing their substance use or abstaining completely (Abdul-Khabir *et al.*, 2014; Baker & Carson, 1999; Benoit *et al.*, 2015; Cleveland *et al.*, 2016; de Souza Ramiro *et al.*, 2018; Goodman *et al.*, 2020; Leppo, 2012; Ovens & Prinsloo, 2018; Stone, 2015; Varty & Alwyn, 2011; Yotebieng *et al.*, 2016). A woman involved in Goodman *et al.*, (2020) recounted how she played her own doctor during pregnancy.

> *"I found out I was pregnant. I continued using Percocets [oxycodone] for about a month. And then, from my prenatal care and my people on the street and friends, I heard about Suboxone [buprenorphine/naloxone]. So, I took myself off of the Percocets, switched myself to the Suboxone*

[buprenorphine/naloxone]... and made it work until I could get in … So, I guess I tried to play my own doctor and tried to do what was right." (Goodman et al., 2020).

Another woman detailed her plans to cut down using drugs by weaning herself off quickly, seemingly unaware of the risk this could pose.

"I tried to wean myself off of it, like [I'm] only going to do this hit today and then tomorrow I'm not even going to do nothing, and then I'll just be good from there on out." (Van Scoyoc et al., 2017)

The information women had about the risks associated with perinatal drug use was often acquired anecdotally from other women who used drugs and from web searches (Alwyn & Varty, 2914; Goodman *et al.*, 2020; Leppo, 2012; Van Soyoc *et al.*, 2017).

"Me and my boyfriend had done our own research after leaving the hospital. Immediately we were on the phone, Googling what to do with an addiction problem and being pregnant." (Goodman et al., 2020).

Participants involved in a study by Van Soyoc *et al.*, (2017) reported searching terms including "meth babies," "methamphetamine use while you're pregnant," "meth faces," "pregnant, drugs, foetus," "heroin and pregnancy," and "dopamine effects.". Often the information they had received from peers (women/ partners who used drugs) informed their decision making around pregnancy and drug use.

For women who use drugs during pregnancy, there is complex interplay between judgment, visibility and managing the risk to themselves and their baby. Developing harm reduction strategies to meet their own needs is perhaps a response to complex interplay but also a way to manage external surveillance. The way in which judgment, visibility and risk is responded to and perceived by women who use drugs, can have a profound impact on the support and care they receive. The difficulty of managing this interplay has the potential to increase their vulnerability and further marginalise them.

4.5 Theme 2: Window of opportunity

Often pregnancy was framed as a "window of opportunity" for women to make changes to their lifestyle and drug use (Abdul-Khabir *et al.*, 2014; Goodman *et al.*, 2020; Hall *et al.*, 2006; Soderstrom, 2012), however, as demonstrated above, pregnancy was not the determining factor in stopping drug use completely (Courvette *et al.*, 2016; Morris *et al.*, 2012; Myra Mrete *et al.*, 2016; Nordenfors & Hojer, 2017; O'Connor *et al.*, 2020; Olsen *et al.*, 2014; Ovens & Prinsloo, 2018; Paris *et al.*, 2020; Sharpe, 2001; Soderstrom *et al.*, 2012; Stone, 2015; Van Soyoc *et al.*, 2017; Varty & Alwyn, 2011; Yotebieng *et al.*, 2016).

For some women, the adversity and trauma they had suffered prior to pregnancy had made reduction and abstinence of drug use difficult and for those who had abstained from using drugs, they found that during the course of their pregnancy, a relapse of drug use occurred (Cleveland *et al.*, 2016; O'Connor et al, 2020; Latuskie *et al.*, 2019).

> *" . . . the third trimester right before the baby is born. It is one of the most dangerous times for women to relapse. It did actually happen to me, six weeks prior to my daughter being born, I did relapse. And it was probably because of the stress of knowing that she was coming so soon and I wasn't really prepared. It made me use." (Latuskie et al., 2019).*

Women spoke about their childhood, introduction to drugs, with many discussing intergenerational drug use (Baker & Carson, 1999; Benoit *et al.*, 2015; Chandler *et al.*, 2013; Cleveland *et al.*, 2016; Courvette *et al.*, 2016; Hall *et al.*, 2006; Howard *et al.*, 2016; Latuskie *et al.*, 2019; O'Connor *et al.*, 2020; Silva *et al.*, 2013; Stone, 2015; Van Soyoc *et al.*, 2017; Varty & Alwyn, 2011). They shared how pregnancy doesn't remove childhood trauma and the adversity associated with drug dependency.

> *"I don't know, like, just because you're pregnant it doesn't magically change what's going on for you and how you've been brought up and all the shit that's happened to you." (Benoit et al., 2015).*

4.5.1 Taking care of baby starts with taking care of self

For many women who use drugs, pregnancy was a pivotal point in their life whereby they had to assess their current lifestyle and make necessary changes to prepare for motherhood (Abdul-Khabir *et al.*, 2014; Benoit *et al.*, 2015; Chandler *et al.*, 2013; Chang *et al.*, 2019;

Cleveland *et al.*, 2016; Courvette *et al.*, 2016; de Souza Ramiro *et al.*, 2018; Frazer *et al.* ,2019; Goodman *et al.*, 2020; Gordon *et al.*, 2019; Hall *et al.*, 2006; Hathazi *et al.*, 2009; Latuskie *et al.*, 2019; Leppo, 2012; Lewis *et al.*, 1995; Mattocks *et al.*, 2017; Mburu *et al.*, 2018; Mejak & Kastelic, 2016; Morris *et al.*, 2012; Nordenfors & Hojer, 2017; O'Connor *et al.*, 2020; Olsen *et al.*, 2014; Paterno *et al.*, 2019; Phillips *et al.*, 2007; Roberts & Pies, 2011; Sheih *et al.*, 2001; Soderstrom *et al.*, 2012; Stengel *et al.*, 2014; Stone, Torchalla *et al.*, 2014; Varty & Alwyn, 2011; Zsusza, 2019). One woman in Goodman *et al.*, study described how pregnancy gave them motivation to abstain from health-compromising behaviours in order to care for herself, notably to stop using drugs:

> *"Just finding out that I was pregnant did give me hope. It made me feel like, wow, I really have – not just for myself-but I have a reason to stop" (Goodman et al., 2020)*

For women who use drugs, pregnancy was a time of responsibility, where they had to consider the needs and outcomes for their baby alongside their own. Often pregnancy was framed as an opportunity for women to change and women often presented narratives that pregnancy and children were the biggest motivating factor to gain and sustain recovery from drug use (Cleveland *et al.*, 2016; de Souza Ramiro *et al.*, 2018; Goodman *et al.*, 2020; Hall *et al.*, 2006; Mejak & Kastelic, 2016). Sometimes women planned their pregnancy to facilitate and incite much wanted changes to their lifestyle and drug use.

> *"My pregnancy was planned, because I wanted this baby so much and I thought that having a baby would change my life. I wanted it." (Mejak & Kastelic, 2016)*

Pregnancy and children was often framed as an opportunity to "save them" from drug use and motherhood was seen as an opportunity to change, but also as an opportunity to shift their stigmatised identity away from drug user, to good mother (Silva *et al.*, 2012). This included changing their bad lifestyle (Olsen *et al.*, 2014).

> *"I didn't know what to do, I felt I couldn't stop taking drugs, how could I be a good mother? Afterwards I could see things more clearly: I could stop it for this child, my baby would save me and it gave me strength enough to carry on" (Silva et al., 2012).*

Some women described that their motivation to stop using drugs, was because they wanted to "keep" their baby (Abdul- Khabir *et al.*, 2014; Paris *et al.*, 2020; Silva *et al.*, 2012). For others, this hope was often hampered by cravings and problematic cycle of drug dependency (Mrete Myra *et al.*, 2016).

> *"It gave me a better reason to stop, but the craving for drugs was still there even though I was pregnant, so it's not enough motivation to quit. It's hard to have an active substance abuse problem and to be a good mother, so I'm very happy that I've managed to stop." (Mrete Myra et al., 2016)*

For many women who used drugs during pregnancy, taking care of their baby in utero began with taking care of themselves, a necessary means to demonstrate that they were caring and capable prospective mothers (Benoit *et al.*, 2015; Chandler *et al.*, 2013; Chang *et al.*, 2019; Cleveland *et al.*, 2016; Courvette *et al.*, 2016; de Souza Ramiro *et al.*, 2018; Frazer *et al.* , 2019; Goodman *et al.*, 2020; Hall *et al.*, 2006; Hathazi *et al.*, 2009; Howard, 2016; Jessup *et al.*, 2003; Leppo, 2012; Lewis *et al.*, 1995; Mejak & Kastelic, 2016; Paris *et al.*, 2020; Roberts & Pies, 2011; Sharpe, 2001; Sheih *et al.*, 2001; Silva *et al.*, 2013; Soderstrom *et al.*, 2012; Stengel *et al.*, 2014; Stone, 2015; Van Soyoc *et al.*, 2017; Varty & Alwyn, 2011; Weber, 2023). Women made changes to their diet and lifestyle, including taking vitamins, in an effort to take care of their baby, even if they could not make changes to their drug use during this time (Courvette *et al.*, 2016; Roberts, 2011; Van Soyoc *et al.*, 2017).

> *"I knew I had been pregnant for six months, so I thought that it's not a big deal anymore, the nervous system was done…. But I did use, not as much. I was convincing myself that I was participating to an OLO program; I was drinking a litre, sometimes two litres, of milk every day. I was eating eggs…. Oranges. Oranges! I was taking my pregnancy vitamins once a day, sometimes twice." (Courvette et al., 2016).*

> *"I started eating more frequently knowing that I'm pregnant and that it's the least that I could do, and sleeping. Even when I was on meth, I would sleep every night and I would eat. Those were two things that I made sure I always did, sleep and eat." (Van Soyoc et al., 2017)*

"I wanted to get as much nutrition, vitamins, minerals and everything that the baby needed as possible. So I made sure that I went to the doctor, and took my pills and ate as healthy as possible" (Roberts et al., 2011)

These verbatim quotes from three unique primary studies demonstrate that most women who use drugs are aware of the importance of nutrition and diet during pregnancy and despite being unable to make changes to their drug use during this time, they did incite other changes in an attempt to optimise the health of their baby.

4.5.2 Perception of risk to self/ baby

For many women pregnancy was a time to reduce or abstain from taking drugs and the associated lifestyle (Abdul-Khabir *et al.*, 2014; Baker & Carson, 1999; Benoit *et al.*, 2015; Chandler *et al.*, 2013; Chang *et al.*, 2019; Cleveland *et al.*, 2016; Courvette *et al.*, 2016; de Souza Ramiro *et al.*, 2018; Frazer *et al.* ,2019; Howard, 2016; Latuskie *et al.*, 2019; Leppo, 2012; Lewis *et al.*, 1995; Mattocks *et al.*, 2017; Morris *et al.*, 2012; Myra Mrete *et al.*, 2016; Soderstrom *et al.*, 2012; Stone, 2015; Van Soyoc *et al.*, 2017; Weber, 2023). Many studies included in the synthesis explored women's perceptions of risk in relation to perinatal drug use (Abdul-Khabir *et al.*, 2014; Baker & Carson, 1999; Benoit *et al.*, 2015; Chang *et al.*, 2019; Cleveland *et al.*, 2016; Courvette *et al.*, 2016; Diez *et al.*, 2020; Goodman *et al.*, 2020; Leppo, 2012; Lewis *et al.*, 1995; Morris *et al.*, 2012; O'Connor *et al.*, 2020; Roberts *et al.*, 2011; Sadeghi *et al.*, 2021; Sheih, 2001; Stone, 2015; Varty & Alwyn, 2011; Yotebieng *et al.*, 2016). One woman described the worry she felt and the need she had to see her baby healthy to know that her drug use had not impacted on her baby's development:

"I just imagine that I would be happy to hold her, especially if she's healthy and to hear her cry. I would feel very happy. I made mistakes during this pregnancy, so I would be happy to see her healthy and not suffer because of my stupidity." (Sheih, 2001).

Many women further demonstrated an understanding of the risks associated with perinatal drug use, specifically that it would be harmful to their baby (Benoit *et al.*, 2015; Goodman et al., 2020; Roberts *et al.*, 2011; Stone, 2015; Van Soyoc *et al.*, 2017; Varty & Alwyn, 2011; Yotebieng *et al.*, 2016). They described the incandescent guilt they felt during pregnancy

because of their drug use and were sure it would impact on their baby's health and wellbeing (Benoit *et al.*, 2015; Hall *et al.*, 2006; Roberts *et al.*, 2011).

> *"That guilt of knowing that you've used, 'cause you know 9 times out of 10 [it] will affect your baby in some way form or another." (Roberts et al., 2011)*

> *"I was really sort of horrified.... I honestly thought that if there was a baby inside me there was no possible way that it could be alive." (Hall et al., 2006)*

One woman involved in Benoit *et al.*, (2015) study described that a good mother should be willing to stop using drugs.

> *"I think it's really selfish if you're gonna use drugs and, continue to be pregnant. I know it's hard, and not everyone can access services, but, if you really wanna be a mom, and a good mom, you're gonna do what you have to do." (Benoit et al., 2015).*

Other women spoke about their concerns that their baby would be born with congenital abnormalities because of substances they used during pregnancy (Cleveland *et al.*, 2016; Courvette *et al.*, 2016; Leppo, 2012; Mattocks *et al.*, 2017; Myra Mrete *et al.*, 2016; Sheih & Kravitz, 2002; Soderstrom *et al.*, 2012; Van Soyoc *et al.*, 2017). Often women presented deep concern and guilt that their babies would be born with extreme and adverse physical and psychological impairments.

> *"Crippled. They are a vegetable for the rest of their life. They are in wheelchairs." (Van Soyoc et al., 2017).*

> *"It's just there is the guilt that you probably would carry around . . .. If he comes out kind of slow or something, I want to deal with that, I want to take care of that. I want to take care of him. I don't want nobody else to take care of him." (Sheih & Kravtitz, 2001).*

"I do wonder what it will be like. All wrinkled and deformed. They said there'd be no side effects to harm the baby, but they don't really know until its born" (Lewis et al., 1995).

Some women were unaware of the risks of intrauterine drug exposure posed to their baby (Chang et al., 2019; Courvette et al., 2016; Ovens & Prinsloo, 2018) and tried to reassure themselves, describing how their peers had used drugs during pregnancy and their children were excelling in contrast to others (Van Soyoc et al., 2017).

"I hate to say it, but I think that a lot of babies that have been drug exposed may be more gifted, more creative, and more beautiful" (Van Soyoc et al., 2017).

"So far from what I've seen, any girl that I know that's done dope throughout their pregnancy, their kids are really overachievers. Which, I'm not trying to say, 'use meth, it'll make your kids smart.' I'm just saying that the ones that I do know, there's nothing wrong with their kids." (Van Soyoc et al., 2017).

4.5.3 Isolation and Fear

Women who use drugs and experienced pregnancy were deeply concerned about the involvement of child protective services (Da Costa *et al.*, 2015; Frazer *et al.*, 2019; Hall *et al.*, 2006; Howard, 2016; Jessup *et al.*, 2003; Latuskie *et al.*, 2019; Leppo *et al.*, 2012; Paris *et al.*, 2020; Phillips *et al.*, 2007; Roberts & Pies, 2011; Stengel, 2014; Stone, 2015; Weber, 2023; Zsuza, 2019). For many women who use drugs, their pregnancy was reported to be marked by fear of losing their baby or having their child removed from their care at birth (Cleveland *et al.*, 2016; Phillips *et al.*, 2007).

"I was scared that if I came here they would dob me in and I would lose my child. I wasn't sure how child welfare was involved and I was scared of that." (Phillips et al., 2007)

Women often described scenarios where they were fearful child protection services would be notified and the implications this would have for them (Frazer *et al.*, 2019; Howards, 2016; Morris *et al.*, 2012; Phillips *et al.*, 2007; Stone, 2015).

"Getting treatment when you have a child is scary because they come and take the baby… We are also discriminated against- because of coming here, CPS (Child Protection Services) automatically is called." (Frazer et al., 2019)

A woman involved in Howard (2016) study described the conflicting position women who use drugs and experience pregnancy are in, particularly in relation to the contradictions of care being offered, and the fear they experience of losing their children.

"You can detox, but if you do we're going to call CPS on you right away. CPS is going to be looking at it, like, oh, you're always at risk for relapse, so we should just stay involved forever just in case you do, you know? And I don't know if it's really like that, but it definitely feels like that sometimes. And that fear is definitely there. When you hear CPS, the fear is definitely there. And just as mothers, you know, the fear is there of I don't want to lose my kids. I want to make sure I'm doing everything I can so I don't lose my kids, which—I'm not doing anything wrong." (Howard, 2016).

One woman involved in Leppo *et al.*, (2012) research described the "power" child protection agencies had over her life.

"They [the child protection services] have so much power over my life. . . but if things run smoothly as they do now, they can't do anything; they can't take a baby away for no reason. They need to have a good reason"(Leppo et al., 2012)

Women who stopped using drugs during pregnancy often reported feelings of isolation and hopelessness (Benoit *et al.*, 2015; Mejak & Kastelic, 2016; Nordenfors & Hojer, 2017).

"I didn't have anyone. He didn't want the child, so he left me, and my mother didn't want any contact with me. I felt so scared about how to handle a child, I was so scared. I was living on the street and didn't have anything. In this situation I had to take something to forget. And I had uncomfortable feelings about my unborn child." (Mejak & Kastelic, 2016)

This isolation was further compounded by other complex vulnerabilities of women who use drugs, including mental health, housing and abuse further marginalised them, making recovery and abstinence difficult to achieve.

> *"Problems with the baby, problems with your household, problems with income. Problems, just, being a drug addict, raising children and having children in that environment…." (Benoit et al., 2015)*

Some women described the importance of the maternal bond they developed with their children in pregnancy and was something that helped to negate the loneliness they were feeling. They described spending time talking to their baby in effort to connect with them (Sheih, 2001; Torchalla *et al.*, 2014). A participant in the Sheih (2001) study, narrated the maternal connection that babies have with mothers in the womb.

> *"The baby hears everything. I know the baby can hear. They go to sleep when they hear the tone of their mothers." (Sheih, 2001)*

Another woman from a Canadian study described the maternal bond with their baby where they shared their love for them.

> *"I always, talked to her in my belly and said, we're gonna, mommy's gonna really gonna do good and mommy's gonna love you. And, keep you and, you know. So, that was one hard thing when um, when yeah, when she was taken away from me." (Torchalla et al., 2014)*

Women who had partners, family or friends supporting them, described how this often resulted in further monitoring of their behaviour and drug use. In most cases, this was a persuasive factor which led women to reduce their drug use and engage with antenatal care (Abdul- Khabir *et al.*, 2014; de Souza Ramiro *et al.*, 2018; Diez *et al.*, 2020; Goodman *et al.*, 2020; Sadeghi *et al.*, 2021; Varty & Alywn, 2011; Yotebieng *et al.*, 2016). One woman described how having a supportive advocate was important to her accessing care:

> *"I was lucky that my husband's mother has been very supportive throughout the whole thing. She would help me do research and stuff. And she was one of those people you would think wouldn't be supportive,*

based on who she is as a person and amongst society. But she turned out to actually be my biggest advocate." (Goodman et al. ,2020)

As demonstrated above, being under the gaze of family in some cases motivated woman to abstain from drug use, however, in others, this surveillance was more nuanced, whereby they were reminded of the disappointment they had brought to others, whilst also, being lonely and isolated from friends (Soderstrom et al., 2012).

"It's that empty space. The first months after I left [the drug scene] I was terribly lonely and I just wanted to get back. I felt totally alone in the whole world. You're sitting there and suddenly you have no friends anymore, nothing. And my family, they didn't believe much in me, so I didn't have any contact with them either. That's reason good enough to back out and crawl back to the scene" (Soderstrom, 2012)

4.6 Theme 3: Fertility and pregnancy continuation

Many studies found that women who use drugs experienced unplanned and unintended pregnancies (Cleveland *et al.*, 2016; Courvette *et al.*, 2016; Da Costa *et al.*, 2015; Mrete Myra *et al.*, 2016; Sadeghi *et al.*, 2021; Sharpe, 2001; Silva *et al.*, 2013; Soderstrom, 2012). Many women had questioned their fertility and unintended pregnancies confronted them with difficult decisions.

4.6.1 Misperception of fertility

Some research found that women were not aware they could become pregnant, assuming their drug use had impacted upon their fertility and ability to conceive (Abdul-Khabir *et al.*, 2014; Courvette *et al.*, 2016; Hall *et al.*, 2006; Sharpe, 2001).

"I never got pregnant; there was time where I had no periods at all. When I realized that I was pregnant, I'd been pregnant for a while." (Courvette et al., 2016).

"I got sick and didn't know I was pregnant until I was about 3 months. I was too busy smoking. I didn't care about the sick symptoms. I didn't pay it no attention. I was still trying to get out money to get crack. I didn't pay none of it [menstrual cycle] any attention. That made it better on me. Not

having a period, I could go out and get more money to get crack." (Sharpe, 2001)

"I didn't think that I could fall pregnant while I was on so many drugs. I thought that was impossible." (Hall et al., 2006)

Lack of periods or believing drug use impacted fertility attached a 'higher meaning' when women discovered they were pregnant and was described through the lens of 'divine intervention' (Cleveland *et al.*, 2016; Da Costa Lewis *et al.*, 1995; Ovens and Prinsloo 2018; Sadeghi *et al.*, 2021; Sharpe, 2001; Zsuza, 2019).

"I was thinking about God and the miracle of my baby [to stop substance abuse]." (Ovens & Prinsloo, 2018).

"…Yes, it bothered me, but when I did get pregnant, it was what the Lord wanted. If the Lord didn't want me to get pregnant, I wouldn't have gotten pregnant." (Sharpe, 2001).

" And then I was scared that, Lord God, life would no longer be about me." (Zsusza, 2019).

Many women who use drugs had their pregnancy confirmed late impacting on their access to health and social care support including antenatal care and access to termination (Abdul-Khabir *et al.*, 2014; Cleveland *et al.*, 2016; Hall *et al.*, 2006; Hathazi *et al.*, 2009; Mejak & Kastelic, 2016).

"I went to the committee because I wanted to have an abortion, but I was not aware that I was that far along with my pregnancy." (Mejak & Kastelic, 2016).

"Yes [I used] with my son because I didn't find out till he was five months." (Abdul-Khabir et al., 2014).

4.6.2 Termination and access to care

Some women discussed terminating their pregnancy and the barriers and motivators to do so (Abdul- Khabir *et al.*, 2014; Benoit *et al.*, 2015; Cleveland *et al.*, 2016; Frazer *et al.*, 2019; Hathazi *et al.*, 2009; Leppo, 2012; Myra Mrete, 2016; Sadeghi *et al.*, 2021; Silva *et al.*, 2013,

Soderstrom, 2012). Often the decision to terminate their pregnancy was because they were concerned about the impact their drug use had on their baby (Abdul-Khabir *et al.*, 2014; Sharpe, 2001; Sodortrom, 2012).

> *"For the abortions, I didn't want to have them [the children] because I was using and thought something was going to go wrong." (Abdul-Khabir et al., 2014).*

> *"I had abortions because I didn't want the babies. I wanted to continue to smoke dope. I didn't want the responsibility. Matter of fact, it was so hard for me to stop smoking to go and have an abortion. . . . The dope boy was the father of all three pregnancies" (Sharpe, 2001).*

> *"Lots of thoughts went through my head, and I said to myself: Now you have a chance to change your life, so now you have to make a choice. Keep the child or abortion? This was a serious thought. This is a chance to get a new life" (Sodertrom, 2012).*

Women who participated in research by Mejak and Kastelic (2016), shared that they were too far along in their pregnancy to access termination/ abortion services, hence they had to continue with their unwanted pregnancy. For women where termination was illegal or forbidden within their countries (for example Iran), participants discussed ways to procure abortion through potentially dangerous and illicit channels (Sadeghi *et al.*, 2021).

Some research explored pre-term birth (born before 37 weeks) (Cleveland *et al.*, 2016). miscarriage (Ovens & Prinsloo, 2018; Stone, 2015; Van Soyoc *et al.*, 2017; Varty & Alywn, 2011), stillbirth (Cleveland *et al.*, 2016; Roberts *et al.*, 2011). In the context of miscarriage, some women who use drugs during pregnancy are concerned that stopping use, including detoxification, could cause miscarriage (Ovens & Prinsloo, 2018; Stone, 2015; Van Soyoc *et al.*, 2017; Varty & Alywn, 2011).

> *"I had been using heroin straight for five years and I know that you can't stop, and I know that it's really bad when you're pregnant. That it [stopping suddenly] can cause a miscarriage." (Van Soyoc et al., 2017).*

"It was just the whole, I guess liability issue of the miscarriage associated with treatment and withdrawal of the pregnancy that really scared people." (Stone, 2015)

"I was concerned about my baby. I'd read that it could sort of, trigger a miscarriage if you were to just stop it, the withdrawals".

(Varty & Alwyn, 2011)

"My body was so used to having it that when I just all of the sudden cut myself off, that it might affect my pregnancy more that way."

(Van Soyoc et al., 2017).

4.7 Theme 4: Shame and self-stigmatisation

Stigma and shame are inextricably linked to the identity of pregnant women who use drugs. Within the synthesis, 34 studies discussed shame, stigma and guilt felt by women who used drugs and had experienced pregnancy (Baker & Carson, 1999; Benoit *et al.*, 2015; Chandler *et al.*, 2013; Cleveland *et al.*, 2016; Courvette *et al.*, 2016; Da Costa *et al.*, 2015; Frazer *et al.* ,2019; Goodman et al., 2020; Hall *et al.*, 2006; Hathazi et al., 2009; Howard, 2016; Jessup *et al.*, 2003; Latuskie *et al.*, 2019; Leppo, 2012; Lewis *et al.*, 1995; Mattocks *et al.*, 2017; Mejak & Kastelic, 2016; Morris *et al.*, 2012; Nordenfors & Hojer, 2017; Olsen *et al.*, 2014; Ovens & Prinsloo, 2018; Paris *et al.*, 2020; Phillips *et al.*, 2007; Roberts & Pies, 2011; Sadeghi *et al.*, 2021;Sharpe, 2001; Sheih *et al.*, 2001; Silva *et al.*, 2013; Soderstrom *et al.*, 2012; Stengel, 2014; Stone, 2015; Varty & Alwyn, 2011; Weber, 2023; Yotebieng *et al.*, 2016).

4.7.1 Shame and guilt

Most women described profound feelings of worthlessness, hopelessness, and culpability as drug users. A participant in Stengel *et al.*, (2014) shared her views on how others viewed pregnant women who use drugs:

"I don't think there's really anything that people hate as much as like, a pregnant woman who uses drugs." (Stengel et al., 2014)

Despite the recognition of the stigma attached to using drugs while pregnant, throughout the studies included in this review, women used stigmatising language to describe themselves

and their peers (Baker & Carson, 1999; Benoit *et al.*, 2015; Chandler *et al.*, 2013; Cleveland *et al.*, 2016; Frazer *et al.*, 2019; Goodman *et al.*, 2020; Hall *et al.*, 2006; Jessup et al., 2003; Latuskie *et al.*, 2019; Leppo, 2012; Morris *et al.*, 2012; Mrete Myra *et al.*, 2016; Nordenfors & Hojer, 2017; Paris *et al.*, 2020; Sadeghi *et al.*, 2021; Stengel *et al.*, 2014; Stone, 2015; Van Socyoc *et al.*, 2017; Yotebeing *et al.*, 2016). This included terms such as "polluting", "dirty", "evil" and "mentally retarded" to describe their drug use and its implications (Latuskie *et al.*, 2019; Morris *et al.*, 2012; Van Soyoc *et al.*, 2017; Yotebieng *et al.*, 2016). In three studies, women referenced the word "junkie", and sometimes in reference to themselves and other times shared their ambivalence to this term (Hall *et al.*, 2006; Leppo *et al.*, 2012; O'Connor *et al.*, 2020). They also described their perspectives of how people see them as women who use drugs during pregnancy (Benoit *et al.*, 2015; Hall et. al., 2006; Nordenfors & Hojer, 2017; Stengel *et al.*, 2014). These perspectives, self-reflections and self-stigmatisation further marginalise women who use drugs and perpetuate the narratives of guilt and shame women who use drugs feel.

> *"[I]t's been very frustrating when people look at you a certain way, and I know I'm repeating myself but, it's true. And it's true for everyone in my position, and others too, men too. You get yourself into trouble, you have to pay your dues. People have a hard time letting that go when they see it come up" (Benoit et al., 2015)*

> *"Some of them just, they looked at you like shite (=shit)…they just didna (didn't) want to know you sort of thing, because 'ou're a junkie or whatev"r." (Hall et al., 2006)*

> *"It is hurtful. It would be okay to ask politely how things are going, but they shouldn't talk to you in a way that makes you feel like a real shit, like you are a really bad person, like it's all your own fault." (Leppo, 2012)*

4.7.2 Stigmatisation of women in primary studies

When synthesising primary studies included in this synthesis, it was noted that alongside the self-stigmatisation that women presented, authors often used stigmatising language to describe women who use drugs during pregnancy (Baker & Carson, 1999; Benoit *et al.*, 2015; Cleveland *et al.*, 2016; Courvette *et al.*, 2016; Frazer *et al.* ,2019; Goodman *et al.*, 2020;

Howard,2016; Jessup *et al.*, 2003; Latuskie *et al.*, 2019; Leppo, 2012; Ovens & Prinsloo, 2018; Sharpe, 2001, Stone, 2015; Varty & Alwyn, 2011). Women were often framed using language that could stigmatise or marginalise them further. For example, Baker & Carson (1999) described when women "failed to be good"; Benoit *et al.*, (2015) discussed women who use drugs as "…breaching the moral code of motherhood" and Latuskie *et al.*, (2019), framed women who use drugs during pregnancy as having "…low self-efficacy". Often there was a dichotomy in this discourse of good/ bad motherhood presented in studies (Baker & Carson, 1999; Courvette *et al.*, 2016; Howard *et al.*, 2016).

"The women recognized and felt guilty about the times in which they failed to be good" (Baker & Carson, 1999)

Many studies discussed "detection" and loss of agency and self-efficacy of women involved in their study (Jesssup *et al.*, 2003; Stone, 2015; Goodman *et al.*, 2020; Latuskie *et al.*, 2019).

"The women believed that detection of their prenatal drug use would inevitably occur, even when in minimal contact with these helping institutions, and that detection would lead to loss of custody of their new born infant and concurrently, to arrest, incarceration, and prosecution." (Jessup et al., 2003)

"Some women, like Denise and Amelia, seemed proud of their ability to avoid detection" (Stone, 2015)

Some authors used stigmatising language throughout their studies to describe the women involved in their research (Courvette *et al.*, 2016; Ovens & Prinsloo, 2016; Sharpe, 2001). A 2016 study by Courvette *et al.*, described women consistently throughout their study as "addicted law-breaking mothers/ women"; under participant quotes, women in Oven & Prinsloo (2016) were defined by their skin colour as "Coloured woman" and Sharpe *et al.*, (2001) continuously referred to children born to women who used crack as "sex for crack conceived baby".

"Maternal Identity of Addicted Law-Breaking Women" (Courvette et al., 2016)

"She managed to obtain custody of her sex-for-crack conceived baby by remaining clean in the last trimester of her pregnancy" (Sharpe, 2001)

Paradoxically, these three studies also featured accounts of women describing the stigma and shame they felt as pregnant women who use drugs. Authors using language to describe women who experience extraordinary stigma and shame in this way further discredits and marginalises them.

4.8 Chapter summary

Within this chapter, the findings of my qualitative systematic review were outlined. The chapter began with a summary of included primary studies. Each theme was then explored in detail, providing an in-depth understanding of the experiences of pregnancy among women who use illicit drugs, while also addressing the review questions. The findings of this review indicate that women who use drugs are aware that pregnancy brings about surveillance of them. For this reason, alongside shame and fear, they avoid or restrict their access to care. This means they are isolated, but also, they devise discursive distraction and implement informal strategies to reduce harm to their baby during pregnancy. Some women reported a misperception of their fertility due to drug use, with some having pregnancy confirmed after the first trimester. The chapter concluded with critical reflection on the language used to describe women who use drugs by the authors of primary studies included in this review. The findings of this systematic review were used to inform my qualitative research (outlined in Chapter 5). The final chapter of this thesis (Chapter 8), will include a discussion of these findings, alongside those of my qualitative research.

Chapter 5: Qualitative Research Methodology and Methods

5.1 Chapter introduction

The aim of this chapter is to outline the methodological approaches and methods used to undertake qualitative research. I begin the chapter by describing the methodology adopted for this study and the rationale for undertaking a qualitative approach to this research. After this has been outlined, I then explore the practical methods undertaken, exploring in depth the strategies implemented from inception to analysis. Part three of this chapter details ethics, ethical considerations, and governance and demonstrate the integrity of this research. Throughout this chapter, the incorporation of patient, public involvement, and engagement (PPIE), will be outlined.

5.2 Qualitative feminist methodology

Feminist methodology is concerned with the production of knowledge, inequalities, and power in relation to women (Leatherby, 2007; Ramazoglou & Holland 2002). According to researchers, feminist research recognises the importance of women's lived experiences and aims to capture them in a respectful manner that legitimises women's voices as a source of knowledge (Campbell & Wasco, 2000; Chatterjee *et al.*, 2018; Angrosino, 2007; Gray 2018). In order to be reflexive about my research design, I must reflect on the implications of choosing one technique over another (Ramazanoglu & Holland, 2002). According to Ramazonglu & Howard (2002):

> *"Feminist social research has thus often equated with woman-to-woman sensitive style of qualitative interview, observation or life history, or one that involves participants in the production of knowledge" (Ramazonglu & Howard, 2002:155).*

As this study is concerned with women's reproductive health and sexual wellbeing, feminist methodology not only aligns with my values but also offered a pragmatic methodological framework to inform this qualitative study.

Feminist researchers employed qualitative methods as early as the 1970s and found them to be "the most appropriate way to produce data on realities of women's lives" (Ramazonglu & Howard, 2002: 155). In contrast, quantitative methods offer:

"… limited access to accounts of experiences, nuances of meaning, the nature of social relationships, and of their shifts and contradictions"
(Ramazonglu & Howard, 2002:155)

Qualitative methods were chosen as I wanted to gather rich empirical evidence of women's perspectives and views of their own reproductive health and sexual wellbeing, alongside practitioners' experiences of supporting them. Qualitative research provides an opportunity to develop an in-depth understanding of the issue under examination and relies heavily on detailed accounts of their experiences (Liamputtong, 2019), in turn producing rich empirical evidence. According to Liamputtong, "feminist researchers strive to strengthen connections between researchers and participants" (Liamputtong, 2019:11). This is demonstrated throughout this study with the continuous and meaningful incorporation of the women with lived experience (Expert Advisory Group/EAG) which is further explored in Chapter 6 of this thesis.

Data collection in feminist methodological approaches often feature in-depth interviews (Liamputtong, 2019). Broadly speaking, qualitative interviews present an opportunity to "...understand experiences and reconstruct events in which you did not participate" (Rubin *et al.*, 2005:3). Qualitative research conducted in this way results in data that is 'very detailed, information rich and extensive' (Moriarty, 2011). Qualitative findings consist of a plethora of detailed information, increasing the depth of understanding of both the people and the topic being researched (Butina, 2015). Interviewing is a popular method of data collection, as it allows the researcher the time and space to collect descriptive narratives, directed by researchers' questions. Interviewing individuals 1-1 can give them the space and time to recount 'thick descriptions' of events, thus, giving the researcher an opportunity to gain an in-depth account of experiences and what underpinned them (Geertz, 1973). Semi-structured interviews guide researchers between themes that need to be covered but can be done so in a broad and flexible way (Alversson, 2011). They also allow researchers to organise the main question, prompts, probes, and follow-up with further exploration (Geertz, 1973; Rubin & Rubin 2005). The main questions give researchers the opportunity to introduce topics and invite participants to share their perspectives, views, and experiences of this. Prompts, probes and follow up questions may be outside of the predefined topic guide; however, they are

used to encourage the participant to expand on what they have said, thus gleaning more insight and understanding of the individuals lived experience (Rubin & Rubin, 2005).

Interviewing does not come without its challenges many of which can be addressed through the incorporation of reflexivity throughout research discussed in depth in Chapter 2 of this thesis. Feminist research calls for methodologies that respect lived experience and reflexivity (Mitchell et. al, 2017; Liamputtong, 2019). Essentially, the predeterminants and flexibility of interviews are what makes them so appealing to researchers, from structured, systematic style interviewing to free and open conversations (Alversson, 2011:51-53). Alongside this, "a reflexive approach demands awareness of the relationship between researcher and researched" (Ramazanoglu & Holland, 2002: 156). Ramazanoglu & Holland postulate that "…taking reflexivity personally means reflecting critically on the consequences of your presence in research" (Ramazanoglu & Holland, 2002:156). Reflexivity, much like analysis is an iterative process which has been embedded throughout this research, both personally and during PPIE. My positionality and lived experiences was previously outlined in Chapter 2 and more consideration of my reflexivity will be discussed within this chapter and the next.

There is no general feminist methodological strategy on interpretation, however, "…it is important to put reflexivity into practice" (Ramazanoglu & Holland, 2002: 160). Making your own interpretation of the data transparent is a time when your power as a researcher is most visible, yet another important aspect of feminist research (Smith, 1989). Being as explicit as possible about interpretation will include taking a position on how you justify your knowledge construction and interpretation (Ramazanoglu & Holland, 2002). Sharing control of interpretations can open up what is going on in an interview, more explicitly, how the researched are connecting ideas and experiences (Ramazanoglu & Holland, 2002).

5.2.1 Study Design

Table 5: Study Design Summary

Study Title	Exploring the reproductive health and social care needs of women who use drugs in the North East of England: a qualitative study.
Study Design	Qualitative design including:

	Semi-structured, one- one interviews with women who use drugs (aged 18-50 years, ~20-25 interviews), and semi-structured one- one interviews with service providers/ practitioners (~15-20 interviews).
Study Participants	• Women who use drugs aged 18-50 years. • Professionals with frontline experience of working with women who use drugs.
Planned Size of Sample	**Approximately 40 participants:** • 20-25 women who use drugs. • 15-20 practitioners and key stakeholders who work in the drug and alcohol sector. Overall sample size may be lower, dependent on interview participants' willingness and data collection sufficiency.
Follow up duration	This study will only ask participants to take part in one interview lasting between 30-60 minutes at a time and location that is best for them.
Study Period	October 2022 – January 2023
Research Question/Aim(s)	To explore the reproductive health and social care needs of women who use drugs.

5.3 Methods

The aim of this study is to explore and understand the reproductive health and social care needs of women who use drugs in the North East of England. In recent years there has been a focus on researching the lived experience of people who use drugs in the North East of England (Adams *et al.*, 2022; Alderson *et al.*, 2021; McGovern *et al.*, 2021; Spencer *et al.*, 2023) however, few studies have focussed only on women's experiences (McGrath et a., 2023). A recent report published in 2023, focussed on 'Dismantling Disadvantage' for women with multiple unmet needs in the North East (Agenda Alliance & Changing Lives, 2023). This report used previous and empirical research to demonstrate the barriers to care for women, including, deprivation and poverty, the 'toxic trio of vulnerabilities' (mental health, drug use

and domestic abuse) and child removal (Agenda Alliance & Changing Lives, 2023). Whilst this report paints a grim picture for many women living in the North East, it did not consider women's reproductive health and sexual wellbeing. This research will begin to address the gap in knowledge around the reproductive health and social care of women who use drugs in the North East and practitioners who support them. This research aims to do so, by addressing the following four objectives:

- To explore the perspectives women who use drugs have of their reproductive health;
- To understand the health and social care services women access to maintain good reproductive health;
- To understand service providers attitudes and understanding of the reproductive health and social care needs of women who use drugs;
- To understand the perspectives women who use drugs have of motherhood.

5.3.1 Eligibility framework

In order to address the aims and objectives of this study and ensure that I have incorporated the views and perspectives of women with lived and living experience and practitioners who support them, an eligibility framework was adopted. The eligibility framework included an inclusion and exclusion criteria for participation. Table 6 (below) illustrates the eligibility framework for this study.

Table 6: Eligibility framework

	Participant Group 1: Women	**Participant Group 2: Practitioners**
Inclusion criteria	1. Women aged 18-50 (of childbearing years) who have lived/ living experience of using drugs and/ alcohol. 2. Women must live in the North East of England.	1. Practitioners who offer direct support to women who use drugs and alcohol in the North East of England (including practitioners; nurses; clinical staff, peer mentors, outreach workers, health and social care workers, volunteers).

Exclusion criteria	1. As the focus of this study is on the unmet reproductive health and social care needs of women who use drugs, men will not be invited to participate in the study. 2. Women who do not live in the North East of England. 3. Women who do not have lived or living experience of drug or drug and alcohol use.	1. Practitioners who do not provide drug and alcohol health and social care support to women. 2. Practitioners who worked outside of the North East of England.

According to Creswell *et al.*, (1998) and Morse, (2000) sample size guidelines range between 20-30 semi- structured interviews to reach theoretical saturation. For this reason, the target sample size for this study was 25 women who have lived experience of drug use and 20 professionals who support them. The inclusion and exclusion criteria was applied rigorously during screening telephone calls to ensure all participants met the study's requirements.

5.3.2 Sampling and Recruitment strategy

To ensure maximum variation in specified characteristics the approach to qualitative fieldwork was undertaken using a purposive sampling strategy. Padgett (2017) defines purposive sampling can be the deliberate selection of certain individuals because of the lived experience they can provide that cannot be obtained through other sources. Purposive sampling allows for better matching of the sample to the aims and objectives of the research, therefore improving the rigour of the research and the reliability of the data and findings (Campbell *et al.*, 2020) This method allows researchers to learn extensively about the issues under examination, to increase the depth of understanding (Campbell *et al.*, 2020; Liamsputtong, 2019). Women were sampled on their age (18-50 years of age), location they lived and lived experience of illicit drug use. Practitioners were not sampled on age, but on that they must engage directly or support women who use drugs in the North East of England.

Although purposeful sampling was the intended method of sampling, during data collection convenience sampling did occur. Convenience sampling in qualitative research is not uncommon and occurs when individuals are invited to participate in the study because they are conveniently or opportunistically available with regards to access, location, time and willingness (Lopez & Whitehead, 2012). In the context of this research, some participant's (both women and practitioners) shared the study details with their friends/ peers/ colleagues, members of the EAG supported the recruitment of participants through their networks and two services placed flyers in waiting areas for service users and staff. Often this was based on the premise that these individuals felt others (friends, peers, colleagues and service users) participation was important to capture in this research. A breakdown of referral method for each participant can be found in Table 9 & 10 (pages 125-126) of this Chapter.

Within the sampling framework outlined above there are limitations and implications for analysis and findings of this study. The limitations of employing convenience sampling during data collection means that there may be over representation within this study of women who are connected to peer support networks and also, professionals involved in third sector support. While it would be imprudent to generalise all findings to women who use drugs, within the sample of included women and professional is variation of drug use (for example cocaine, heroin) and other lived experiences (including mental health, domestic abuse and intimate partner violence, child removal), however, findings may be useful for policy and practice to consider the wider needs of women who use drugs (Andrade, 2020; Lopez & Whitehead, 2012).

Sampling and recruitment of women

Women who use drugs may be harder to reach. Previous research has suggested this is not uncommon in qualitative research, especially among marginalised groups (for example, drug users, people experiencing homelessness, sex workers etc) who are difficult to find or unlikely to take part without referral (Liamputtong, 2007; 2010; 2017; Padgett, 2017). Vulnerable and hidden populations (such as women who use drugs) may be more difficult to recruit due to social location, they may be at risk of harm, experiencing difficult life circumstances or because no record of their drug use exists (Ellard-Gray *et al.*, 2015).

In order to overcome these barriers, sampling and recruitment were initially facilitated by the EAG and guided by the eligibility framework. The researcher was not involved in the initial approach of women, however, the EAG used the inclusion criteria to guide the identification of potential participants. The sharing of the study information by the EAG validated the study and confirmed my credibility, vouching that I was a safe person to speak to. This involvement enhanced recruitment and sampling of women involved in the study.

Women from the EAG reached out to their network and peers via WhatsApp and Facebook groups to share the study information and encourage participation. Attached to these posts/ messages was the research flyer which contained an email address and research contact number. If members of the EAG were contacted directly about the study, they would share the information sheet and then ask to the potential participants to share their telephone number with the researcher (CS). For those who contacted the research phone: they telephoned the research number and I answered, if unavailable some left a voicemail for me to return the call; or they sent a text message. If I answered the call, I would introduce myself and ask if they were happy to speak with me. If a voicemail was left, I would follow up with a text message asking them to contact me or if I had their permission to return their call at a time that was best for them. Any text messages received about the research, prompted a return text message to ask if they were comfortable with a telephone call to discuss the research. During this phone call a screening process (guided by the eligibility criteria) was undertaken. For those who contacted via email, a response was returned within 24 hours and an information sheet and consent form was attached for their consideration. Within the email the eligibility criteria was outlined. Potential participants were informed that they did not have participate and could withdraw at any time. In some instances, information sheets and consent forms were posted with a return address envelope enclosed. Many women requested a paper copy of the information sheet and consent form as they did not have access to digital software to sign and return information.

During one screening call a potential participant was declined participation by the researcher on the basis they lived out of area (Brighton) and the focus of this research was women who lived in the North East. Another woman met the inclusion criteria, completed the consent via post and returned and a time and online meeting was arranged. When the online interview

began (via Zoom) the woman ended the call. A follow up email was sent, to check it was not a connection issue. No response was received, so it was assumed this participant had withdrawn from the study. No further contact was made. All other women who provided initial consent to be contacted, took part in the study. Within the early stages of recruitment, the majority of participants were aged 35 years and older. As a result, the EAG began to purposively sample women under 35 to participate in the study.

Table 7: Sample identification (women)

1. Posters/flyers: Participants will be able to contact the research study team if they wish to participate in the study after seeing publicity material. Posters were placed in drug and alcohol services located in Newcastle-upon-Tyne and Northumberland with a brief overview of the research and telephone contact number.
2. Members of the Expert Advisory Group (EAG) shared the details of the study with their peer network. They did so via WhatsApp and through their own personal Facebook network and a Facebook group they had created and managed since 'lockdown' 2020. There were in excess of four thousand women following this Facebook group.
3. Gatekeepers: the initial approach to potential participants could be made by a gatekeeper. Professionals in a service in Newcastle supported the research and attempted to identify/ recruit and encourage participation of service users who attended their project. Practitioners at these services gave women who met the inclusion criteria my telephone number, a flyer(which also contained my contact details) and an information sheet. In the interest of safeguarding, and to ensure that participants were not intoxicated or vulnerable at time of interview, it was decided all interviews with women attending this service would take place at this location at a time agreed in advance. Due to the transient nature of the women attending these services, alongside extensive vulnerabilities these women presented with, it was decided that it was not possible to gain ethical and informed consent, particularly with 48 hour cooling off period. For this reason, no women were recruited at this site.

Sampling and recruitment of professionals

Findings from my qualitative systematic review evidenced that women who use drugs and experience pregnancy are judged and stereotyped. For this reason, professionals were invited to participate in interviews to provide their perspectives and views on providing care and support for women who use drugs. Although the focus of this research is reproductive health of women, men were also invited to participate in this aspect of the study. Within health and social care services, often men are first point of contact or case workers with women who use drugs. For this reason, I felt it important to capture their experiences of providing support for women and their understanding of reproductive health. Recruitment of practitioners took place in tandem with the recruitment of the women participants. Practice networks were utilised to approach services and ask them to share information about the study with colleagues. To maximise variation practitioners were sampled from a range of health and social care services providing care to women who use drugs, including drug and alcohol support services, harm minimisation, housing support, key stakeholders, and prescribers. Professionals were asked to share the following demographic information: gender, age, ethnicity, role/ profession, years in service.

Table 8: Sample identification (professionals):

1. The researcher attempted to visit different settings, including service providers and third sector organisations in the North East, to share information about the study. Practitioners were encouraged to participate via team managers.
2. Information about the study was shared with the researcher's network and contacts within the sector. This was done via email and advertised on LinkedIn.
3. I also advertised the study and contact details at the end of a number of presentations I did for Public Health England and NHS in advance of the project launch.

5.3.3 Approach to interviews (women and practitioners)

Informed consent

All individuals who made contact regarding participation (via telephone or email) were provided with an information sheet and consent form. Those who met the eligibility criteria were invited to participate in the study. Informed consent was sought in advance of

participation. In order to ensure participants had time to consider participation, every participant was given a 48-hour cooling off period between agreeing to participate and the interview taking place. If they were happy to proceed and participate in an interview, all participants were required to sign and return the consent form. The consent form required individuals to tick all boxes declaring they had read the information sheet, were happy to participate in the study and had the right to withdraw at any time. An optional box was inserted at the end of the consent form to track what participants would like a summary report of the findings when the report was completed.

Throughout this research study, participants were made aware that they had the right to withdraw from the interview at any point. The right to withdraw was clearly stated on the consent and information sheet (co-designed by EAG to ensure they were accessible and non-confrontational for participants) and was verbally discussed at the beginning of every interview to ensure participation in the study was informed and ethical. While some women were active drug users at time of interview, no participants were intoxicated at time of interview.

Semi-structured interviews

The approach to interviewing was designed to make them accessible for women and practitioners by allowing them to choose a space they felt most comfortable with. Leatherby (2007:108) suggested that undertaking research in a participant's own space "…will usually make them feel more in control". To extend this offer and give participants autonomy and preference in the interview environment, they were offered flexibility in both time and location. Both women and practitioners were offered in person or virtual interviews at a time that suited them including evenings and weekends. Having a flexible approach to interviews was aimed to facilitate interviews but also to acknowledge the other responsibilities participants may have (for example, caring responsibilities, employment).

Both interview topic guides (women and practitioner) were codesigned with individuals with lived experience (Expert Advisory Group/ EAG) and aimed to explore participants' perspectives of the following topics:

- Perspectives and understanding of reproductive health.

- Maintaining reproductive health.
- Fertility and family planning.
- Support services they access for reproductive health.

During consultation with the EAG, women expressed discomfort with the term reproductive health. After discussion, women involved in the study and topic design expressed they felt the term 'Women's Sexual Wellbeing' was more appropriate for the study. The study was renamed the 'Women's Sexual Wellbeing study' and all branding assets were updated to include this final iteration. After reviewing and discussing the topic guide with the EAG, the suggested to include a retrospective question into the interview. They felt this question would demonstrate their views and perspective of family before drug use and would complement other questions in the interview and demonstrate how this changed and why. No changes were made to the practitioner topic guide in this consultation. A copy of both topic guides (including probes and prompts) and additional recruitment flyers can be found in Appendices C-E.

Interview participants, both women and professionals, were offered a £20 shopping voucher (Love2Shop) as reimbursement for their time and contributions to this project. Reimbursement was detailed in flyers, information sheets and during eligibility. Vouchers were given at the end of in person interview or were posted on the day of interview for virtual (online) interviews.

5.3.4 Interview process and data generation

Interviews for both participant groups began on the 30th of September 2022 and concluded on 10th of January 2023. The data collection for women was swift with 15 (n=18 full sample of women) interviews taking place in the first six weeks of data collection. Practitioner work capacity and commitments meant participation in the study was more protracted.

A hybrid offer for interview was given to participants, allowing them to decide which platform or location worked best for them. Eleven women chose in-person interviews (five in their own homes and three on university campus) and seven chose online interview via Zoom. Five practitioners participated in their place of work, given leave of absence from work by their

line manager to do so. The five other practitioners who participated did so outside of their working day and some took place on weekday evenings.

All interviews were recorded using a digital audio-recorder and I made notes preceding, during and subsequent to interviews. These notes were used as a reference point to track demographics and characteristics and also, to collate emerging themes and further probe on these in subsequent interviews. For example, within the initial topic guide, women were not asked about the regularity of their periods, however, during early interviewing women shared that when using drugs, they didn't have periods during this time. After this emerged with a number of participants, I probed further with others in an attempt to gauge their views and understanding of their fertility, and if this impacted on their sexual health and wellbeing.

Recruitment for interviews continued for both women and professionals until data saturation was reached. According to Liamputtong (2019), saturation occurs when few new data are generated in successive interviews. A systematic review by Hennik & Kaiser (2022) found that in most datasets reached saturation between 9-17 interviews. Eighteen women and ten professionals were interviewed, at which point data saturation was deemed sufficient.

Interview duration ranged from 22-56 minutes for the whole sample; the mean interview length was 40.5 minutes for women and 29.8 minutes for practitioners. Table 9 and 10 below outlines in more detail the length of interview for each participant and location where they took place. Interviews were transcribed verbatim by an approved transcription company (UK transcription) that has signed a confidentiality agreement with Newcastle University Population Health Sciences Institute. I transcribed one interview at the request of the participant. Once returned from the transcription company, all interview transcripts were anonymised and were imported into the NVivo 11 software package for coding and analysis.

Table 9: Referral method, length and location of interview for women

Participant ID (women)	**Referral Method**	**Length of interview**	**Location of interview**
W01	Self- referral	36 minutes	In person at W01 home.
W02	EAG referral	42 minutes	Online (Zoom).
W03	EAG referral	35 minutes	In person at W03 home.
W04	Self- referral	50 minutes	Online (Zoom).
W05	Self- referral	36 minutes	In person at W05 home.
W06	Self- referral	33 minutes	In person at W06 home.
W07	Self- referral	44 minutes	In person at W07 home.
W08	Self- referral	56 minutes	Online (Zoom).
W09	Self- referral	45 minutes	In person at W09 home.
W10	Self- referral	34 minutes	Online (Zoom).
W11	Self- referral	39 minutes	In person on university campus.
W12	Self- referral	35 minutes	In person on university campus.
W13	Self- referral	27 minutes	In person on university campus.
W14	Self- referral	34 minutes	Online (Zoom).
W15	Self- referral	35 minutes	In person at W15 home.

W16	Self- referral	52 minutes	In person at W16 home.
W17	Self- referral	45 minutes	Online (Zoom).
W18	Self- referral	52 minutes	Online (Zoom).
		Total 730 minutes (average 40.5 min per interview)	

Table 10: Referral method, length and location of interview for professionals

Participant ID (professionals)	**Referral Method**	**Length of interview**	**Location of Interview**
P01	Flyer in service	29 minutes	In person at work site.
P02	Flyer in service	26 minutes	In person at work site.
P03	Flyer online	35 minutes	Online (Zoom).
P04	Flyer online	30 minutes	Online (Zoom).
P05	Flyer online	23 minutes	Online (Zoom).
P06	Flyer in service	27 minutes	In person at work site.
P07	Colleague referral	27 minutes	In person at outreach site.
P08	Flyer in service	26 minutes	In person at work site.
P09	Colleague referral	53 minutes	Online (Zoom).
P10	Self-referral	22 minutes	Online (Zoom).
		Total 298 minutes (average 29.8 minutes per interview)	

A total of 1,028 minutes of recorded interview data.

5.3.5 Data analysis and methods

Data was analysed using Braun and Clarke's (2006) iterative process of reflexive thematic analysis using the following steps: familiarisation, coding, generating themes, reviewing themes, defining, and labelling themes and write up.

Analysis began with familiarisation, whereby I read and re-read interview transcripts from women and professionals in tandem. Together with my supervisory team, we read the first transcript and discussed as a team. This enabled me to reflect on the topic guide, my approach to interview and explore further areas to probe in future interviews. During this stage of analysis, it became apparent that there was significant overlap between two data sets (women, professionals). In many instances women and professionals had similar lived experiences (particularly those in recovery). For this reason, the dataset was combined, and both were uploaded to a single file in Nvivo for coding. During the familiarisation process, I also kept a separate working Microsoft Word document which included characteristics/ demographics of participants, rich quotes and emerging themes. This document was also used to facilitate discussion with the team, allowing me to present further emerging themes and engage with the research and consider alternative interpretations of the data.

Thematic analysis involves the identification and reporting of patterns in a data set, which are interpreted for their inherent meaning (Braun & Clarke, 2006), these patters can be found on the basis of understanding the meaning of keywords used by participants. Line-by-line coding was undertaken on each transcript and coding began with transcripts from women. Each sentence which related to the topic being researched was given at least one code, with some having many codes. In total 48 codes were ascribed to the data and used to build a codebook. Codes were revisited and data was reviewed to ensure the appropriate code was applied. I coded all transcripts and my supervisory team each coded one transcript each independently and then we met one to one, to discuss similarities and differences in coding. This allowed me to reflect on my approach to coding and reduce bias I may have unconsciously been applying to my analysis.

After this was completed, codes were ordered in hierarchy to generate descriptive themes. Descriptive themes (derived from line-by-line coding) were then collated to develop themes

and sub-themes. The inductive analysis of descriptive themes, alongside iterative and comprehensive discussions with my supervisory team and the EAG guided the generation of analytical themes. Appendix F demonstrates the approach to inductive thematic analysis with exemplary quotations used to illustrate how descriptive and analytical themes emerged.

Wider discussions with other PhD students and early career research colleagues supported and challenged my interpretation of the data from my empirical study. I shared excerpts from two transcripts with the 'Qualitative Special Interest Group'; which consists of a diverse range of experienced qualitative researchers from across the Population Health Sciences Institute and Faculty of Medical Sciences (Newcastle University). Within this two-hour meeting, I presented the data and discussed my analysis. We also considered ways in which the data could be presented in write-up so not to lose the richness in the transcripts during the writing up phase.

5.4 Ethics and governance

Data management, confidentiality, risk management and governance are integral to undertaking and producing ethical research. Throughout this research I have endeavoured to ensure ethical procedures were undertaken and consideration was given to any mitigations throughout.

5.4.1 Ethical approval

Initially, Health Research Authority (HRA) ethical approval was sought, and an application was submitted and reviewed by HRA using the IRAS (Integrated Research Application System) application platform. Upon discussion with HRA, it was confirmed the study did not require HRA approval, as the recruitment of NHS staff or NHS patients on site was not the remit of the study. A favourable opinion was then sought from the Newcastle University Faculty of Medical Sciences Research Ethics Committee for the study protocol, informed consent forms and other relevant documents e.g. information sheets. Ethical approval was granted by the Faculty of Medical Sciences: Ethics Committee on the 22nd of September 2023 [ref: 2356/24186/2021]. A copy of the consent form and the ethical approval letter can be found on Appendix G, H.

5.4.2 Assessment and management of risk

The topic I have chosen to research is a sensitive subject, with an underserved population. As a researcher, I was aware that I may encounter vulnerable individuals during fieldwork. The safety of all participant's during research was imperative. Having previously worked in various practice roles in the health and social care field, I have extensive experience of discussing sensitive topics with vulnerable populations and asking difficult and often, very personal questions. All participants were made aware in advance of interview that if a situation arises where a participant indicates that they are of risk to themselves or others, I would be obliged to take the appropriate action to maximise their safety and the safety of others, which may mean breaching the confidentiality agreement if required. This was also outlined in detail in the participant information sheet. At no point during interview did safeguarding concerns arise.

In addition, and given the nature of the topics being explored, it was important to mitigate any potential distress or concern prior to data collection. One rationale for the co-design of the topic guides with women with lived experience was to ensure the topic guide was focused, yet sensitive and free from stigmatising language. This was done so to ensure the language in interview was sensitive and non-judgemental. Before interviews participants were reassured that if they did become distressed or upset, that I would stop the interview until they were happy to continue, if they were not happy to continue the interview will be stopped. In one interview I paused the interview as a participant became tearful, I applied the measures outlined above, however the participant assured me they wanted to continue with the interview and thus, the interview resumed once they felt comfortable to do so.

At the end of each interview, participants were asked for feedback on their experience of taking part in the study. Participants were also directed to the contact details of the research team which were included in the information leaflet, should they have any questions about the research. Each participant was given a debrief sheet at the conclusion of interview. Incorporated in the debrief was signposting to appropriate services that may benefit participants of the study, such as counselling services, sexual and reproductive health care services etc. A copy of the debrief sheet can be found in Appendix I.

5.4.3 Data protection and confidentiality

Maintaining confidentiality and adhering to data protection is an important aspect of ethical research. An important aspect of confidentiality is the consent process in research. Every participant was required to give written consent in advance of interview. Personal data (names, addresses and telephone numbers) were only used for recruitment purposes and where women or professionals would like to receive a copy of the outcomes of the study. Upon completion of the study, personal details were deleted. Consent forms were stored on Newcastle University premises in a locked cabinet in compliance with Newcastle University's Data Retention and Storage policy. Only I had access to any participant identifiable data. At point of interview, each participant was given an identification number (P0#) to give maximum anonymity. Throughout the findings of the study, direct quotations have been used, but all are anonymised, removing identifiable information to the best of my ability. Key evidence and statements presented in the workshops, conferences and paper write up will not contain any personal or identifiable details, and all findings have been anonymised.

5.5 Chapter Summary

This chapter has outlined the feminist methodology approach and methodological framework for my qualitative research. I also outlined in detail the methods used to undertake research including, eligibility framework, approach to interview, recruitment strategies and sample identification, interview process, data generation and analysis. The robustness and rigorous approach to research was demonstrated through the implementation of ethical approval and governance and outlined in detail in chapter. The importance and influence of EAG was demonstrated throughout this chapter and will be further outlined in Chapter 6, from inception to completion of this thesis.

Chapter 6: Incorporating the voices of lived experience into my qualitative research

6.1 Introduction

This chapter aims to outline the impact Patient Public Involvement and Engagement (PPIE) had on my Doctoral research. According to feminist methodologists (Moran-Ellis, 1996; Grbich, 2013; Furlin, 2015), researchers must be transparent about the way in which their own experiences as women and researchers impacts on the conduct of their research and sharing of their subjectivities with their research participants. This chapter aims to give a detailed account of my approach to PPIE and the way in which it shaped my qualitative research. The chapter begins by describing the importance of PPIE in research with a focus on incorporating voices from underserved populations. I then present my PPIE throughout my qualitative research study. During this section I detail how women became involved in the research, how we worked collaboratively and our collaborative dissemination activities. The chapter concludes with strengths and challenges associated with PPIE work during my PhD, with brief suggestions on how this could be improved to better support meaningful PPIE in doctoral research.

6.2 Public Patient Involvement and Engagement in research

Public, Patient Involvement and Engagement (PPIE) is an important part of contemporary research and in recent years it has become a requirement in funding bids, and some journals publications (McGrane *et al.*, 2023; Troya *et al.*, 2019). NIHR (National Institute for Health and Care Research) define PPIE in research as being "with" or "by" members of the public rather than "to" or "about" them (NIHR, 2021). Using this definition, and in the context of health and social care and public health research (McGrane *et al.*, 2023), PPIE means working collaboratively with patients, people with lived experience, service users, carers and families who access health and social care services. Evidence of the benefits of PPIE in qualitative research has been well documented (Brett *et al.*, 2012; Gray *et al.*, 2021; Gilchrist *et al.*, 2022; Islam *et al.*, 2021; McGrane *et al.*, 2023), however, there are few publications which relate to PPIE in doctoral research (Troya *et al.*, 2019).

Undertaking PPIE for research with 'hard to reach' and vulnerable population groups is sometimes considered as being too difficult to facilitate (McGrane *et al.*, 2023). As previously

outlined in Chapter 5, vulnerable, underserved, and hidden populations may be difficult to engage with because they may be at risk of harm, disenfranchised, due to social location or because no legal record of them exist (Ellard-Gray *et al.*, 2015). According to the NIHR guidance 'INCLUDE' underserved groups may include: women of childbearing age, socioeconomically disadvantaged, experiencing homelessness, people who do not attend regular health appointments, socially marginalised, stigmatisation, mental health conditions and people with addiction (NIHR, 2020). One potential barrier to inclusion in research was the feeling unqualified to take part due to lack of education- an important caveat for researchers to reflect upon when considering the power dynamics of PPIE (NIHR, 2020). While some researchers report they have difficulty in reaching participants to engage in PPIE, lack of PPIE may result in difficulties in capturing the insider perspectives (Islam *et al.*, 2021). This poses the important question suggested from Islam *et al.*, (2021)- are populations hard to reach or do they find it hard to trust researchers who have their best interests and will listen to their perspectives and views. This further underscore how disenfranchised populations may be cautious or ambivalent to collaborating and participating in research.

PPIE can be both rewarding and burdensome for both researchers and members of the public (Gray *et al.*, 2021). Incorporating PPIE requires practical considerations, and it is fundamental that researchers consider these in advance. Practical aspects include planning (particularly time commitment for researchers and PPIE members), resources needed and funding available for reimbursement (McGrane *et al.*, 2023). Further reflection should be given to the needs and capacity of PPIE members; the extent of involvement and resources required, prior to approaching or working collaboratively with PPIE (Troya *et al.*, 2019). Discussions about the roles and responsibilities of participation is essential to avoid over burdening PPIE members, alongside consideration of their wellbeing and safety (Islam *et al.*, 2021; Gray *et al.*, 2021). A recent study by Gilchrist et. al.,(2022) on experiences of being a PPIE member found that no compensation (reimbursement for their time) and outcomes of the research being rarely communicated led to the "erosion of trust". With these two barriers in mind, reimbursement for PPIE should be ring fenced in doctoral funding (if available) and communication of the findings and outcomes of the study should be prioritised in order to ensure PPIE members feel valued and included in the process.

Research has indicated that PPIE positively affects the quality of research and strengthens the methodological rigour of the results (Brett *et al.*, 2012; Gray *et al.*, 2021; Gilchrist *et al.*, 2022; McGrane *et al.*, 2023; Troya *et al.*, 2019). A systematic review from 2012 found that incorporating PPIE into research had a positive impact which enhances the quality and appropriateness of research (Brett *et al.*, 2012). PPIE gives cultural relevance and a broader understanding for the researcher undertaking the study, which is in turn translated into the findings, making them more relevant and more likely to impact and inform policy and practice (Brett *et al.*, 2012; Gray *et al.*, 2021; McGrane *et al.*, 2023). Credibility of findings with stakeholders is important when attempting to influence policy and practice, and PPIE allows researchers and its public contributors to identify gaps and plan future collaborative research projects (Brett *et al.*, 2012). This was further demonstrated by Troya *et al.*, (2019) whereby her PPIE group had informed her PhD research on self-harm in older adults. The incorporation and prioritisation of PPIE are clear, however, this requires researchers to engage in quality PPIE, moving beyond what some have referred to as 'tokenistic PPIE' (Islam *et al.*, 2021; Gray *et al.*, 2021; Gilchrist *et al.*, 2021). Researchers can overcome tokenistic PPIE by establishing a pre-defined model and involving PPIE from inception to dissemination (Gilchrist *et al.*,2022).

6.3 Incorporating the voices of lived experience in this research

6.3.1 Establishment of the Expert Advisory Group

Patient, public involvement and engagement was central to the design and development of the empirical qualitative research. Initial contact was made with one woman with lived experience, who later referred three more women to consult on the research. An Expert Advisory Group (EAG) was formally established in January 2022, with four women from the North East of England who have lived or living experience of drug use. Aside from all women having experience of drug use, the four women involved in the EAG had many other lived experiences which they drew upon to support and inform the development of this research. These lived experiences included: mental ill health; domestic violence and abuse; sexual abuse; adverse childhood experiences; child removal and involvement with the criminal justice system. All of the women were mothers. Two of the women involved in this research actively run groups for women who have experienced adversity (their roles within these grassroots organisations evolved over the course of the study) and the two women accessed a range of community support organisations.

Within the INCLUDE guidance, the NIHR (2020) motto: 'no decision about me, without me' was the ethos of incorporating the voices of lived experience of PPIE members in my qualitative research (NIHR, 2020). To gain an in-depth understanding of women's reproductive health and to elucidate rich accounts and perspectives, the EAG were fundamental to designing the project and ensuring the research (including the language used) is accessible and free from stigma (a prerequisite by them to this collaborative work). Cresswell (2013) denotes that research studies can contain an "action agenda for reform" which address issues such as empowerment, inequality, oppression, domination, suppression, and alienation which may encourage them to design questions, collect data, analyse information, or reap the rewards of the research. The women used their lived experiences and understanding of the needs of women like them to guide and inform the study and advocate and present the vulnerabilities women who use drugs may have. For all of the women involved in the EAG, this was their first time being involved in research as PPIE members and they felt it was a new challenge and opportunity for them to empower others.

6.3.2 Women's Sexual Wellbeing Study

Members of the EAG emphasised that their involvement was important to them as they felt "heard". As previously mentioned, consultation with the EAG women led to the study being renamed as the 'Women's Sexual Wellbeing study'. This was because they felt using the initial research title was "too academic" and specifically, they felt the term reproductive health was confronting and "too clinical". Under their guidance, the study was renamed the 'Women's Sexual Wellbeing' study. Having the study titled as the 'Women's Sexual Wellbeing', the EAG felt it was a way to empower women and increase likelihood of participation. This also demonstrated to them that their perspectives and contributions were "heard" and were valued.

The EAG also challenged me on aspects of the topic guide and the relevance and importance of some questions in relation to the research. They made suggestions for improvement throughout. One suggestion was *Question 9* of the women's topic guide (Appendix C). The EAG designed this question for inclusion in the study as they were interested how women's views may have changed due to drug use. They were also interested in incorporating a question relating to children's social services (based off their own lived experiences), after

further discussion between the team, we decided to see if this topic would come up naturally during interview, as opposed to probing the subject with participants. Working collaboratively on the development of the topic guide, built rapport between the team, demonstrated that their suggestions were important to the research and also improved the quality of the data collected.

During the recruitment process women shared extensively with their networks encouraging participation in the study. They demonstrated the importance of this research and validated that other women's views and perspectives were important to capture in order to give the research the best opportunity to influence change. Sharing the study on their social networks should not be undermined here- this was a clear endorsement of the study and one which was most helpful for recruitment. The support of the EAG expediated recruitment, meaning most of the data collection for women was complete within the first four weeks of data collection. In order to incorporate variation in the age of women included in the research, the EAG actively recommended and encouraged participation of women under 35 across their network.

As outlined in Chapter 5, the EAG were not involved in the coding of data or anonymised transcripts. Other research studies have collaboratively undertaken the task of coding anonymised transcripts, however, given the sensitivity of the topic, their own lived experiences, and that woman had supported recruitment across their networks, we felt this may make women identifiable, but also, this may be triggering to members of the EAG. Women involved did collaborate on sense making of the codes and findings in a series of online meetings and a mapping workshop. In our meetings we reviewed and discussed codes and emerging themes. We used these emerging themes to co-design an upcoming presentation, recognising this conference dissemination as another opportunity to review our interpretation of the findings. The final themes workshop took place in July 2023 and during this meeting we discussed the relevance of the findings to ensure they included a cultural and broader understanding of the reproductive health and social care of women who use drugs (Brett *et al.*, 2012). We also discussed how the results could be translated to improve policy and practice and how they could best be disseminated. A timeline of the EAG involvement can be found in Figure 2 of this Chapter.

Figure 2: Timeline of EAG involvement

6.3.3 Practical considerations

Throughout the PPIE it was important to discuss with the EAG about their involvement, time and reimbursement. The EAG were offered flexibility - an opportunity to contribute to aspects they felt comfortable with and had the time to do so. I was mindful of the sensitivity of the topics covered in this research and that it may be triggering for women involved in the EAG. At the open and close of all meetings, I made members aware they could contact me directly if they had any concerns and I would be happy to listen and direct to further support if needed. They were also made aware of reimbursement they would be offered for their time. For reimbursement, I followed the recommendations outlined in the NIHR INVOLVE guidance (NIHR, 2021).

As a researcher, it is important to reflect on the privilege of the insights given by PPIE. The incorporation of the voices of lived experiences has added immense value to the methods

and findings of this research. The EAG has added richness to the study, but this did not come without significant time investment and communication between the EAG and I. For women who have been involved in the EAG, they have been invited to co-author a publication related to this research, and also, co-produce further research supporting their interests in this sector. This is intended to encourage them to exercise their lived experiences and reinforce the importance and value of their voices in future research.

6.3.4 Collaborative Dissemination

Throughout PPIE for this study, the EAG and I have undertaken a variety of collaborative dissemination opportunities. These have included: blog posts[4]; podcasts[5], People with Lived Experience conference (York)[6] and International Women's Day conference.

International Women's' Day 2023

On International Women's Day (IWD) 2023 we organised and cofacilitated a research event which focussed on embracing equity by celebrating resilience and showcasing the lived experiences of women in the North East of England. This was a FUSE (the centre for translational research in public health) funded event which featured research and community involvement from the NIHR Applied Research Collaboration (ARC) North East and North Cumbria (NENC), REFORM (charity), and Changing Futures Northumbria (voluntary, third sector organisation). The overall aim of IWD 2023 research event was to give an overview of current research exploring women's health inequalities, how this was experienced, and the current unmet need within the region.

The EAG and I were focussed on making the conference as accessible as possible and to ensure the event attracted a diverse range of people with an interest in women's health and wellbeing. This included researchers, stakeholders, policy and practice and people with lived experience. In order to make the conference inclusive and to make attendance accessible, the EAG recommended the timings of the event be considerate of those with caring responsibilities (during school time), that the location was accessible via public transport and that all information about the event be in plain English and free of stigmatising language. We

[4] FUSE blog post can be found here: https://fuseopenscienceblog.blogspot.com/search?q=Claire+Smiles
[5] Collaboratively Speaking with University of Southampton: https://shorturl.at/aCOPV
[6] PwLE conference at York University- keynote guest speakers

co-facilitated our presentation, which included two members of the EAG reading poetry they had written about our research. Copies of these poems can be found in Appendix J.

Figure 3: Photographs of the EAG[7] from IWD 2023

In preparation for the day, we had discussed that some of the research findings may be 'heavy' and difficult to listen to. In an attempt to mitigate this, the EAG members suggested ending the day with a wellbeing activity. Two members of the EAG conducted a wellbeing workshop for conference delegates and speakers to attend. Within this workshop there was

[7] All members of the EAG have given permission for their photograph to be included in this thesis.

a gong sound bath and a guided meditation, giving people the opportunity to decompress from the day.

The International Women's Day event was a positive experience which had in excess of 80 attendees who listened, contributed and supported a range of research which focussed on women's health and wellbeing in the North East. From a PPIE perspective, the event was an invaluable opportunity to evidence how co-production can be achieved through careful planning and engagement with people with lived experience. For all of the EAG involved in this research, they found the event to be a beneficial and empowering experience which they were proud to be a part of.

6.4 Challenges

The incorporation of the EAG enhanced and improved the study, however, it is important to acknowledge there has been challenges associated with PPIE. Although PPIE in research has become expected, there is little guidance for how to undertake PPIE in PhD research, including the pros and cons of doing so. Incorporating the voices of lived experience in research design and development brings about the responsibility of managing expectations both of the research parameters and of the PPIE involvement, which many PhD students may have little experience of. This occurred throughout my PPIE and was on occasion challenging to overcome. Each member of the EAG were articulate and challenged me on preconceptions, or oversights within the project. They each also have unique life journeys and have their own lived experiences, and some were frustrated with aspects of the health and social care system. In some instances, this resulted in our meetings deviated from the research study and into their personal experiences. While it is important to reiterate that their lived experiences are important and the sharing of those are valued, it was sometimes difficult to shift the focus back to the research study. Having a predefined plan for PPIE involvement (including an agenda for each meeting) may help mitigate some of these challenges, but this requires flexibility from the researcher to ensure PPIE members are not overwhelmed or burdened by participation, whilst also informing them of the parameters of the research being undertaken.

PhD students are often novice researchers, and some may have no experience of engaging with the populations they are researching. For this reason, and as detailed by Troya *et al.*, in

her PPIE work, PhD students "may require expert advice and support on how best to work with vulnerable populations sensitively" (Troya *et al.*, 2019:627). Although having almost a decade of experience of working with vulnerable populations in practice this helped me to engage with women with lived experience of drug use with ease, I did have to unpick some of the conditioning from my practice roles. For example, wearing a lanyard if we met in public made my EAG feel like I was a worker and therefore, they would be viewed as a service user. Once I was made aware of this by an EAG member, I no longer wore my University lanyard for our meetings. This highlights the reflexive approaches and the importance in communication that PPIE requires.

As previously noted, PPIE requires time, planning and resources in order to build meaningful engagement and rapport. The EAG were involved in this project for almost two years. During these two years they sustained and maintained regular contact, planned and attended meetings and conferences, recorded podcasts and organised events. While this research has now concluded we continue to work together on co-authoring a book chapter on our co-production work. For those who women who have capacity and interest in research, they have been invited be involved in other projects with colleagues and one has been named on a successful funding bid. This demonstrates that investment (time and resources) can help build collaborative partnerships with members of the public and those with lived experience in future research projects. Incorporating the voices of lived experience in PhD research adds value and richness and overcoming the challenges associated with PPIE is achievable and worthwhile.

6.5 Chapter Summary

This chapter outlined the importance of PPIE in PhD research. The chapter began with an overview on approaches to lived experience involvement in research, including considerations for incorporating underserved populations. I then discussed the approaches I used to develop and work alongside my EAG, detailing how we worked together to promote inclusive collaboration, which in turn enhanced my qualitative research findings. In the last section of this chapter, I reflected upon the challenges PPIE may have for PhD students, giving examples from my work with women with lived experience.

Chapter 7: Findings from the 'Women's Sexual Wellbeing Study'.

7.1 Chapter Introduction

The chapter presents the findings from my qualitative study which explored the reproductive health and social care needs of women who use drugs in the North East of England. Eighteen women with lived and living experience and 10 practitioners who support women who use drugs and alcohol were interviewed for this study. The findings are organised into four main themes: 1) body sovereignty and societal expectations; 2) exercising agency; 3) trauma and relationships; and 4) access to care and visibility. Each theme is discussed individually and the interplay between them is highlighted throughout the chapter. Verbatim quotes are used throughout to illustrate the findings.

7.2 Participant demographics (women)

A total of 18 women were interviewed for the study and they came from across the North East of England: Durham(n=5), Darlington(n=1), Gateshead(n=4), Newcastle(n=4), Northumberland(n=1), North Tyneside(n=1), Middlesborough(n=1), Sunderland(n=1). Interviewees were aged between 30- 50 years of age (mean age 39 years) and most (n=14) had previously given birth; with a range of 1-6 children (mean of 2.2). Participants were not asked to disclose their sexuality, however, two women shared they were lesbian. All of the women identified their ethnicity as White British, except one who was British Asian. Women involved in the study described lived and living experience of a broad range of drug use including heroin; cocaine; amphetamine; benzodiazepines; illicit pregabalin; MDMA and other psychedelic drugs such as novel psychoactive substances (NPS) and cannabis. Some women reported alcohol use alongside their drug use. Table 11 (page 142) further illustrates the demographics and characteristics of women who participated in this study. Women's quotes are presented as *W01-W18*.

Table 11: Characteristics of women

Participant ID	**Age**	**Location**	**Ethnicity**	**Relationship status**	**Employment**	**No. of children**	**Drug use (*H- history; **ATI- at time of interview).**
W01	43	North Durham	White British	Complicated	Employed	3	H- heroin use. ATI-In recovery-current psychedelic use.
W02	41	County Durham	White British	Not in a relationship	In education	4	H- heroin, cocaine use. ATI- In recovery- drug free >6 months.
W03	41	Darlington	White British	Relationship	Not working	4	H- cocaine and alcohol use. ATI- In recovery- >3 months drug and alcohol free.
W04	42	South Durham	White British	Not in a relationship	Not working	6	H- heroin, cocaine, amphetamines, cannabis. ATI- In recovery- drug free 4 years.

W05	31	Gateshead	White British	Lesbian, not in a relationship	In education	1	H- cocaine and alcohol use. ATI- In recovery- >3 months drug free.
W06	50	South Durham	White British	Separated	Not working	1	H- alcohol use, cannabis use. ATI- In early recovery- detox <4 months ago.
W07	40	North Durham	White British	Not in a relationship	Not working	1	H- heroin, crack cocaine use. ATI- In recovery- 3 years drug free.
W08	48	Gateshead	White British	Not in a relationship	Full time employment,	0	H- alcohol and drug use. ATI- In recovery- drug and alcohol free.
W09	32	Gateshead	British Asian	Not in a relationship	Not working	0	H- MDMA, cannabis. ATI- Valium, cocaine and alcohol use.
W10	34	Newcastle	White British	In a relationship	Not working/ in receipt of benefits	2	HI- Heroin and other drug use.

							ATI- In recovery- drug free 3 years.
W11	38	Newcastle	White British	Married	Not working	7 (6 birth children)	H- Heroin use from 15. In treatment for 23 years. ATI- In early recovery.
W12	48	Newcastle	White British	Single	Unemployed	2	H- Heroin and crack cocaine (both smoked) for over 26 years. ATI- In early recovery- completed rehab 4 months previously.
W13	34	Gateshead	White British	In a relationship- Lesbian.	Unemployed	0	H- crack cocaine and alcohol. ATI- In early recovery- >3 months.
W14	37	Northumber-land	White British	Single	Working	1	H- Cocaine, Ecstasy Alcohol. ATI- In early recovery- >3 months.
W15	43	Newcastle	White British	Single	Unemployed	3	H- Amphetamine, Heroin.

							ATI- In early recovery- >3 months
W16	32	North Tyneside	White British	Single	Unemployed	2	H- Pregabalin, Alcohol, Cocaine, Mephedrone. ATI- In early recovery- >3 months.
W17	30	Middles-borough	White British	In a relationship	Employed	0	H= Alcohol, MDMA pills, powder, cannabis use. ATI- In recovery- drug and alcohol free 3 years.
W18	31	Sunderland	White British	In a relationship	Employed	1	H- alcohol use, amphetamine use, heroin use. ATI- In recovery- drug and alcohol free.

7.3 Participant demographics (professionals)

Ten professionals working across a range of support services participated in the study. Eight women and two men aged between 35 and 53 years shared their perspectives and practice experience from a range of services across the North East. All of the participating practitioners had frontline experience of working with women who use drugs and alcohol. Although not directly asked, seven of the practitioners who participated shared they also had lived experience (self-described as "in recovery") from substance use. Practitioners who described themselves as in recovery often reflected on their own experiences and perspectives of using drugs during interview. At times, there was a distinct overlap between their accounts and the women's narration of experiences and in some cases (particularly female practitioners in recovery), they spoke as an ally or voice for other women who use drugs. Table 12 (below) provides further details of the characteristics, professional role and work location. Professional quotes are presented as *SP01-SP10*.

Table 12: Characteristics of professionals

Participant ID	**Gender**	**Age**	**Ethnicity**	**Location of Service**	**Role**
SP01	Female	47	White British	Newcastle	Harm Reduction
SP02	Female	44	White British	Newcastle	Volunteer Harm Reduction
SP03	Female	53	White British	North East	Manager Hep C
SP04	Male	48	White British	North East	Peer Coordinator Hep C
SP05	Male	47	White British	Newcastle	Recovery Coordinator
SP06	Female	41	White British	Newcastle	Intervention Coordinator
SP07	Female	35	Polish	Newcastle	Nurse
SP08	Female	37	White British	Newcastle	Manager
SP09	Female	51	White British	North East	Volunteer-Peer
SP10	Female	36	White British	Newcastle	Women's Charity

7.4 Theme 1: Body sovereignty and societal expectations

Body sovereignty is the concept that individuals have the right to make decisions about their own body and for women, reproductive choices are central to this. Linked with Petchesky (1984) theory that women have the "right to choose" alongside Hakaar (2021) women as "free agents", this theme seeks to explicate the body sovereignty women who use drugs have in relation to their reproductive sexual health and wellbeing. As described in Chapter 2, women are often considered to be responsible for pleasing men and producing children. Findings from this research supported the theory that women must adhere to an unwritten, yet deeply embedded code of moral expectations. Women who use drugs and alcohol are often seen as breaching societal expectations of them as women and as mothers, and it is accepted, they are more stigmatised than their male counterparts.

> *"You do sleep around, but as a woman as well, I think as a female addict, we get judged much harsher than the males. So you can have a male and female together, whilst if the female, the mother is taking drugs, she gets so judged compared to the male, to the dad. I think that's wrong in society because women are supposed to be caring mothers, but unfortunately, we're not very well people." (SP02, F, volunteer)*

As demonstrated in the systematic review (Chapter 4), women who use drugs and alcohol are in an arduous position, viewed as immoral, uncaring and selfish and because of this receive little compassion from society. For this reason, they are stigmatised, shamed and marginalised within their own families, friends and the wider community. Women involved in this research reported shame was not uncommon and something they had experienced during their early life. They described how were often shamed by their own mothers, particularly in relation to their reproductive health and sexual relationships.

> *"My mum always shamed me for sexual behaviour. I lost my virginity when I was 14 and she shamed me for any kind of sexual behaviour, including masturbation, saying that it was disgusting, it was dirty, it was filthy, she called me names, she called me a slag, she called me a slut….So, basically, when my mum called me things like that, I decided that, you know, if*

you're going to go to call me it, I'm going to be it. So, I've got a lot of trauma, surrounding, like, sort of, sex." (W03, age 41)

Women who use drugs often have complex physical and mental health needs which further compounds their ability to meet societal expectations and their body autonomy and challenges their body sovereignty. Women involved in this research reported they were diagnosed with a range of conditions including: Emotionally Unstable Personality Disorder (EUPD), ADHD, diabetes, renal failure, kidney disease, Wernicke-Korsakoff syndrome, endometriosis, two women were living with the effects of a stroke, one woman had suffered a brain injury as a result of a physical attack. These physical and mental health conditions, often exacerbated or incited by drug use and trauma, impacted women and their ability to take care of themselves:

"I've struggled with addiction probably since I was about 12, 13. I didn't realise at the time. Alcohol, drugs. It has affected my health, I'm diabetic, I'm Type 1 diabetic, I'm now in renal failure. But it is what it is, I'll start crying if I go too much into it.

It's caused by my diabetes, but it's the fact that I haven't looked after my diabetes, which was because of that addiction, basically. I've got problems with my sight as well, off the back of it." (W18)

"I think with my mental health and my addiction in the past, sticking to appointments or getting the pill, it just wasn't something that… I miss my tablets as it is, never mind sticking to a pill." (W11)

Alongside this, women reported they had experienced significant intimate partner violence and sexual abuse throughout their lifetime of using drugs which further exacerbated and impacted on their perspectives of reproductive autonomy and sexual wellbeing. The illustrative quotes above highlight the complex physical health and social needs of women who use drugs (including those in early recovery) and demonstrates the challenges they face to address these.

7.4.1 Keeping yourself "safe"

Women involved in this research were asked about their perspectives and understanding of reproductive and sexual wellbeing. For most women, sexual and reproductive health and wellbeing was about protection from disease and prevention of pregnancy. This was presented as self-care, but also that they were responsible.

> *"Sexual wellbeing means taking care of yourself, knowing that you're okay. Because like I say, out there, I didn't care. Today, I do care, I really do care. If I was to sleep with somebody and I thought there was something wrong with me or I had something, then I wouldn't want to be passing it. Because I've got a conscience, I can't live with that. I can't do that, I'm not prepared to do that to somebody. And that's the difference." (W02, age 41).*

Women involved in this study were often keen to present themselves as responsible, aligning with moral and societal expectations.

> *"But I was responsible, on the whole, that I would either be on a contraceptive pill, or I'm saying, "Oh, it's not always, but the morning-after pill as well." So, I was aware that those things were available, and I did use them regularly." (W07, age 40)*

For some women, sexual wellbeing was not only about safety, but also about being informed and body awareness.

> *"Sexual wellbeing to me would mean being informed on contraception. On the safeness and/or the risks of having sexual partners. On periods. And knowing your body. Getting to know your body, how it all works and how you can work with it. And I'm thinking of the wellbeing word as well. So, that would mean, like, kind of taking some of the shame out of it." (W01, age 43)*

Both practitioners and women echoed that women's sexual wellbeing is about "keeping yourself safe" presenting the consequences and risk they pose if they don't "keep safe", both of which fall into the repsonsibilization rhetoric outlined by Luption (2012).

> *"It's like I'm not going to say to somebody, "Don't do this, don't do that." I am just going to say, "If you are going to do this keep yourself safe." "Do*

you know the consequences of getting an STD down the line?" Things like that, and with your reproduction." (SP03, F, Manager)

Practitioners involved in this research reported that they did not consider sexual health routinely, nor did they discuss family planning (unless it related to prescribing medication) with women they supported. Discussing sexual and reproductive health was only considered important when women were involved in sex work. This suggests that services are focussed on STI/ STD, blood borne virus transmission and the avoidance of risk (particularly high-risk) rather than the health and wellbeing of service users. As demonstrated in the quote below, practitioners often framed sex for women who use drugs in the context of sexual risk taking or exploitation.

"The female service users that come in here that we would be concerned about their reproductive and sexual health would be the sex workers." (SP06, F, Frontline Practitioner)

For women who use drugs and alcohol, discussing sex and sexual relationships within the remit of wellbeing posed a number of challenges, particularly as they felt this was not an aspect of their lives which they had positive experiences. This challenges the theoretical perspectives of "free agent" and further reinforces the ideology that women are agents of performativity, in the hope of being received as socially and physically desirable. Throughout interviews with both women and practitioners, there was a distinct void of intimacy and pleasure within their descriptions and accounts of sexual wellbeing. Sex and sexual relationships were often performative actions- something they had to do. The nuance being here is that is that for women involved in this study, sexual wellbeing was primarily focused upon pleasuring and performing for men, or reproduction.

"I've had a lot, a lot of sexual partners, but I've probably only seen about half a dozen willies, if that makes sense, because I would always close my eyes." (W03, age 41)

"So, I've been illicit substance-free (Laughter) for probably over two years now, and what I've found in myself is actually I've got a lot of shame attached to being a woman, and periods, and my body. And I'm quite prudish about sex. And the thought of navigating a sexual relationship

now, in recovery, is scary. And I think, in the past, I've maybe used drugs as a coping strategy for that." (W07, age 40).

Both *W03* and *W07* discussed the methods they used to cope with sexual relationships, indicating sex and intimacy was not only an uncomfortable interaction, but potentially, something that was perceived as shameful for them. The shame associated with sex and intimacy demonstrate the performativity of sexual relationships for their male partners and casts shade on the sovereignty and autonomy women who use drugs have in relation to sexual relationships.

7.4.2 Sexual exploitation, abuse and survival sex

Often women involved in this research presented narratives which described a transactional perspective of intimacy and sexual relationships. Within this research, women described experiences where they had engaged in sex in exchange for drugs. Women spoke openly about this transactional sex which they viewed as an expected or normalised behaviour and as a means to an end.

"But if I had to sleep with somebody, which I did a couple of times, for a bag, then I would have. You know? That's how it went. But I had no sex drive at all. I think that's the case for a lot of women using heroin, a lot of women." (W02, age 41)

During these narratives women deemed themselves responsible for 'placing themselves' in risky positions and avoided blaming the men who had exploited their vulnerability at the time. In this context, transactional sex could be viewed as survival sex. At these times women were concerned about or were experiencing drug and alcohol withdrawal (and the physical and psychological effects of this). To avoid this, they sometimes found themselves in situations whereby they were offered drugs in exchange for sex to meet that need. Women were also acutely aware that sex in exchange for an illegal substance could legally be viewed as prostitution (transactional sex), with additional legal consequences, further compounding their shame and stigma in reporting sexual violence.

"Yes, like a lot of us have been sexually abused and stuff like that, due to drugs. A lot of us, like myself, to be fair, don't report it, because we feel like

it is partly our fault. A lot of us, we put ourselves in really bad situations to get drugs, and it's turned out something bad has happened. And in the end, you feel like, "I can't really report it because I shouldn't really like…" like what I said, "I shouldn't have really met a dangerous man for a line of cocaine," I mean, how low did I get?" (W05, age 31).

Rape and sexual assault were commonly reported by the women who participated in the study. Women often blamed themselves for sexual assault as they felt responsibility for placing themselves in these vulnerable or risky situations, particularly, if they were intoxicated. One woman described how sexual assault seemed an inevitable consequence of their vulnerability.

"…but it's more I'm putting myself at risk of diseases and stuff like that. Also, for how drunk I get, well I do get taken advantage of, but I could end up getting taken- well, the states I get in are very dangerous. I'm surprised it hasn't already happened, kind of thing." (W09, age 32)

Sometimes women blamed the substances they were using (both drugs and alcohol), or their intoxication, or indeed themselves as being at fault as opposed to the perpetrators of sexual assault. Women regularly recounted occasions when they recognised that sex had occurred without any recollection of this, of giving consent or situations where they did not have capacity to consent.

"…Obviously I've been raped and stuff in the past because of the drink. Well, not because of the drink, but I've put myself in a vulnerable situation." (W13, age 34).

"Yes, because I don't know if I've slept with someone and I might be pregnant, kind of thing. Do you know what I mean? I have had a few times where I have been late and I'm like, "Right, shit, I'm two days late now. What am I going to do? (W12, 48)

Women feel assault and rape were a consequence of their actions and for failing to keep themselves safe. One woman shared about how she was in intoxicated all the time and could

not remember having sex, despite waking up on numerous occasions with evidence that sex may have occurred.

> *"And I have another daughter to him, and I do not know how I got pregnant. I think my last child was the product of rape. I was in blackout. I drank to blackout. I can't remember having sex. I can remember sort of like mornings where I'd wake up and my pyjama bottoms would be off, or I'd be all skew whiff. And I'd be like, "Did I have sex last night?" and I didn't know, and I couldn't remember. And he did this prolifically because I was in blackout a lot of the time." (W03, 41)*

The sexual assault abuse and exploitation (perpetrated by both intimate partners, associates and strangers) that was experienced by many of the women involved in this research, had impacted on their perception of intimacy and how they engage in intimate relationships. This demonstrates Foucualt's theory of "subjective agency" whereby women attempt to enforce their own autonomy, however, this agency has been influenced and shaped by the abuse they have experienced. For some women, sex often triggered memories of past traumatic experiences, making them question their autonomy and why and who they are engaging in sex for.

> *"I'm not going to lie, I clam up, because I start thinking about things that have happened to us, how awkward I feel when I'm getting intimate, because of stuff that's happened. But I would still like to talk about it. So I've been abused, and that has affected how I am intimacy wise in a relationship, I struggle to relax. It sort of triggers me sometimes. I don't like being touched certain ways or in certain places. Even though I know that my partner does love me, I feel like, if there's no respect there when we're being intimate, I just feel like it's dirty and I've been used. Because of all that other stuff that comes up." (W18, age 31)*

Sexual abuse can severely impact upon women's intimate partner relationships and their perspectives on sex. In the case of the participant above, she has chosen to become celibate. Celibacy was a way for her to protect herself from triggers but also, to have some control and not feel she was being used as an object for someone else's pleasure.

7.4.3 Sexual wellbeing in intimate partner relationships: violence and abuse

Within intimate partner relationships, domestic violence was common. They discussed frequent experiences of physical abuse, sexual violence and coercive and controlling behaviours. Women discussed how they had intimate partner relationships with much older men during their teenage years and had experienced brutal physical violence during pregnancy. *W15* was 16 years old when she began a relationship with a man in his mid-thirties.

> *"It lasted six years but, God, out of the six years it was horrible when I think back. Like I say, he used to hit me really bad as well. I was pregnant and he would… like you couldn't recognise my face and he kicked me down the stairs." (W15, age 43)*

Abuse that wasn't physical was often minimised or acknowledged as abuse by women. *W02* described coercive control, stalking and psychological abuse as "ridiculous things", underplaying how frightening these experiences must have been.

> *"He used to give us hell all the time, like putting my windows out and turning my electric off when I was in the shower, stuff like that. He even killed my daughter's guinea pig. He was sick, really sick. Like slashed all my clothes on the line. Just ridiculous things, I know." (W02, age 41)*

Women sometimes described abuse through self-blame- a common behaviour of women involved in domestic abuse and coercive control relationships.

> *"And it wasn't- it was violent, but he wasn't making me stay with him. It wasn't that kind of relationship. I was voluntarily in that relationship, and it was volatile. And I was obsessed with that guy, do you know what I mean?" (W07, age 40)*

Women often normalised abuse within relationships and at times, downplayed the gravity of the offending towards them. One woman discussed how she responded and engaged in an abusive and violent relationship, having extensive experience of domestic abuse relationships.

"Just constantly fighting with his dad, it was a very volatile relationship. That's one relationship that I won't say it was 100% all him, it was both, I could be just as bad. I would goad him as soon as I got drunk and thoroughly enjoy making big- we were both just as toxic, it was a very toxic atmosphere. But he wouldn't have us pinned up in the corner abusing us like other exes have, we would just fight. It was a very volatile situation." (W16, 32)

Whilst women came to expect violent relationships and were largely accepting of its occurrence, they were often not passive. Women would attempt to exert "subjective agency" in a number of ways, making efforts to take some control. For some women this involved fighting back, whilst others would deliberately provoke partners during periods when they believed violence was imminent in order to 'get it out of the way'.

7.4.4 Fertility: periods and menopause

Throughout the research, women reported that while using drugs they had interrupted and irregular periods, with many having none at all (for example, *W14* reported she had not had periods for 26 years while using opioids and crack cocaine). Women felt that this was 'one less thing to worry about' during this time in their lives. Alongside this, some practitioners, particularly those who were in recovery from substance use, were aware that women who use drugs may experience missed or late periods, often having experienced this themselves. They often attempted to address this gap and inform women using their own lived experience to explain to women that despite irregular periods, they were still able to conceive.

"I mean a big problem with a lot of the females we come across, stop having periods. I mean mine stopped for seven years and a lot of the misconception is, they're thinking if they're not having periods then they can't get pregnant, which is obviously so wrong. I always make a point of stressing that to them, first hand." (SP09, F, Volunteer).

"I've had past girlfriends who didn't get periods while they were using, didn't get anything. As soon as they stop, they all came back." (SP05,M, Frontline Practitioner)

Both women and practitioners involved in this study, detailed how this was normalised amongst women who use drugs (particularly, but not restricted to, opioid use). Both stated that periods were an inconvenience to women who use drugs both physically and mentally. Women described how periods were disruptive to their lives and required them to prioritise their hygiene, which at times they were neglecting. Purchasing sanitary products was also a financial burden, so interrupted menstruation was often considered a benefit.

> *"The general consensus with that one is obviously, they go, "Ah, good my periods have stopped." In general. They don't even think about the medical or the worrying side of it. I mean I can remember [interviewer], at the time I wasn't bothered that they'd stopped, and I was like, "And…" Do you know what I mean? To be honest as a working girl they were a hinderance, because a working girl sees it as a period is lost money." (SP09, F, Volunteer).*

> *"I wasn't bothered. I didn't have to buy pads. I didn't have to buy tampons. I wasn't inconvenienced with bleeding like a stuffed pig for five days" (W03, age 41).*

For many women not having periods was a relief, as they no longer had to think about the menstrual cycle, buying and using sanitary products or worrying about contraception. Most assumed they could not get pregnant and did not use contraception for this reason. However, given the societal expectations to be responsible, this may have been a way for them to resist judgement if they did become pregnant.

> *"…most of us would always say, "I didn't know I could get pregnant, because my periods were all over." And I know for a fine fact I've said that quite a few times myself." (W11,6 children, age 38)*

Anecdotal discussions from friends led many of the women to conclude that for the most part women who use opioids may have a disrupted menstrual cycle, although women did not know physiologically, why they had stopped. In the context of the body sovereignty for women who use drugs, there is complex interplay here between irregular periods, questioning fertility and perceived judgement if they do become pregnant, however, and as reported by participants in this study, it is difficult to make decisions if you are not properly

informed or educated on them. One professional suggested that women who use drugs and alcohol have a dearth in knowledge around reproductive health.

> *"Yes. Some women have had periods stop for prolonged periods of time. Other women have been unsure whether or not they were in the menopause. Some women were incredibly late to have periods. Some women, when they are told the stories, they didn't know how babies were conceived and they had already conceived." (SP10, F, Women's Charity)*

Women who participated in this research discussed their fertility while using drugs and questioned their capacity to conceive while using substances. Many women (including those in practice with lived experience) questioned if drug use had impacted on their fertility.

> *"Yes, definitely. I thought I would have problems because of my health. Because of all the crap I've put into my body, I wondered whether I could ever get pregnant. I was quite surprised that I did, to be honest. Yes, but I'm happy that everything is working and stuff." (W18, age 31)*

> *"Well, I just thought my period's stopped and I can't have children, that was it, you know, I can't have children." (SP02, F, Volunteer)*

As previously outlined, both *W11* and *W18* had experienced irregular or no periods, despite this, both had experienced pregnancy. Both women reported that they had assumed that because their menstrual cycle was irregular, they could not become pregnant and for this reason, did not use contraception. This wasn't uncommon within the sample of women, *W18* here describes how she believed she was infertile after having unprotected sex with her partner for many years without pregnancy occurring.

> *"It's mad me saying that because I wasn't taking any other precautions, but I was with somebody I think it was for about six years. And when we slept together I never, ever fell pregnant but I was using and I just thought everything was safe. And it was right at the very end of the relationship because that was another bad one, really bad relationship. And I fell pregnant just at the end of- in bad circumstances to be honest with you, I fell pregnant under bad circumstances… And we had been together years*

and I just thought because I was using heroin and stuff like that it wasn't happening." (W15, age 43)

Similar to findings from the qualitative systematic review, some women reported that they had terminated pregnancies because they were aware their lifestyle and relationships were not suitable to bring children into. Women discussed this as a way of demonstrating responsibility to themselves, their children, and societal expectations of them.

Yes, and I mean, two of those abortions, the ones in Aberdeen, I was in quite a violent relationship at the time…But part of the reason why I didn't have the babies was because it was violent. I was sensible enough to think, "Well, I don't think this is a great place to bring a child." (W07, age 40)

One woman involved in care proceedings with her children, chose to terminate her pregnancy. Pregnancy termination was a way for her to demonstrate she could prioritise her children and perform to the expectations social care agencies had of her (not to become a repeat child removal case).

"It was the same situation, but it happened this time round when I had the abortion, that's how this time round I thought, "No, I'm not doing it again, it's not fair on [Child 1], it's not fair on the kids." [Child 2] came round but I felt different, I felt happy, I felt like a mother, it was different than this time." (W16, age 32)

Despite this and other challenging complex physical and mental health, one woman described how her reproductive health and wellbeing was the one thing that probably was working, given the other complexities with her health.

"Women's health-wise, I think I'm lucky that everything is alright because everything else is dropping to bits. That's probably one of the only things that's working." (W18, age 31)

Women were aware limitations of their fertility and referred to their "biological clock", reiterating Weber (1998) that women have been rationalised by the biological factor that women can bear children.. A minority of women spoke about this as a potential influencing factor in terms of family planning and whether or not to have children.

So it's not that- I've always said that if I end up with kids, it's because that whole biological clock thing's kicked in. It's not that I want love and adore them, and do my best by them, but it's not a choice that I feel I've consciously made." (W17, age 30)

Women who use drugs were also concerned about menopause, their access to care and ultimately, menopause marks the end of their fertility, meaning they are no longer 'useful' as reproductive vessels (for others and also, for themselves to become mothers). Alongside this, many women raised concern about symptoms and mood change and questioned if they were associated with peri/ menopause or substance use.

"I used to have, like, hot flushes now and again but that's even gone now, so I don't know whether that was just alcohol or whether it was the two combined." (W06, age 50)

As demonstrated in Chapter 4, women who use drugs are highly stigmatised. Women involved in this study were aware their drug use is perceived to be 'irresponsible' and that it does not comply with being a 'good mother'. Unplanned pregnancies are seen as further evidence of their lack of responsibility. Women involved in this study frequently highlighted why they believed they were unable to become pregnant and may in some way be forfeiting the responsibility and expectations society have of women who use drugs. It may also be a way for them to provide some defence from this stigmatised judgement.

7.5. Theme 2: Exercising agency

Agency and sovereignty are related concepts, however, women who use drugs often lacked rulership over their own bodies and exercised agency in resistance to this (where they could). Despite the sense of a lack of autonomy and body sovereignty women who use drugs and alcohol have over their sexual wellbeing, some appeared to exercise agency surrounding their reproductive health. They do so by accessing contraception methods that suit their needs, but also, by exercising their reproductive right to have children.

7.5.1 Choice and method of contraceptive care

One way in which women described exercising agency was through their choice, method and rationale for contraception use or non-use. Women involved in this study used a variety of contraceptive methods including the contraceptive injection (n=3); contraceptive pill (n=3); contraceptive implant (n=3) and intrauterine devices (n=3). Six women reported they were not taking contraception at the time of interview, mostly because they were not in a relationship and therefore did not need to take contraception. Condom use was rarely reported by women involved in this research, meaning women who engaged in sex were often at risk of contracting STI, STD and blood borne viruses.

Women shared how they would access contraception care across the region. Women in County Durham/ Darlington found waiting times for appointments were a barrier to care for them (with some citing they had previously had a four week wait); women in Gateshead had positive experiences of postal sexual health screening and women in Newcastle felt confident they could a range of sexual healthcare within the city. Most of the women spoke most frequently with their female friends about contraception method and choice as opposed to partners or health care professionals.

Many women were averse to utilising the contraceptive pill due to concerns regarding weight gain and body image, but also because of the burden of daily use and remembering to take the pill. Instead, they chose methods that suited their needs and that they could manage and regulate.

> *"Aye, and I've never wanted to go on the pill because I worry about my weight and I've heard it can make you gain weight. Anything that can make*

you gain weight, I've avoided. I think that's how I ended up settling with the coil and the fact that it didn't have hormones as well." (W09, age 32)

For many women involved in the study, choice and use of contraceptives was influenced by the perceived impact of this upon their mental health and wellbeing and not to prevent pregnancy. Women shared their ambivalence to synthetic versions of female hormones, demonstrating they were informed about contraception and had the ability to exercise choice over a variety of methods they could access and use.

"I don't take any contraception because I'm not very good with fake hormones. I'm not very good with hormones, full stop." (W03, age 41)

One woman discussed how contraception for her was about 'mood modulation' and was a medicine as opposed to pregnancy prevention tool.

"…I don't use contraception as a way to not get pregnant. I use it as a mood modulator. So, for me, it's a medication. Or at least that's the box I put it in, that's my mindset on it." (W17, age 30)

Some women utilised contraception methods to manage hormone imbalance and perimenopausal symptoms, particularly after protracted interruptions to their menstrual cycle, which was associated with their lifestyle and drug use.

"I'm on the pill now. This has been for the last- Since – what day are we on, Friday - Tuesday, I just started taking the pill. And that's for my periods though, [Interviewer], because I didn't have a period for five years. And it came back with force. Bad, really bad. And like I say, I'm 41 now, they need to calm down, they need taming." (W02, age 41)

For others the motivation for not using contraception, specifically for those in early recovery, was about being free from all medication, prioritising their mental health and wellbeing and exploring how they felt with their hormones and hormonal changes.

"Yes, and I just like the idea of my body being at its baseline without anything in there interfering." (W14, age 37)

For women involved in this research, long-acting reversible contraceptives (LARCs) were preferred methods of contraception for them. LARCs were considered to require less maintenance but primarily, they required less engagement with healthcare professionals which allowed them to be less visible.

> *I think I was offered a range, but when it comes to the pill, my memory is ridiculous. And so that was the best option for me. Because I knew as well obviously, being addicted to drugs, I knew I wouldn't keep up with like, regular appointments, do you know for the injection and stuff. So I thought, 'Yes, get this in my arm, I can have sex with whoever I want', do you know what I mean?... So that gives us another three years to pretend to be okay, you know? Do you know what, it made me feel safe and secure from doctors and stuff like that." (W10, age 34)*

For the few women who were not taking contraception, nor had they done so for many years, avoiding pregnancy was not a priority for them and if they did become pregnant, they felt this was 'meant to be'.

> *"…But I am having unprotected sex, and if it happens, it happens. I keep saying I'm too old, I'm this, I'm that. I keep making excuses, but at the end of the day if it happens, it happens. I wouldn't be opposed to having more children. (W03, age 41)*

7.5.2 Reproductive agency: "fix me"

For many women exercising agency was about exercising their right as women to have children and many women spoke about how they hoped children would "fix" them. For many, maternal identity and motherhood was important and something they had thought about from an early age.

> *"I never thought about how many. I just knew that I wanted to be a mum, and I wanted that from an early age. But, I think in my mind, it was like, I don't know, I thought that would fix something in me. And it did. It did for a while. Because I was very young. I was 16 when I fell pregnant. And I absolutely loved being a mum." (W01, age 43, 3 children)*

Children were often perceived to offer a catalyst of change for women. Children may offer women more opportunities to access care, perceived protection from violence and abuse and also, be a motivating factor to reduce or abstain from drug use.

> *"Oh, without a doubt. And I think, each time I had the children, I kept thinking, "Maybe this one, this one is going to be the one that saves us, this one is going to be the one that changes everything, this is one… Without a doubt, I think each and every one. The youngest, definitely- Changes then did start to happen. But God, it took many attempts and many kids for that change to happen." (W11, age 38, 6 children)*

For women who use drugs, children offer them an opportunity to be saved or fixed by them, wherein the identity as a mother may replace their stigmatised identity as a drug user. It also offered a deep and valued connection with another being, filling a void the women often reported within their life.

> *"I had children for selfish reasons, because I thought they would fix me. I thought I didn't want to be alone, because I wanted a family of my own." (W04, age 42, 6 children).*

> *"So, I thought well, maybe if I have these children, that they will fix me, I will be a really good mum, these children will help me to sort my life out." (W10, age 34, 2 children)*

For some women involved in this research, each child offered a new opportunity to begin the process of change. *W04* and *W011* each had six children to exert their reproductive agency as women and to incite change to their drug use and lifestyle. One professional suggested that women continued to have children after removal to fill the 'void' that they have within their lives.

> *"But I think there is a trauma response to it as well in that when they lose that child one of the women said, It's empty arm syndrome." That they have empty arms that they need to fill. Every time she tells us then she just holds her hands to her chest." (SP10,F, 36)*

One practitioner shared an account of her work with a service user who was a victim of domestic abuse for many years and during that time she had experienced consecutive child removal. Although the practitioner was supporting this woman in terms of her drug use, she described how her service user was resistant to contraception and affirmed she would continue to have children until she was permitted to keep one.

> *"And the other one had multiple children, all of her children taken away, and she categorically refused contraception because her mindset was around I'm just going to keep having one until I can keep one." (SP08, F, Manager)*

As evidenced in theme one, women who use drugs are disenfranchised and often have little autonomy over their lives. Their reproductive agency may be one aspect of their lives they feel they have the ability to exert power and control over and they exercise this right regularly despite the risk and consequences of child removal.

7.6 Theme 3: Trauma and Relationships

For women involved in this research, childhood trauma and relationships with their parents had a profound impact on their life trajectories, which shifted and shaped their views, perspectives and experiences of reproductive health, sexual wellbeing and relationships.

7.6.1 Childhood trauma

Almost all of the women involved in this research reported adverse childhood experiences and trauma. This included childhood sexual abuse, physical and emotional abuse, neglect and abandonment. For women who had experienced adverse childhood experiences, this was often given as the catalyst for their drug and alcohol use. They often began to use drugs at a young age (12- 13 years of age). One woman reflected on how childhood sexual abuse had impacted her life course.

> *"I was sexually abused by a neighbour for 3 years of my life. I think that had an impact on my behaviour, and obviously the drugs and the alcohol. I think I went to prison, 16 years of age I first went to prison." (W13, age 34)*

Many women described accounts of sexual abuse in childhood and one woman recounted having an abortion at 13 years old.

> *"I had an abortion when I was quite young. It was like, you know, I'd suffered sexual abuse. So, I had an abortion when I was quite young, and maybe about 13, or something." (W04, age 42)"*

Despite sexual abuse being commonly reported by the women throughout their childhood, women accepted these experiences without reflecting on the criminality of this abuse or that they were vulnerable victims. As outlined in themes 1 and 2, sexual assault and rape was viewed by women as something that was done to them for the perpetrators pleasure and at their expense. These adverse childhood experiences and trauma deeply impacted their life trajectories, which culminated in their use of drugs and alcohol as a coping mechanism but fundamentally, it normalised abuse and violence within their lives.

Throughout the study, women shared experiences of their childhood alongside those of their own children. Women involved in this research demonstrated that their childhood experiences had a significant impact on their perspectives of family. A couple of women had

experience of being in care, with one woman sharing that she was removed from her mother's care at five years old. She was subsequently adopted but re-entered care system in her early teens. At the time of interview, one of her children was subject to a Special Guardianship Order (SGO) and her younger child was going through court proceedings to determine where was best for them.

> *"A special guardianship order is a choice for him, but I genuinely don't think it'll get that far. Because we were talking about adoption to start with and then he couldn't stay at my mum and dad's, they're too old, they can't look after two kids, this, that, and the other. They've had my head done in with it, but now it's at the stage where he's at my mum and dad's. My brother's moved back into the house so if he has to stay there more permanently under a special guardian then he'll stay at my mum and dad's because my brother's moved back in. Because my brother, luckily, wants them obviously to stay together, my brother's fighting for that."*
>
> *(W16, age 32)*

W16 highlights the intergenerational impact of trauma, being a child removed from her mother and now her own children are in a similar position with ongoing court proceedings. Other women reflected on the impact of not living with their children and having interrupted contact with them throughout their lives.

> *"I do it to the best of my ability. Like, being a mother for my kids, but I'm not a traditional mother. All the children, I suppose, really, they don't have that bond with me." (W04, age 42)*

Adverse childhood experiences caused feelings of isolation and abandonment for women. Both *W04* and *W016* discussed abandonment they have experienced, but also abandonment of their own children who were not in their care.

> *"I was taken off my mum when I was four and then I was adopted when I was six. But I had major, major abandonment issues, because obviously at four or six you're old enough to know what's going on. My brother got adopted with us and he was just a baby so he didn't see any of what was*

going on. I think I had major abandonment issues and that resulted in us just going downhill, really." (W16, age 32)

"She will always have that fear, in her mind that, "My mum's going to abandon me again." I did abandon her, and I get it because I've had it done to me, with my own mother." (W04, age 42)

The abandonment felt by both *W16* and *W04* and the impact this had on their own life was significant. Having a fractured relationship with their own mothers, or no relationship at all, had been a catalyst for their poor mental health and drug use. Their isolation was exacerbated by domestically abusive partners and motherhood was an opportunity for them to build their own family. At time of interview, neither of these women had their children in their care and this demonstrates the intergenerational impact of trauma and abuse and the profound consequences it has on their lives.

7.6.2 Relationship with own parents

Women who used drugs and alcohol discussed the relationships they had with their mother and father. For women, their mother was of significant importance on their perspectives of reproductive health and wellbeing and intimate partner relationships. In particular, some women described difficult and strained relationships with their mothers throughout their childhood and early adulthood. Women also described how their mothers' put men and their intimate partner relationships above the needs of them.

"She was very narcissistic, and she was very unwell, and she was like, you know, she was very shaming, and she was always more bothered about men, than me." (W04, age 42)

Throughout accounts of childhood and relationships with parents, women often focussed on their mother's failure to protect them. However, women rarely reflected of the interplay between an absence of positive male role models in their childhood and teenage years and their subsequent intimate partner relationships.

"My mum died when I was very young, I was three years old. My grandma brought me up. She died of acute leukaemia. My dad was a Royal Engineer based in Germany, so we didn't have a lot to do with him." (W02, age 41)

Conversely, some women described how their fathers would provide more support and guidance, with one woman describing how her father explained about puberty and sanitary products because her mother avoided any discussion of puberty or sex.

> *"But growing up in that environment where it was never talked about, I never got the sex chat. I had the period talk off my dad only because I pestered the life out of him and asked him what tampons were, because people were throwing tampons around on a bus, that I'd heard. I wasn't on the bus. So, I pestered the life out of him to tell me what Tampax were, and that's when he gave me the period talk. My mum never talked openly."*
> *(W03, age 41)*

For some women, their parents' relationship and the subsequent relationship breakdown had made them consider whether they wanted a family.

> *"I think my family background was difficult anyway because there was a lot of- my parents argued a lot. My mum wasn't very well mentally. So, I think, from that standpoint, it was already like, "Oh, I don't know whether I want to have a family because of that. I don't want that to be repeated."(W07, age 40)*

As presented in theme 2, women shared that having children was not only a chance for them to remedy the love they had not received from their parents, but also an opportunity to demonstrate they were capable of being better mothers than their own.

> *"Yeah, because I wanted to be a better mum than my mum was, and being an addict, since I've realised, since doing work on myself, I've got a hole in my soul, and I want to fill it, I want to nourish it, but it's never going to be filled because I have a hole in my soul…So, I wanted a baby, but I wanted to fill that hole in my soul. I wanted to be a better mum than my mum was... I wanted to show them love that I never got. Does that make sense?" (W03, age 41)*

Women discussed occasions when their parents and siblings attempted family 'interventions'. Interventions would take the form of rehabilitation programmes/ treatment referral;

encouraging termination and supporting them with access to do so; or interventions during pregnancy and thereafter as an appropriate guardian to care for their children.

> *"I got in a relationship. I ended up pregnant with twins and at the time… like, I've always been a really, like, very emotionally sensitive type of person and just, I would say, lost all my life because I've never had a steady ground…So anyway, I had wanted to keep them. My sister talked me out of it. I had an abortion…So then my family sent me to rehab, but I really didn't want to go and I wasn't ready." (W09, age 32)*

Women would withdraw from family support either because of their drug use and, or domestic violence and abuse, both of which had an impact on their physical appearance.

> *"And I would isolate totally from my family. My family would let me just get on with it, and one day they came to my house and they saw the state of my face, unrecognisable, and that's when they intervened." (W15, age 43)*

However, for those women who had continued support from family, especially their mother, this had significant positive influence on not only their recovery but also on them retaining care of children and continuation of their family unit.

> *"And my mum would always say, "I know." Because I used to say, "Why do you stick by me, after everything?" I took everything from my family, literally, I got them- Not in debt, I took every bit of money. I stole £50,000, all my sister's jewellery, robbed houses. You know, I'd done everything…And my mum would always say, "I know [what I put] inside you, this isn't who you are." I think, now, I've come to accept that that isn't who I was, this was the drugs. It has just completely taken over me and making me into somebody that I'm definitely not." (W11, age 38).*

7.7 Theme 4: Access to care and visibility.

7.7.1 Access to care and surveillance.

Women who used drugs and alcohol seemed to be cognisant that access to care meant they would not only become 'visible' as drug and alcohol users, but also, that this was likely to mean ongoing surveillance from health and social care agencies. Professionals were similarly aware that they were monitoring service users throughout their treatment and care. This surveillance intensifies during pregnancy. One professional reflected on a service user and the approach herself and her colleagues had taken.

> *"Basically, this lady was told from the start that, you know, the chances of baby staying with you are slim to none. [Service user's name] hoyed the towel in straightaway. Stopped going to [treatment service], came off script, lost a ridiculous amount of weight and all the safeguarding plan, because we used to be part of the… baby was put straight on... And every time she presented we stuck to the plan by encouraging, it was so we could have eyes on [service user's name] and monitor the baby as opposed to monitor [service user's name]. Can we get you into treatment? There was never… I honestly hate myself when I'm saying this because you stick to the script and you're, like, can we walk you down [treatment service]? Is there anything we can do to get you involved? Can we ring your midwife? Not once, like, can we have a cup of tea and sit down and really see how you are, like when I'm seeing these things, like it's absolutely horrendous, but that is what we do." (SP087, F, Manager)*

This awareness and acceptance from professionals that their approach to practice ("eyes on" service user) signify that treatment is about surveillance, risk assessment and foetal protection and less about compassion and care for the woman's vulnerabilities. Professionals have a duty of care to undertake and report safeguarding concerns for children whose parents use drugs and are often blamed if a child is harmed, for failing to intervene.

Women involved in this study demonstrated an awareness of the surveillance from statutory agencies and support services and in an attempt to avoid this surveillance, many women restricted their engagement with care, particularly if they are parents. Women involved in

this research did so to protect themselves and their children from statutory social care intervention, as ultimately, their biggest fear is their children will be removed.

> *"I've said I know there's a lot of women in drug addiction who will have baby after baby after baby because they're scared to go to the doctor's and ask for contraceptives, or do you know for an abortion and stuff like that, because they're addicted to drugs, and it will all flag up in the system and they might have other children. (W02, age 41).*

> *"But that was my biggest fear. If I was going to ask for help. Because I had an abortion whilst I was addicted to heroin and I was absolutely petrified that the blood test was going to come back, it was going to go my doctors, it was going to get reported to Social Services, and I was going to lose my two other children." (W10, age 34)*

W02 also reflected on how she navigated the safeguarding surveillance during her own pregnancy and the approaches she took to have her child returned to her care after birth.

> *"Obviously because I couldn't drink anymore, I turned to that, so I started smoking heroin. I finally got the hang of it, I was doing it myself. Through my pregnancy, right through my pregnancy, I was smoking it…Had the bairn. She got taken off me at birth, obviously because of my past and that. I had contact with her every day though, five days a week. I sustained that. Social Services always thought that it was the drink with me, it was the alcohol, they had no idea about my drug use. So they hair strand-tested me, for alcohol, not for drugs, so I passed the hair strand test…Within four months, I got my daughter back, all the while being a heroin addict." (W02, age 41)*

Changing her drug use from alcohol to heroin helped her self-medicate her trauma (domestic abuse, abandonment, social service intervention, partner died from overdose) but also helped her avoid detection from agencies.

Some women described how having had experience with children's social care either during their childhood or historically with their own children, had armed them with the knowledge needed to perform to the system and navigate through it. One woman detailed how she was

"always on the ball" with children's social care having had a history of statutory involvement, and demonstrated she knew what was expected of her in order to be considered as caring for her children and meeting their needs.

> *"Because I worked with the social for quite a while because if I got involved with someone they would get always involved, put it that way. And they could never fault my parenting, it was my addiction, my [urine] samples, I was never caught where I couldn't- just in a mess you could say. I was always on the ball, my home was nice and tidy when they would come and visit." (W15, age 43)*

Both of these women were aware that drug testing or hair strand testing would reveal their drug use and the implications this would have and attempted to dissuade agencies of their drug use, in order to retain their children in their care. Physical presentation was an important tool (how they looked and how their home was presented) to demonstrate they had the ability to care for themselves and their children. Sharpe (2015) describes this as 'precarious maternal identities', however this also draws attention to Neale *et al.*, (2010) proposal that professionals have the ability to reinforces your identity and in essence. With the hope of being endorsed as 'good mother' women were aware of the ways in which they needed to perform to professionals' expectations, for example, a clean home, food in the fridge, children dressed etc. There is distinct interplay here between presenting self well and attempting to avoid surveillance. These methods of surveillance and monitoring demonstrate the adversarial interventions children's social care were perceived to offer, and indicating an absence of supportive interventions for women who use drugs. Women hiding their drug use increases their vulnerability, access to health and social care and increases the risk of repeat child removal.

Mutual aid and informal peer support was important to women involved in this study and they used this support system to respond to surveillance from agencies. As drug and alcohol treatment services were typically designed for men (because they are the most visible population in drug treatment statistics) and not readily available or accessible to women, they created a network of lived experience peers across the region. Women relied on these networks to advise and guide them either into recovery or to support them in navigating this

surveillance they are experiencing. Women discussed health and social care interactions and their views and perspectives of these experiences. Women gave accounts of interactions with health and social care agencies where they felt judged.

> *"But through the drug use, I think what's happened most of all is- and this is my opinion on things, I personally think that heroin is such a stigmatised substance out of all of the ones. There's a hierarchy of drug use and that's the bottom, do you know what I mean...And I think because of that, you get more marginalised. You get more- people lose all faith in you. You don't get very much support. There's an attitude within services that's kind of like, "Well, you're a heroin addict, you're not going to change." (W07, age 40)*

This perception of judgement and stigma was further reinforced when *SP08* described motherhood as a privilege, indicating women who use drugs should not have children.

> *"But to me to have a child, to become a mother it's a privilege. And to be a good parent you've got to put your child first no matter what…So in all the years of my addiction, if I would have had a child that would have been for me, for selfish reasons, and that's not putting the child first. So I've always made sure that… It's better not to put yourself in the position and get contraception rather than, at that time, it would come up and then have to deal with it." (SP08, F, Volunteer)*

This practitioner has lived experience and supports women who use drugs and alcohol in the community. These descriptions were not uncommon from professionals with lived experience and seem to suggest their practice is shaped by "othering" and shaming, but most importantly distancing themselves from the stigmatised identities experienced by women who use drugs. In contrast to this, one practitioner reflected on the importance of investing support in women.

> *"Well I think there needs to be specific services, specifically for women…But if we are wanting women to bring up children, our next generation, we need to invest in these women." (SP03,F, Volunteer)*

7.7.2 Visibility: Good enough mother/ Bad mother

For women who used drugs and were mothers who use drugs and alcohol, visibility was something they were fearful of and avoided care and treatment in order to pursue anonymity. For women motherhood and visibility produced two divergent paths: "good enough mothers" and "bad mothers". Good enough mothers are those deserving of a second chance where they must work with the system and comply and conform to what is being asked by agencies. If they do what is required (comply and conform), they are presented with the opportunity to keep their baby, keep their family and keep their identity as a mother. However, this nuanced performativity is not always achievable and often women who use drugs and alcohol fall into the category of 'bad mother'. A bad mother (undeserving) is one who fails to meet the needs required of her by society in relation to herself, her children and her choices and for this reason is deserving of punishment. This punishment comes in the form of social service intervention and women involved in this research were referenced child protection plans; child removal; special guardianship order (SGO); subject to family drug and alcohol courts (FDAC). Each of these statutory interventions threaten their identity as a mother and confirm their failures to care and protect their children from harm or neglect.

W15 described being transparent about her drug use and lifestyle when in care proceedings, to protect her children and explain she was unable to care for them at this time. This was also an opportunity to avoid the stigmatised identity of being a 'bad mother' because she had relinquished them from her care as opposed to child removal.

> *"I thought it wasn't fair for the boys anymore. It went to court. It was supposed to last two to three days in court, it lasted 25 minutes because I was so open and honest. The judge actually gave me credit for that and he said, "You can bring this back to court when you show stability."… I could have kept probably maybe ducking and diving and lying but I just thought it needs to be done properly this. It was so- I mean the boys said to me, they said to me a while ago, "Mum, why are we in care? Is it because we didn't come off the computer for school?" so it just shows I wasn't a bad mother." (W15, age 43)*

Similarly, *W07* demonstrated compliance with agencies whereby she accepted the removal of her baby at birth was in her best interests. She also states she didn't feel like she could be a "good enough mother", and relinquishing care signifies her compliance with authorities, but crucially it demonstrated her concern for the safety and wellbeing of her baby.

> *"…because I felt like that because I think I felt that I wasn't- I could never be a good enough mother anyway. I gave up. I didn't fight because I thought, "Well, this is probably the right thing to do anyway." And I remember saying that to Social Services, really early on. "Well, the truth is I don't want my daughter to be brought up in a situation where she's at risk. So, if removing is the best, safest thing to do, I think you should do that." Which is probably a very different way other people approach it, I imagine." (W07, age 40)*

In order to demonstrate that they were capable of prioritising the health and wellbeing of their children over their drug use and its associated lifestyle, both women relinquished part of their parental rights and responsibilities to the local authority. For these women, sacrificing their mothering identity and access to their children was necessary and was used to negate the perception they were bad mothers. However, this also left themselves open to further stigma and shame as mothers who don't have their children within their care.

For one mother who had six children (all in her care), she had become reliant on this surveillance and support, to hold her to account, but also to reaffirm that she was considered a good mother who could retain her children in her care.

> *"I think that's another thing, I think I got stuck in that cycle, as well, of having a team of people around me. Whether it be Social Services or the drug and alcohol midwife. And then, when they were leaving, I'd panic and do something stupid, where they'd have to come flying back in. Because I think I'd become dependent on it. And it has taken me a while to get out of that mentality." (W11, age 38)*

Many women who use drugs and have children feel a sense of failure as mothers. They spoke of an urge to rectify this and for those in recovery, they now had an opportunity to demonstrate they could be 'good mothers' without social services interventions.

> *"But definitely for a long time there was a real, real, real urge to do it again and do it right because I felt like I'd failed in some way." (W14, age 37)*

> *"And probably to prove to myself as well. Like you can do it all right. That's not a good enough reason to have a child though, you know?" (W10, age 34)*

Both of these narratives reinforce the binary of good enough mother/ bad mother and illustrate the stigma and shame of motherhood for women who use drugs. Participation in this research made women question the adversarial support available to them and how they can engage with this, without stigma.

> *"And I think there's just no support around women's sexual health in this area. And there's no support for addicts either. It's all well and good sending addicts to treatment centres and threatening them with piss tests and hair strand tests and all this, that, and the other, because if you don't pass you'll get your kids took off you. Where is the actual proactive help? Where are these people who work with families in addiction? Where are these people who prevent addicts having children until they're in a better frame of mind to be able to care for children? I just feel like there's nothing. And after speaking to you today, [Interviewer], I do feel like there's absolutely nothing for addicted mums, apart from the threat of social services and you'll get your kids removed. And, you know, "If you don't get clean, this, that, and the other." Why isn't there anything positive, like, "If you get clean this is what… together we can achieve great things. Like, we'll work with you." And I don't mean social services because people mention social services and women shrink, they're absolutely terrified. Why is there all this stigma? An addict is just a normal human being who has got lost in life." (W03, age 41).*

Women who use drugs and alcohol want to be given the same care and treatment as those who do not use drugs, but also be offered the support they require without stigma and judgement.

7.8 Chapter Summary

This chapter began with participant demographics and characteristics of both women who use drugs and alcohol and professionals who support them. The findings of this chapter indicate that women who use drugs have experienced significant trauma and abuse throughout their lifetime and are constrained and subjected to the societal expectations of them. This further impacts on their agency and body sovereignty. Women who use drugs value the connection that motherhood may offer alongside the ability that motherhood offers, to potentially shift their stigmatised identity. Professionals involved in this research indicated while they can understand that women have complex and challenging needs, often they are limited to what is a priority for their service at that time. While many women wanted support that was non-judgemental, professionals with lived experience tended to enact 'othering' within their practice. While this may be a way for them to reinforce their recovery and distance themselves from their drug use, at times appeared as derogatory and shaming, thus further reinforcing the stigma felt by women involved in this research. Women who use drugs were aware of the surveillance they were under and often ignored their own physical and mental health needs in order to avoid becoming visible to agencies. Within this chapter, supporting quotes have been presented to illustrate the findings.

Chapter 8: Discussion

8.1 Chapter introduction

There have been two research components presented in this thesis: 1) a qualitative systematic review of lived experience of pregnancy among women who use drugs and, 2) the analysis of interviews with women who use drugs and practitioners who support them. This chapter aims to draw together these two components with a discussion and interpretation of key findings, guided by the theoretical and conceptual understandings outlined in Chapter 2 of this thesis. In order to do so, the first section of this chapter is dedicated to the discussion and interpretation of key findings from the two research components. Within this section I draw on literature included in the review and further studies related to this topic are used to illustrate and compare key findings and their importance. The strengths and limitations of the research included in this thesis are then considered. The chapter concludes with the implications this research has for policy and practice and the recommendations for further research.

8.2 Discussion and interpretation of key findings

The aim of the research presented in this thesis was to explore and understand the reproductive health and social care needs of women who use drugs. Each objective was addressed in detail in the qualitative systematic review and empirical research with women and practitioners. Key findings from this research included: 1) Women's perspectives and understanding of reproductive health and wellbeing is influenced by adverse childhood experiences and the lack of healthy intimate partner relationships; 2) motherhood is important to women who use drugs, however, they are marginalised and isolated by society and a system which offers adversarial support; 3) contraception choice and method is one of the few ways women who use drugs can exercise some form of agency. In the following three sections, interpretation of key findings from this thesis will be outlined.

8.2.1 Weaponising vulnerability

Women who use drugs often report that their experiences of multiple vulnerabilities during childhood and early adulthood can then be weaponised against them in later life to describe them as "unfit" parents (McGrath *et al.,* 2023). Almost all of the women who participated in interview research had some form of adverse childhood experiences (ACE) including

childhood sexual abuse, neglect, abandonment and physical abuse. For these women, this was often described as a catalyst for their drug use in their early teens and as a way to suppress the trauma they endured (Flacks, 2023). Throughout both the review and interviews there appeared to be a profound absence of support, care, and protection for many women during their own childhood, which continued into adulthood when their drug use escalated.

Women who used drugs shared nuanced narratives on the relationships they had with their own mothers. There was often an absence of fathers or positive male role models within their childhood. For women, their mother had pivotal importance on their perspectives of reproductive health and wellbeing. For women who had supportive parents, often they were sympathetic to their needs and advocated on their behalf. In contrast to this, many women also described how they perceived themselves to be inferior members of their families, whereby their mothers' put their intimate partner relationships above them. This perceived subservience in childhood, appeared to influence and shape their views on intimate partner relationships, but also their self-worth and positioning within wider society. Women provided accounts of their mothers often not intervening or noticing the abuse and exploitation that they were experiencing as children. There was also a distinct failure from statutory services to safeguard and intervene in women's childhood, meaning they were continuously exposed to trauma, unhealthy relationships and adverse experiences.

Women involved in this study consistently reported experiencing significant domestic abuse and sexual assault throughout their lifetime of using drugs. This abuse further compounded their perspectives and autonomy of their own reproductive health and sexual wellbeing, but primarily, it impacted on their understanding of healthy relationships. Sexual assault and rape was reported to be commonly experienced by women who use drugs, however, often they felt responsible for placing themselves in risky situations and this prevented them from reporting sexual assault to statutory services. Many women were resigned to the fact that abuse and exploitation was an inevitable consequence of their vulnerability and gender. Safeguarding themselves was something they had to employ throughout their life, given the little state intervention or support in childhood, which meant that women 'responsibilize' themselves when they experience abuse, rather than the perpetrator or those who failed to

intervene (Flacks, 2023). The abuse and trauma they experience exacerbated their physical and mental health needs, adding complexity and further increasing their vulnerability.

This research supports previous research findings, that many women who use drugs value motherhood (Olsen *et al.*, 2011; Lewis *et al.*, 1995; Holt & French, 2019). Often the fractured relationships and experience of adversity in childhood motivated women to want to be better mothers than their own mothers. Within this research women who use drugs stated that children offer them an opportunity to "save them" or "fix them", offering a deep and valued connection with another being and filling the void of care they had experienced during their own childhood. Findings from the systematic review and my qualitative research indicate that women who use drugs have a distinct lack of attachment with others, due to the stigma of their drug use, adverse relationships with family and friends and abuse that they experienced. Often children offer an opportunity to remedy this and to form attachment. Although many women who use drugs experience unplanned pregnancy, for many the maternal identity as a care giver, was important and something they had thought about from an early age. Sharpe *et al.*, (2015) described how motherhood engendered an identity shift for women, whereby they are accountable as a caregiver and in opposition to their stigmatised identity of drug user. Both the review and interviews within this research corroborated that both pregnancy and motherhood are viewed as an act of fulfilment, however, this risks the exposure of their vulnerabilities to scrutiny.

Research has evidenced that women who use drugs experience significant stigma and shame in relation to motherhood, having been constructed as 'dangerous' and 'bad mothers' with little consideration being given to their own childhood trauma (Baker & Carson, 1999; Broadhurst et. al., 2013; Courvette *h*, 2016; Holt & French 2019; Howard *et al.*, 2016; Klee, 1998; Radcliffe, 2011: 986). Policy and practice professionals, the wider public, and indeed some of the women themselves, tended to focus on the failings of women who use drugs to prevent pregnancy, to stop their drug use for the sake of their (unborn) child/ children and the irresponsibility of continuing to use substances that may harm them. The social implications of being a dangerous or bad mother are profound and include social exclusion or becoming a social pariah. As demonstrated in my qualitative systematic review, women who are pregnant or mothers often experienced adverse and judgemental encounters with health

and social care professionals, which further impacted on their access to care and compounded their sense of fear and isolation (Broadhurst & Mason; 2013; Klee, 1998; Renberger *et al.*, 2020). Previous studies into practitioners' attitudes to reproductive health of women who attend drug treatment services, suggest that practitioners' beliefs could be a significant barrier to supportive interventions for reproductive health with women who use drugs (Black *et al.*, 2016; He *et al.*, 2014). The discourse and experiences women had with health and social care professionals evidences the systemic prejudice some women who use drugs experience when engaging with health and social care professionals. It also demonstrates that while women who use drugs are presented as inherently vulnerable, this vulnerability is weaponised when they become pregnant or are mothers and is used against them, positioning them as a threat to their children (Flacks, 2023).

8.2.2 Pregnancy and Motherhood: A window of opportunity for who?

Pregnancy among women who use drugs is often framed as a "window of opportunity" for intervention and change (Abdul-Khabir *et al.*, 2014; Black *et al.*, 2012; Chou *et al.*, 2018; Goodman *et al.*, 2020; Hall *et al.*, 2006; Milligan *et al.*, 2011; Soderstrom, 2012). Women are cognisant that accessing care means they will be monitored and put under surveillance. As demonstrated in this research, pregnant women and their foetuses are potent "focal points for regulation and control" and this regulation and control is implemented and enforced through the surveillance of them (Lupton, 2012:330). Often this surveillance goes beyond that of professional monitoring and women are often supervised by strangers or acquaintances and are chastised for breaking the rules (Longhurst, 2005).

Throughout this research and others, many women reported their intention to retain care of their children and often they would employ a number of strategies to avoid surveillance or will perform particular behaviours so that they are seen as conforming (Lewis *et al.*, 1995; Holt & French, 2019; Hathazi *et al.*, 2009). Both Hakaar (2021) and Lupton (2012) described throughout their research that women are expected to be responsible for protecting the foetus and must do so, by taking care of self. For some women the termination of pregnancy was felt to be the right thing to do due to violence, hardship or because they were currently engaged in childcare proceedings. To be accepted as a credible and caring mother, women who use drugs need to present favourable social appearances during pregnancy and present

themselves as “plausible” mothers (Radcliffe, 2011; Yuill *et al.*, 2020). For women who use drugs, balancing and meeting the expectations of these conflicting identities is precarious and challenging, particularly as drug use and its associated lifestyle is not acceptable within society (Courvette *et al.*, 2013). Previous research (Valentine and Sporton, 2009; Kunitz, 2008). indicate that pregnant women rely on their identity being endorsed and reinforced by professionals (midwives, nurses, GP and drug workers) who have the power either to make the label of drug user and uncaring mother, stick or to endorse the new identity. For women who use drugs, this endorsement is of paramount importance and both the review and interviews demonstrated that women would present as “performing” to expectations of them. As outlined by Neale *et al.*, (2010) previous “poor performances” in the context of projected identity are usually rectifiable, however in the context of drug use during pregnancy, the risk of child removal is a tenable outcome for these women, further compounding women’s autonomy decision making.

Throughout my research, pregnancy and motherhood confronted women who use drugs with a precarious and difficult balancing act of managing drug dependency and taking care of their children. Women involved in these interviews described the “fear” of social service involvement and described how accessing care placed them in an arduous position which risked them having their children removed. As outlined in my systematic review, in order to negate or manage this surveillance, women will sometimes avoid care completely. When they do engage with health and social care services, they do so intermittently and at times when they can present their ‘best self’, wherein they conform to what is prescribed and expected of them as pregnant women. Previous research (Hakaar, 2021; Politt, 1990; Bertin, 1995). has postulated that women who use drugs and experience pregnancy avoid healthcare to impede existential social alienation, which limits their agency and autonomy over their reproductive health and social care needs but also their wider health and wellbeing. An example of this from my qualitative systematic review was when some women discussed how they avoided or delayed attending antenatal appointments, as they were aware drug testing would be undertaken and the implication’s a positive toxicology screening may have for them (Stone, 2015; Jessup et al, 2003). Drug testing is an essential tool in the surveillance of women, however, given the limitation of the information it provides, it is merely used as a tool to disprove drug users lies (Flacks, 2023). This surveillance and monitoring only marginalises

vulnerable women further, inadvertently causing harm to their health and wellbeing and amplifying their unmet needs.

Avoiding care in pregnancy is almost impracticable for women, meaning they have to access care, but do so in discursive ways. The findings of the qualitative systematic review indicate that while pregnancy may see a shift in drug use, pattern or type, often pregnancy does not incite the changes one would associate with opportunities. This could be related to the fact that if women report their drug use and associated lifestyle honestly, they risk being the subject of stigma and if they deny their drug use, their reputation as uncaring, dishonest is confirmed (Wolf, 2007).

This research found that women who use drugs will implement informal harm reduction strategies around their drug use and associated lifestyle, to reduce risk to themselves and their children. They often make these changes independently, without consulting health and social care professionals. The information to do so was often acquired anecdotally from peers and other women who use drugs. This is evidenced within the qualitative systematic review whereby women emulate interventions of their peers ('playing doctor') while simultaneously, consulting them for advice on how to navigate the system. Women who participated in the field interviews reported that mutual aid programmes and informal peer support was important for them gaining recovery. Notwithstanding this, it also offered freedom from the intense surveillance experienced under health and social care agencies. Women rely on these networks to advise and guide them either into recovery or to support them in navigating this surveillance they are experiencing. This underscores the need for an educational and supportive health and social care response, whereby women can access clear guidance safely, which will in turn encourage them to make informed decisions.

This poses the question on whether women implement changes to their drug use to reduce the risk to their baby or to avoid identification of drug use. Research presented within this thesis demonstrates the rationale for this is still not clear. However, I infer that the reason why some women do this, is to manage and mitigate the outcomes, reduce their visibility as a drug user, but also, to be seen as conforming (in some capacity) to societal expectations of

women, and for some pregnancy and motherhood. There is a complex interplay here between the motivation behind these strategies which requires more research.

It is evident throughout the qualitative evidence synthesis that pregnancy and motherhood may present a "window of opportunity" for services to engage and provide interventions that 'support' women, including those who use drugs. However, a system built on surveillance and monitoring is adversarial and harmful for women and their children. A system focused upon managing the risk that women who use drugs pose to their babies appears unconducive of supporting change in women. Rather, it restricts and marginalises them further. Statutory child protection agencies and drug treatment services see mother and child as independent of each other (McGrath *et al.*, 2023). The "splitting of the needs" of women and their children means that interdependency between them is not considered to be important (McGrath *et al.*, 2023; Whittaker, 2019). This research underscores the need for supportive interventions for women who use drugs, which include opportunities for them to address their needs, alongside the needs of their current or prospective children. Given the abuse described by many women included in this research, interventions need to be trauma informed and consider the stigmatisation this population receives and the barriers this poses for them.

8.2.3 Fertility, agency and choice

Throughout the qualitative research, women reported that while using drugs they had interrupted and irregular periods, with many having none at all. This supports findings from previous research (Olsen *et al.*, 2014; Lewis *et al.*, 1995; Black *et al.*, 2011) where women believed that their drug use made them infertile. Women detailed how this was normalised amongst women who use drugs and that they never spoke about this with health and social care professionals. This could be ambivalence, embarrassment or indeed the shame of periods, it could also be that menstruation (or lack thereof) is an aspect of their lives they keep private. Both the qualitative review and the interview study found that women who use drugs often have unexpected pregnancies as a result of a misperception of their fertility, precipitated by irregular or absence of menstrual periods. This supports previous research findings (Olivia *et al.*, 1999; Olsen *et al.*, 2014: Lewis *et al.*, 1995), suggesting that this impacts upon women's contraceptive use and places women who are sexually active and use drugs at the highest risk of unplanned pregnancy. They also stated that periods were an inconvenience

to them both physically and mentally and a financial burden. This misinformed perception of fertility emphasises the urgent need to address the myths that surround fertility for individuals that use drugs.

Alongside this, practitioners involved in the interviews also demonstrated they were aware women who use opioids may not have periods, however, they rarely spoke to women about their reproductive health. For this reason, they had few, if any, discussions about periods and/ or fertility. However, they may also avoid discussion about periods and fertility as they are uncomfortable with doing so or they are uncertain about women's reproductive health in general. It could a suggest that women's reproductive health is not a priority for their service or organisation. Most practitioners preferred to ask "are you keeping yourself safe?", which they perceived to be a non-confrontational way to ask a difficult question and which also encouraged women who use drugs to practice safe sex. However, the avoidance of directly discussing fertility and periods was evident, meaning there is scope for practitioners to discuss this further with woman and inform them of the interplay between drug use and fertility, and to support them with further access to care.

Despite the lack of autonomy and body sovereignty women who use drugs have over their sexual wellbeing, they did exercise some forms of agency surrounding their reproductive health. Within the empirical study included in this thesis, women described exercising agency through their choice, method and rationale for contraception use or non-use. Given the restrictions placed on women in relation to their reproductive health and the expectations on them to prevent pregnancy, contraceptive use and chosen method did give them some autonomy. For women involved in this research long-acting reversible contraceptives (LARCs) were preferential methods of contraception for them, supporting previous research in Australia on this topic (Black *et al.*, 2012). For the women participating in my study, LARCs were generally seen as less maintenance but primarily, they required less engagement with healthcare professionals, allowing them to be less visible. Contraceptive use for women was about taking care of their mental health, body image, but also a way to mitigate the burden of daily use and remembering to take the pill. For others the motivation for not using contraception, specifically for those in early recovery, was about being free from all medication, finding that baseline and exploring how they felt with their own hormones and

hormonal changes. Another aspect of exercising agency was taking responsibility for an unplanned pregnancy and undergoing a termination. Women shared their decision making in doing so, with women stating they couldn't bring a child into the "madness" they were in. Women shared how and why they access abortion services, and the impact pregnancy termination has had on them. Decision making included protecting the children they currently had.

In the context of sexual and reproductive health, practitioners who were interviewed mostly referred to sex workers as being the main focus of intervention. This could be interpreted as a potential bias in the service offer that women who use drugs only have sex for survival purposes and sex outside of survival sex is not their concern. However, women involved in this research often had a misinformed perspective on intimacy and sexual relationships and many women described scenarios where they had engaged in transactional sex for drugs. During these narratives, women deemed themselves responsible for placing themselves in risky positions and avoided blaming the men who had exploited their vulnerability at the time. Many women shared accounts of sexual experiences whereby consent was not explicit but did not consider this to be rape or sexual assault. Transactional sex, sexual exploitation and consent need to be explored further with women who use drugs, to ensure they are aware of the support available to them, but most importantly, so they understand their rights within the framework of the law.

Previous research (Clergue- Duval *et al.*, 2017; Finer & Henshaw, 2006; Terplan *et al.*, 2015) recommends that during standard care for drug and alcohol dependency, contraception and the desire to be a parent should be discussed and that service providers should aim to help women plan pregnancies through the use of well-suited and effective contraceptive methods. Interviews with practitioners demonstrated that this is not something routinely offered in practice, with the main focus having been risk reduction and monitoring. Catalo *et al.*, (2019) posited that by offering targeted and supportive preconception care to this population would allow for health and social risk factors to be addressed before there is explicit intention to conceive. However, as demonstrated within both the systematic review and qualitative research, consideration of the wants and needs of women needs to be probed and explored before implementing interventions (Gutierres & Barr, 2003; Catalao *et al.*, 2019). For women

who use drugs, the optimal time for sexual and reproductive health intervention is at the inception of methadone maintenance programmes (Keen, 2001). However, as evidenced within this research, women who use drugs are ambivalent about accessing treatment and will avoid health and social care services to manage their visibility and the implications being seen may have for them. Introducing the concept of family planning to women who use drugs gives them the knowledge and ability to plan pregnancies at a time that is best for them, improving outcomes for women and their families, however, further research is necessary to understand the most appropriate and effective way to offer this intervention.

8.3 Strengths of this research

Women's reproductive health and social care is an important issue, particularly research that is focussed on vulnerable populations. The voices of women who use drugs was a central focus of this study. The incorporation and co-production of the empirical research alongside women with lived experience has facilitated in depth discussion, allowing me to ensure the research was appropriate and sensitive, whilst also being of importance and relevant to women. It also allowed for discussion of the analysis and interpretation of findings to ensure new knowledge was generated from this research. Finally, there is a dearth in research exploring the reproductive health and social care needs of women who use drugs, particularly in the UK. This study will add to the small existing literature available and begin to address the paucity in research on this topic.

8.3.1 Strengths of qualitative systematic review

To my knowledge, this is the first comprehensive systematic review of the lived experience of pregnancy among women who use illicit drugs. This review included 49 qualitative studies from across the globe, which included women from a range of ethnicities, age ranges and drug use type. The pre-defined and transparent methods of the review which followed a systematic strategy to searching, a robust inclusion criteria, detailed overview of steps taken during screening and the approach to decision making and quality appraisal and synthesis strengthens the findings of the review. Following these steps systematically has given the review rigour and makes this review reproducible.

8.3.2 Strengths of qualitative research

The strengths of this study include the use of qualitative techniques- semi-structured interview guide; audio recording, transcription verbatim, interview, coding through NVivo; iterative thematic analysis based on internal discussions with supervisory team and women with lived experience (Lincoln & Guba, 1985; Miles & Huberman, 2004). The incorporation of women with lived and living experience (outlined in Chapter 5 and 6) into the design and co-production of qualitative research enhanced this research study, ensuring it was sensitive and of importance to women who use drugs. The involvement of the EAG supported the recruitment of women who use drugs in across the North East, adding diversity within the sample. This included diversity in locality, age range and variation drug use. Having the EAG endorse the project and me as a researcher, meant that women shared deeply personal, rich narratives and lived experiences of sensitive topics, which they might not have done without the validation from the EAG that they were safe to do so.

Incorporating professionals who support women who use drugs and alcohol in a range of services in the North East was essential to understanding their views and perspectives of the interventions they provide to women in relation to their reproductive health. This allowed me to consider where there may be unmet need within the health and social care treatment offer in the North East and how this could be improved.

8.4 Limitations of this research

There are many limitations to qualitative research and some of which will be addressed below. Like most qualitative research exploring lived experiences, they represent a small number of women at a snapshot in time, meaning there is limitation of the generalisability of the findings. It is acknowledged that a limitation of this study is that interpretation of qualitative findings cannot be completely objective, a common theme of qualitative research. However, this was mitigated by the interpretation of key findings being guided by existing conceptual and philosophical theory and also, through reflexivity and the work undertaken with women with lived experience.

8.4.1 Limitations of qualitative systematic review

Qualitative systematic reviews are important pieces of research which draw together all available literature on an existing topic, however, reviewers are working a step away from

primary studies and thus are reliant on the skills and interpretations of reporting authors. In the context of this review, some primary qualitative research studies presented limited data and in turn the findings of this review may not be fully inclusive of all perspectives of women who use drugs and experience pregnancy. No grey literature was included in this review; however, the inclusion of research reports may have added more data to the review which was not found in included primary studies. Finally, three studies included in this review were translated using Google Translate, a method previously used by colleagues undertaking systematic reviews; however, it is important to consider that direct translation means that some context may have been lost.

8.4.2 Limitations of qualitative research

This research was undertaken in the North East of England with a small sample of women and professionals. Experiences and access to care may differ in other parts of the country. Only one woman in the sample of women came from an ethnically diverse background (British Asian) meaning the study lacked the diversity necessary to be inclusive of all women who use drugs in the North East. Although the recruitment of women was seen as a strength of this research, it could also be perceived as a weakness, given that many of the women involved were connected to a large network of women who use drugs, which may have impacted on the views and perspective women had. No professionals working in social work, midwifery or sexual health were recruited, despite my best efforts to do so. Given the focus many women and practitioners had on safeguarding, child removal and fertility, having the views and perspectives of these professionals could have added more nuance to the study findings.

8.5 Implications for policy and practice

This are number of implications to the findings of this research which can be used to inform policy and practice change. Three key implications from the two research components of this this thesis are outlined below, with suggestions on how they could inform practice. At the end of this section a proposed action for change is presented (Figure 4).

Implication 1: Addressing the trauma and abuse experienced by women who use drugs

The findings of this research and supporting literature within this thesis evidence that women who use drugs have experienced significant abuse in childhood and adulthood. This abuse

often incited their drug use and exacerbated their physical and mental health, in turn increasing their vulnerability. Due to multiple and repeated experiences of abuse, many women who use drugs are resigned to the fact that abuse and exploitation is an inevitable consequence of their vulnerability and gender. Often, they presented themselves as responsible for the sexual and physical abuse they experienced when using drugs as opposed to holding the perpetrator to account. This often resulted in them being further marginalised and experiencing residual stigma and shame.

This research found that if women did attempt to access health and social care their vulnerabilities (often as a result of trauma and abuse) were then weaponised against them, particularly if they were pregnant or mothers. Women involved in this research spoke of the "fear" of accessing care and demonstrated that the potential outcomes were too grave a risk for them. Research has demonstrated that women who use drugs are some of the most stigmatised individuals in society, and the findings of this thesis have demonstrated that adversarial and judgemental approaches within health and social care agencies, compound and reinforce their shame and stigma. This judgement was often based on the assumption that drug use was a choice, without consideration for the wider trauma and abuse they were subjected to.

The findings of this research indicate that a system wide change is needed to prevent interventions for support from being adversarial and judgemental to those with complex and often extensive vulnerabilities. While there are current strategies, legislation and investment aimed to address childhood abuse and trauma, and violence against women and girls, we need further investment for adult victims recovering from these, particularly those from marginalised backgrounds. Policy and practice should consider the wider health and social care and address the holistic needs of women who use drugs. Trauma informed care should be implemented across multiagency partners to ensure each professional who has contact with vulnerable can deliver support and interventions sensitively and appropriately.

Implication 2: Reproductive health and wellbeing interventions for women who use drugs

The current access and pathways to care, particularly in relation to their reproductive health and wellbeing are not designed to support the needs of women who use drugs. It has been

well documented that treatment services were designed for men and that drug treatment services needed to consider the life course of women, particularly if and when they transition to parenthood (Sun.,2004; Clergue-Duval *et al.*, 2017). A range of interventions including access to free contraceptive care may reduce unwanted and unintended pregnancies for women who use drugs, but crucially, this offer needs to be universal.

Policy and practice need to provide support to women who use drugs around pregnancy and family planning and encourage this as a motivation for recovery. Informed conversations regarding pregnancy and potential outcomes (including intrauterine drug exposure) coupled with a package of support should be implemented within health and social care services, to ensure women exercise this right are aware of the risks and consequences this may have for them and their children (current and prospective).

The findings of this thesis suggest that there is also scope for services to provide educational interventions aimed at increasing body awareness around reproductive health and wellbeing and the impact of drug use on fertility. Within these educational interventions, there is also a valuable opportunity to discuss consensual sex, intimacy and pleasure. This is of particular importance to health and social care services commissioned to support vulnerable populations (for example, needle exchange services, hostel and supported housing, women's groups). There is also a golden opportunity to deliver these interventions in 'Women's Health Hubs' after significant government investment in the Women's Health Strategy for England (2024) and the suggestion within this guidance of the creation of care pathways for women who use drugs.

Implication 3: The value of motherhood among women who use drugs

As outlined previously, women who use drugs see motherhood as an act of fulfilment, however often this places them in a formidable position. Often women who use drugs are framed as a risk to their children because of their drug use and trauma. Women who use drugs are aware they are seen within the narrative of dangerous and deviant. For this reason, pregnancy and motherhood incite fear in women who use drugs, and most often they are concerned about statutory interventions and child removal. Punitive approaches to women who use drugs during pregnancy increases risk of harm to women and their unborn children.

While the monitoring of women who use drugs and experience pregnancy is a necessary safeguarding, it should be approached with a non-judgemental attitude and offer the opportunity to access a range of health and social care support with the aim of keeping families together where possible.

This research found that current approaches to safeguarding have incited fear of child removal as an inevitable outcome of social service intervention, further marginalising vulnerable women due to the adversarial interventions imposed upon them. Approaches which are supportive as opposed to adversarial are likely to improve outcomes for women who use drugs and their children.

Implication 4: Drug testing as a method of surveillance

Drug testing patients in health and social care services is often standard practice during pregnancy and prescribing. As demonstrated within this thesis, women who use drugs are aware that they will be tested when accessing treatment services and for this reason they attend sporadically, with many withdrawing completely. Often this is a way of protecting their own families or retreating from their stigmatised identities as a woman who uses drugs.

For health and social care services drug screening is used as surveillance to inform other agencies. It is often used to discredit patients and prove they are untrustworthy. This tool of surveillance and monitoring is a barrier to care, marginalising women who use drugs by inadvertently amplifying their unmet needs causing distinct harm to this population. Removing drug testing in treatment may encourage rapport and forge trust between professionals and women and reduce this barrier to care.

Figure 4: Proposed action for policy and practice to address the reproductive health and social care needs of women who use drugs

- Raise awareness of the adversity and trauma women who use drugs have experienced. This should be partnered with current anti-stigma campaigns being promoted nationally.
- Inform all women and girls about domestic violence, abuse and consent in sexual relationships. This should also include their rights within the framework of the law.
- Promote reproductive health and wellbeing interventions for women who use drugs. This should include family planning, informing women of the impact of drug use on their fertility and the promotion of healthy intimate partner relationships.
- Implement a system wide change to trauma informed care across all multi-agency partners to ensure they have the skills and knowledge to address the needs of women who use drugs.
- Remove drug testing in all treatment centres with the aim of reducing barriers to care and the building rapport between services and women.
- Develop a strategy to which aims to address child removal among women who use drugs.

8.6 Further research

There are many implications to the findings in this thesis which require further research. Five recommendations for future research based of the findings of this study are listed below:

1) More research is required to ascertain the influence and impact services, wider support and societal expectations have on women who use drugs and experience pregnancy. This could include the influence of surveillance and monitoring and the impact adversarial interventions have on women's perspectives of treatment and care.
2) In both the qualitative systematic review and my qualitative research, women cite a misperception of fertility due to drug use. Further research is necessary to examine how best to intervene with women, so they are better informed and therefore, better able to perform body sovereignty. This research could then be used to build the foundations for a pilot intervention aimed at educating women who use drugs about their fertility, alongside training health and social professionals how they can discuss and support women with their reproductive health and wellbeing.

3) There are many forms of contraceptives available in the UK, however, little qualitative research has been undertaken to establish the uptake and attitudes women who use drugs have towards them. My research presents a small insight into the perceptions women who use drugs have of contraceptive use, however, further research in different regions, with women from different ethnic and cultural backgrounds is needed to gain further insight into the unmet needs of this population.
4) As mentioned throughout this thesis, stigma has a profound influence on women's access to care. In recent years stigma has become a hot topic within research and policy with campaigns and studies ascribing stigma as the existential crisis within marginalised communities. Little consideration has been given to the driver of stigma and the theoretical rationale why it exists and is reinforced. Research which focusses on the drivers of stigma among marginalised groups may be more beneficial to addressing it.
5) Finally, within primary studies included in this review, some authors used stigmatising language within publications (for example, "addicted law-breaking mothers/ women" and "sex for crack conceived baby") to describe women who use drugs during pregnancy. Paradoxically, these were in studies were women described the impact and effect stigmatising and judgemental language had on their self-worth and access to care. Qualitative researchers have significant opportunities to contribute to system change and influence policy and practice. For this reason, researchers should be mindful and considerate of the language they use within future research and publications, to ensure that it does not cause further stigma or harm to the communities they are researching

8.7 Conclusion

This research aimed to explore the reproductive health and social care needs of women who use drugs. In order to address this aim, a qualitative systematic review and an empirical research study was undertaken. Within them, the aims and objectives were met, and the interpretation of key findings were discussed above.

In summary, women who use drugs have often experienced profound trauma and abuse in both childhood and adulthood which has impacted on their understanding and autonomy of

their reproductive health. Women who use drugs are often isolated and sexual encounters are less likely to be about intimacy and pleasure, but performativity or transactional for partners. Women's vulnerabilities are often weaponised where they are constructed as unfit women, mothers, and partners. Despite this, many women who use drugs value motherhood and should be allowed to exercise their reproductive rights at a time that is best for them. Where health and social care agencies are involved, this should be undertaken without adversarial or punitive interventions with the aim of supporting women and their children, promoting the best outcome for them both.

Outputs

Book Chapter

Smiles, C., McGovern, R., Kaner, E., Rankin, J. (2023). Drug and Alcohol Use in Pregnancy and Early Parenthood. In: Borg Xuereb, R., Jomeen, J. (eds) Perspectives on Midwifery and Parenthood. Springer, Cham. https://doi.org/10.1007/978-3-031-17285-4_9

Blogs

Population Health Science, Newcastle University

International Women's Day 2022

https://blogs.ncl.ac.uk/phsi-edi/2022/03/07/international-womens-day/

FUSE

International Women's Day 2023

https://fuseopenscienceblog.blogspot.com/2023/03/north-east-women-share-their.html

Conference Presentations

People with Lived Experience (PWLE) Conference York University

June 2023 (in person)

Invited Guest Speakers

Title: 'Incorporating the voices of lived experience in PhD research'

Stigma Surveillance and Violence Conference

May 2023, Newcastle Upon Tyne (in person).

Invited Guest Speaker

Title: 'Stigma, surveillance and mothers: barriers and motivators to access health and social care for women who use drugs'

Public Health and Health Inequalities Theme, PHSI

April 2023 (online)

Chair and Theme Member

Title: Exploring the reproductive health and social care needs of women who use drugs in the North East: Findings from the 'Women's Sexual Wellbeing' Study.

FUSE Research Event- International Women's Day 2023 Conference

March, 2023. Newcastle upon Tyne (in person)

Conference coordinator, keynote speaker, workshop facilitator.

Title of presentation: *Exploring the reproductive health and social care needs of women who use drugs and alcohol in the North East. Findings from the 'Women's Sexual Wellbeing (WSW)' study*

North East Postgraduate (NEPG) conference.

October 2022 (in person)

Invited Guest Speaker

Title: From policy and practice to PhD: Starting your career in Public Health

Maternal and Child Health Research Event

March 2022 (in person)

Guest Speaker

Title: Exploring the unmet reproductive health and social care needs of women who use drugs and alcohol in the North East: A qualitative study.

ARC SPHR PhD conference

March 2022 (online)

Guest Speaker

Title: Exploring the unmet reproductive health and social care needs of women who use drugs and alcohol in the North East: A qualitative study.

North East Drug and Alcohol Specialist Group (NEDASG) Conference.

May 2021 (online)

Invited Guest Speaker

Title: 'Exploring the unmet reproductive health and social care needs of women who use drugs and alcohol in the UK: a qualitative study'

NHS Virtual Safeguarding Conference (invited guest speaker).

November 2020 (in person, hybrid)

Title: Drug and Alcohol use during pregnancy.

Podcasts

‘Why I research’, Newcastle University

Title: Episode 5: Women’s Health with Claire Smiles

[https://open.spotify.com/episode/7nuvpd5aaMm6Xf8JLY8naP]

‘Collaboratively Speaking’, University of Southampton

Title: Episode 3, Women’s Health with Claire Smiles and Donna Kay

[https://open.spotify.com/episode/23BAObYnlypngEbNvlqORl?si=9b7ff42e36804a79…&nd=1&dlsi=aff21cf5aeeb481f]

Appendices

Appendix A: Master Search Strategy

Master Search Strategy

SPIDER:	Keywords:
Sample	Pregnancy; pregnan*; unintended pregnancy; unplanned pregnancy; planned pregnancy; pregnancy planning; pregnant women; pregnancy intention; intention; pregnant women; substance-exposed pregnancy; childbearing; fertility; family planning; family intention; family planning service provision; reproductive health; reproducti$; female healt$; contraception; contraceptive; Child; infant; prenatal; parenting; birth outcomes; children of prenatal substance abuse; children of drug us$; children of drug addict$; children of prenatal substance abuse; children of prenatal drug user; children of drug addict$; drug exposure during pregnancy; gestation$ drug use; miscarriage; birth outcomes; mother; motherhood; parental drug use; parental substance use; parental substance misuse; troubled famil$; vulnerable famil$; parenting self-efficacy;
Phenomenon of Interest	Dru$ use; drug us$; drug dependenc$; drug abuse; drug misuse; substance use; substance abus$; substance dependenc$; substance misuse; substance use disorder; drug addict$; illicit drug use; illicit substance; addiction; recreational; recreational drug use; recreational substance use; recreational drug abus$; prenatal substance abuse; prenatal drug use; prenatal drug dependency; prenatal substance use; prenatal substance use disorder; prenatal substance abuse; prenatal substance dependency; parental drug misuse; parental drug use; parental substance misuse; parental substance use; parental substance abuse; parental drug dependency; parental substance dependency; maternal drug use; maternal substance use; maternal drug dependency; maternal substance use disorder; drug using women; drug using females, women who use drugs; female drug use; substance abus$ care; substance abus$ treatment; drug use treatment; injecting drug; injection drug use; opioid; opiate; heroin; crack; cocaine; stimulant; opioid drug use; amphetamine; cannabis; substance use intervention; substance use treatment; opiate substance use treatment; drug rehabilitation; substance use rehabilitation
Design	Interview OR grounded theory OR ethnography OR interpretative phenomenological analysis OR phenomenology OR focus group OR content analysis OR thematic analysis OR constant comparative OR participant observation
Evaluation	perceive OR perception OR perspective OR view OR experience OR attitude OR belief OR opinion OR feel OR know OR understand

Research type	Qualitative OR qualitative analysis OR qualitative research OR mixed methods

Appendix B: Descriptive and Analytical Theme development (QSR)

Descriptive- Analytic thematic analysis process				
Statements/ Quotations	**Codes**	**Sub-themes**	**Themes**	
"I trusted the drug specialist and I was stable on methadone during the entire pregnancy, but I worried that the social worker would not accept my decision and I was afraid that they would take away my child" (Mejak and Kastelic, 2016)	Healthcare interaction	Surveillance from health and social care professionals	Surveillance and ambivalence to medication	Interpretation and Conceptualization
"Sometimes I think maybe I should have got clean on the street instead of coming here cause even though I have clean urines the whole time I've been here, they said since you're still on methadone, CPS is still gonna.. (Frazer *et al.*, 2019)	Consequences			
If you have another [drug-exposed] child within a three-year period, even if you're staying clean and sober, your child will be taken from you, and can be automatically be placed for adoption…[it is a] state policy…I wanted to come here [to the treatment program] and there wasn't an opening… I didn't go to my doctor at that time [in pregnancy] because of my name being on that list…I was really scared of that . . . that's what kept me from going to prenatal care. (Jessup *et al.*, 2003)	Child removal			
"…I would do it on days like, 'cause you know, that stuff lasts in your system for three to four days, so I would make sure not to do it around the time of the appointment, just to be on the safe side." (Stone 2015)	Self- regulation	Responding to Surveillance		

“Me and my boyfriend had done our own research after leaving the hospital. Immediately we were on the phone, Googling what to do with an addiction problem and being pregnant.” (Goodman *et al.*, 2020)	Harm reduction strategies			
"I was back using heroin but very little, but I thought it was better using very little than going back on methadone" (Hall, 2006)	No OST	Ambivalence to prescription medication		
““. . . finding out I was pregnant, and being on methadone, was kind of tough, because I did not want to have a baby that had to be detoxed or addicted to drugs, you know?” (Howard, 2016)	Seek treatment			
“I stayed going to the doctor…cause I loved myself and I loved my baby, but I just have a problem with drugs. I didn’t want to hurt my baby…I was [fearful], but then I needed the prenatal, so I knew I did wrong, but I knew I had to go to the doctor, to see what was going on with my baby…” (Jessup, 2003)	Take care of baby	Taking care of baby starts with taking care of self		
“All the women expressed a desire for healthy babies and a desire for more robust information regarding potential risks.’ (Chang *et al.*, 2019)	Preparation for motherhood			
“That guilt of knowing that you’ve used, ‘cause you know 9 times out of 10 [it] will affect your baby in some way form or another.” (Roberts, 2011)	Aware of risk	Perception of risk to self/ baby	Window of opportunity	
“In most cases, either remaining stable or reducing OST during pregnancy was framed as being the ‘best thing’ for the baby” (Chandler *et al.*, 2013)	Impact of drug use			
“Before the pregnancy, drug consumption was an integral part of the relationship and it was difficult for	Intimate partner relationships	Isolation and Fear		

them not to use when their boyfriend had not stopped." (Courvette, 2016)				
"I don't know, like, just because you're pregnant it doesn't magically change what's going on for you and how you've been brought up and all the shit that's happened to you." (Benoit *et al.*, 2015	Relapse trigger			
"I never got pregnant; there was time where I had no periods at all. When I realized that I was pregnant, I'd been pregnant for a while." (Courvette *et al.*, 2016)	Fertility	Misperception of fertility	Fertility and pregnancy continuation	
"She [the midwife] found out that I was about 20 weeks pregnant I had an ultrasound check. She said that usually one could not have an abortion beyond the 12th week. But if I wanted, she could still arrange it so that I could have one." (Soderstrom *et al.*, 2012)	Pregnancy confirmation			
"The second one: yes, because I wasn't going to keep the kid. If I were to keep the kid, I would stop." (Abdul-Khabir *et al.*, 2014)	Decision making	Termination and access to care		
"'it was so shameful, when the midwife said … 'when did you use?' … I had to say the day before … it was then it hit me, and I thought 'oh my god, what have I been doing to this baby?' … I basically gave my daughter heroin it was just- oh it's horrific, and she was so small'. (Varty *et al.*, 2011)	Drug use in pregnancy	Shame and Guilt	Self- stigmatisation	
"When you are pregnant and using some sort of substance, there is a ton of stigma around that and there are a ton of fears, you know, fear that [the government agency] is going to take your baby away…" (Paterno *et al.*, 2019)	Shame			

“Maternal Identity of Addicted Law-Breaking Women” (Courvette *et al.*, 2016)	Language of the author	Stigmatisation of women in primary studies		

Appendix C: Topic Guide (women)

Topic Guide 1(Women)

- Inform participant of format of interview and approx. length of time (30-60 minutes).
- Emphasise confidentiality.
- Emphasise there are no right or wrong answers.
- Remind that they don't have to answer any question that they would prefer not to.
- Remind participant that they can stop the interview at any point.
- Inform the participant that there are resources to support them in case they feel upset due to the interview. Let them know you will have to stop the interview and discuss their information with other members of the team in the case of them disclosing any information which makes you concerned about their safety or the safety of others around them. State that this is so we can support them as best as possible to ensure they are safe.
- Emphasise (here and again throughout interview) that if they choose to answer any of the interview questions, they do not need to go into great depth if they feel it could be a distressing experience for them in any way.
- Warm up conversation and testing sound on audio recorder, with a question: "How is it going?"
- Take notes and return to unanswered and unclear responses at the end of interview.

Characteristics to be recorded: Age, Ethnicity, Employment, Substance use, children (if any).

Introduction:

1.Could you start by telling me a little bit about yourself?

Prompts if information not provided:

- Age.
- Marital status.
- Ethnicity.
- Employment status.
- Number of children.

2. Can you tell me how you heard about this study?

Perspectives of reproductive health:

3. This study is interested in women's sexual wellbeing. Can you tell me what this means to you?

Prompts: periods, contraception, fertility, pregnancy.

4. How do you feel about your own sexual wellbeing?

Probes: Are you happy/ unhappy with your own reproductive health? /
Is it something you have ever thought about? Why? How do you feel about talking about your sexual wellbeing?

Maintaining your reproductive health:

5. Can you tell me about your of contraception practice over the last 12 months?

Probes: Yes- what types? / No- is there a particular reason why you don't? / Have you ever used contraception? Influence of contraception.

Prompts: type of contraception (condoms, the pill, the coil, contraceptive injection etc).

6. Can you tell me about your experience of this method?

Prompts: Do you find this method works well for you?

7. Who would you talk to about contraception and fertility?

Probes: How do these conversations come about? Are they helpful? Where there any services you attended that supported you with contraception and fertility.

Prompts: partner, friends, family, GP, worker.

8. Have you ever attended a service you attend that specifically support you with contraception/ family planning?

Probes: How did you find them? GUM/ family planning.

Fertility:

9. Before you began using drugs did you think about having a family? How has your experience with substance use changed your perspective on having a family?

Prompt: If so, how and why? How do you feel about this now?

10. You said you had X child/ children?

Probe: Was this something you planned? / Have you ever thought about having children?

11. Would you like have a family in the future?

Prompt: Tell me what that looks like for you.

Closing question:

I have come to the end of my questions. Is there anything that you would like to add?

- Thank the participant for taking part in the interview.
- Remind them that the interview will be transcribed and all identifying information will be removed.
- Remind of confidentiality.
- Remind that they have 48 hours if they don't want their interview to be included and how they can inform you of this decision.
- Take participant through the debriefing form. If the participant is upset in anyway, interviewer will not end the interview until the participant is ok.
- Ask participant how they would like to receive their voucher as a thanks for taking part (email addresses may have already been collected, confirm they are happy to receive by email. If not, ask for alternative e.g., postal address).
- Ask participant if they know of anyone else who might be interested in taking part in the study.

Appendix D: Topic guide (professionals)

Topic Guide 2 (Service Providers):

- Inform participant of format of interview and approx. length of time (30-60 minutes).
- Emphasise confidentiality.
- Emphasise there are no right or wrong answers.
- Remind that they don't have to answer any question that they would prefer not to.
- Remind participant that they can stop the interview at any point.
- Inform the participant that there are resources to support them in case they feel upset due to the interview. Let them know you will have to stop the interview and discuss their information with other members of the team in the case of them disclosing any information which makes you concerned about their safety or the safety of others around them. State that this is so we can support them as best as possible to ensure they are safe.
- Emphasise (here and again throughout interview) that if they choose to answer any of the interview questions, they do not need to go into great depth if they feel it could be a distressing experience for them in any way.
- Warm up conversation and testing sound on audio recorder, with a question: "How is it going?"
- Take notes and return to unanswered and unclear responses at the end of interview.

Introduction:

1. Could you start by telling me a little bit about yourself?

Prompts if information not provided:

- Age.
- Gender.
- Level of education.
- Ethnicity.
- Employment status/ Role.
- Service.

2. Can you tell me about your role and what a typical day looks like for you?

Sexual and reproductive health:

3. What are the priorities of your service?

Probe: In your view, can you tell me how important you think sexual and reproductive health important within your service?

Prompts: fertility, contraception, pregnancy.

4. How do you feel about talking about relationships, contraceptives, and family planning with service users?

Probes: What do these interactions look like? Do you feel confident talking about these issues? How do service users engage with these conversations?

Prompt: Men? Women?

Pregnancy:

5. Have there been times when you felt it was important to discuss pregnancy with a service user?

Probes: Can you tell me why you felt it was important? How often do you have these conversations? How did these conversations go?

6. Can you describe what advice/ support you would offer to a woman who presented as pregnant?

Probes: Have you any first-hand experience of this? Can you tell me about it?

Service support and care:

7. Do you think improvements or changes are needed to support service users with their sexual and reproductive health?

Probe: Describe how that could look? Do you think this is a priority? How could this be implemented?

Closing question:

8. I have come to the end of my questions. Is there anything that you would like to add?

- Thank the participant for taking part in the interview.
- Remind them that the interview will be transcribed and all identifying information will be removed.
- Remind of confidentiality.
- Remind that they have 48 hours if they don't want their interview to be included and how they can inform you of this decision.
- Take participant through the debriefing form. If the participant is upset in anyway, interviewer will not end the interview until the participant is ok.
- Ask participant how they would like to receive their voucher as a thanks for taking part (email addresses may have already been collected, confirm they are happy to receive by email. If not, ask for alternative e.g., postal address).
- Ask participant if they know of anyone else who might be interested in taking part in the study.

Appendix E: Information Sheet and Recruitment Flyer

Women's Sexual Wellbeing Study

Exploring the reproductive health and social care needs of women who use drugs.

What is the research about?

You are being invited to take part in an interview which explores the reproductive health and sexual wellbeing of women who use drugs and alcohol.

Who is conducting this research?

Interviews will be conducted by the lead researcher, Claire Smiles. The wider team (supervisors) are Ruth McGovern, Eileen Kaner and Judith Rankin, Newcastle University.

What does taking part involve?

Taking part will involve being interviewed by Claire, either face-to-face or via telephone. The interview will last about 30-60 minutes, will be audio-recorded using a digital recording device and typed up afterwards. Interviews will take place at a time and location, which is best for you.

Do I have to take part?

No, it is your choice. If you decide to take part in the study, you will be asked to give verbal and written consent. You are free to change your mind at any time; you will not need to give a reason. Your legal rights will not be affected in any way.

Confidentiality

Everything will be done to ensure you are anonymous – the lead researcher (CS) will remove any names, places or dates that could identify you from the data. Each interview

Claire Smiles
(lead researcher)

Tel: 07*********
(designated research phone).

Email:
c.smiles2@newcastle.ac.uk

Available between 9am -5pm weekdays.

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recording is given an identification number (ID) and names are removed. Only the research team will have access to the interview notes. Data from the study may be used in publications, reports, web pages, and other research outputs, and will preserve the confidentiality of the information requested in the consent process. You will not be named in any report. All the information collected will be treated as confidential and will only be disclosed to other agencies with your consent, except where required by law or where you or another person is at risk.

This study was approved by the Faculty of Medical Sciences Research Ethics Committee, part of Newcastle University's Research Ethics Committee. This committee contains members who are internal to the Faculty. This study was reviewed by members of the committee, who must provide impartial advice and avoid significant conflicts of interests.

What will happen with the results of this study?

A summary report will be produced. Findings from the study will be published in academic journals and will help to shape policy and practice. We can provide a summary of the findings of the research if you would find this of interest.

WHAT IF THERE IS A PROBLEM?

Any complaints or concerns about the study or how you were treated should be made within 7 days and in writing to: Dr. Ruth McGovern [r.mcgovern@newcastle.ac.uk]. If you remain unhappy and wish to complain formally, you can do this through Newcastle University complaints procedure; details of which can be obtained from 0191 2227045.

TAKE PART IN A STUDY

Exploring the reproductive health and social care needs of women who use drugs.

We are looking for women who use drugs and alcohol aged between 18-50 years to participate in a study exploring women's sexual wellbeing. We want to talk to you about your views of sexual wellbeing and the experiences you have of accessing services. This study is open to women in the North East.

£20 VOUCHER AS A THANK YOU FOR YOUR TIME

Contact Claire Smiles at:

c.smiles2@newcastle.ac.uk

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Claire Smiles 07415768749

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Appendix F: Inductive thematic analysis framework (QR)

Inductive thematic analysis framework				
The aim of this study is to explore and understand the reproductive health and social care needs of women who use drugs.				
Statements/ Quotations	**Codes**	**Sub-themes**	**Themes**	
"Sexual wellbeing is like obviously being safe during sex, using protection." (W13) "In my current role, no, I don't talk about pregnancy" (SP04).	Protection and prevention	Women's Sexual Wellbeing	Societal Expectations and body sovereignty	Interpretation and Conceptualization
"Yes, with two in particular recently, they were both sex workers and I always asked them when they come 'are you keeping yourself safe'" (SP01).	Keeping safe			
"I've actually been pretty reckless when it comes to practicing safe sex over the years but I've actually been very lucky but I've always gone for screenings and things like that." (W14)	SRH/GUM			
"You know when I was out there? I had no sex drive at all, nothing, it was completely dead, you know, Claire, completely dead. When I started getting clean, that all came back, and I was proper promiscuous for the first, I'd say six months, of me getting clean." (W02)	Intimacy			
"I don't know. I don't necessarily have the greatest experiences with it. I always felt like it was something that I had to do." (W07)	Performing for men			

“Yes, like a lot of us have been sexually abused and stuff like that, due to drugs. A lot of us, like myself, to be fair, don't report it, because we feel like it is partly our fault. A lot of us, we put ourselves in really bad situations to get drugs, and it's turned out something bad has happening. And in the end, you feel like, “I can't really report it because I shouldn't really like…” like what I said, “I shouldn't have really met a dangerous man for a line of cocaine,” I mean, how low did I get?” (W05)	Transactional sex			
“Social Services, being a mother, dealing with post-natal depression. Like I say, I lost my partner, he killed himself. I had my oldest daughter removed. But then my mum stepped in and brought her up. So just all of it.” (W11)	Mental illness/ disorder	Mental/ Physical Health Fertility		
“It lasted six years but, God, out of the six years it was horrible when I think back. Like I say, he used to hit me really bad as well.”(W15) “The other lady had multiple children removed after they were born. Six when I worked with her. She was in abusive relationship. I always remember her saying: ‘I am going to keeping having one until you let me keep one’. But that was never going to happen because she was never going to leave her partner (SP08).	Domestic violence			

“Obviously I've been raped and stuff in the past because of the drink. Well, not because of the drink, but I've put myself in a vulnerable situation. Well, the police obviously came and they caught the guy in the act, do you know what I mean, kind of thing?” (W13)	Sexual assault			
“No, I think the guilt and shame of trying to take my own life and stuff, when I was pregnant. And still taking drugs at times. And the girls coming out withdrawing, and maybe using in hospitals. It kept us ill for some time, after.” (W11)	Suicide			
Korsakoff syndrome(W13); Type 1 diabetic in renal failure (W18)	Complex physical health			
“I wasn't bothered. I didn't have to buy pads. I didn’t have to buy tampons. I wasn't inconvenienced with bleeding like a stuffed pig for five days.” (W03)	Periods (irregular)	Fertility		
“She has wanted me to give her my eggs and stuff to obviously have a baby.” (W13)	IVF			
“But I think that because of the damage I've done, drugs and alcohol-wise, maybe I can't have kids anyway.” (W13) “I tell them I’m not clinical. It seems to be the people who aren’t using have more chance of getting	Capacity to become pregnant			

pregnant than the ones who are. I've had past girlfriends who didn't get periods while they were using, didn't get anything. As soon as they stop, they all came back. It does affect it, but we don't come across it that often." (SP05)				
"Because it could put me into early menopause, which the side effects of that could be worse than the PMDD effects that I have, and she also brought up my using, that it affects your bones, so your bone density decreases and bones can break easily and stuff, and the fact that I've been a drug user, I was probably malnourished in the past, which I don't think I was, but. Yeah, my diet wasn't great, though, so I can understand why that would be a concern with them." (W01)	Menopause			
"So I got given the mini-pill while I was on a wait list for the implant, then they gave me a Depo injection while I was waiting, because I was that scared of being on the pill. My partner wouldn't go anywhere near me, because he was that scared as well." (W18)	Injection (depo)	Contraception	Exercising agency	
"Aye, and I've never wanted to go on the pill because I worry about my weight, and I've heard it can make you gain weight. Anything that can make you gain weight, I've avoided." (W09)	Pill			
"I was actually on the implant when I was using drugs and it was only supposed to last for three years. And	Implant			

through total fear and lack of self-care, I actually had that implant in my arm for eight years. “ (W10)				
“I would say the fact that I am on protection, like I’ve got the coil in. So I won’t get pregnant because I don’t want to have kids.” (W09)	Coil			
“But I was responsible, on the whole, that I would either be on a contraceptive pill, or I'm saying, "Oh, it's not always, but the morning-after pill as well."” (W07)	Morning after pill			
“I went up to the sexual health clinic because I didn't use a condom (Laughter) as you do, and I was on the pill” (W07)	Condom use			
“I think with my mental health and my addiction in the past, sticking to appointments or getting the pill, it just wasn’t something that… I miss my tablets as it is, never mind sticking to a pill.”(W11)	Motivations and rationale for use/non use			
“This one is the one that will change us [me]. But it took many attempts and many children for that change to happen” (W11).	Save us	Children and family		
“I wanted to be a better Mam than my Mam” (W03).	Connection			
“I had children for selfish reasons, because I thought they would fix me. I thought I didn’t want to be alone, because I wanted a family of my own.” (W04)	Maternal identity			

“I always wanted children…. Sometimes, I wish I never had them and it’s not because I didn’t love them, it’s because I loved them” (W01)	Dreams			
““None of them were planned, but none of them were mistakes either, if I can say it like that, because I loved them. I do love them, but… If it wasn’t for the drugs, I probably would have been a happy little wifey, settled down with the kids and all that. But that wasn’t meant for me, was it?” (W02)	Family planning			
“Because I had an abortion whilst I was addicted to heroin and I was absolutely petrified that the blood test was going to come back, it was going to go my doctors, it was going to get reported to Social Services, and I was going to lose my two other children. Now fortunately, that didn't happen, but that sort of thing could have stopped me from having that abortion, and then I could have had an unwanted child.” (W10)	Decision making	Abortion		
“So I was petrified to go and get tested in case I had anything, you know, even like Hep C or something, something that’s not sexually related, I was petrified, again in case it come back that I was using heroin and I would get my children removed.” (W10)	Access to abortion			
You know, there is a lot of truth in that, but it’s just the way that my sister tried to talk me out of it and how it destroyed me afterwards, yes” (W09)	Impact of abortion			

“I got abused from being a child, I was four, and I had a quite bad life. So I thought most of us that took drugs had had a quite bad, crappy life.” (W05)	Adverse childhood	Childhood trauma	Trauma and relationships	
“How long did my drug-using, substance use go on for? From about the age of 12, until I was 38, or something.” (W04)	Age of drug use			
“I was sexually abused by a neighbour for 3 years of my life. I think that had an impact on my behaviour, and obviously the drugs and the alcohol. I think I went to prison, 16 years of age I first went to prison.” (W13)	Sexual abuse			
“My mum died when I was very young, I was three years old. My grandma brought me up. She died of acute leukaemia. My dad was a Royal Engineer based in Germany, so we didn’t have a lot to do with him. So my grandma, my mum’s mum, brought me up. Until I was 14. When I was 14, my grandma died.” (W02)	Bereavement			
“So I started to grow a big resentment towards the police, I always blamed them for taking us off my mum when I was younger, obviously with us being adopted.” (W16)	Care experienced			
“She will always have that fear, in her mind that, “My mum’s going to abandon me again.” I did abandon	Intergenerational impact			

her, and I get it because I've had it done to me, with my own mother. So, it's not like, you know." (W04)				
"I collected the milk money on a Friday, and I bought my own sanitary products, because she wouldn't buy me any sanitary products. I've got a lot of trauma surrounding my mum, a lot of emotional trauma." (W03)	Relationship with mother	Parents		
"So like I say, my mum's reported a few things with social. Callum's had to go and live with my mum just on a temporary basis, until I have six months completely clean, where I haven't had a line, a drink or anything." (W05)	Family interventions			
So I know how much it damages a child, having parents that aren't emotionally present. That unpredictability of how they act when they're under the influence of something. Not having that unconditional love, the selfishness, all of that, I knew what it would do to a child, and I didn't want to make my child" (W18)	Influence of family/parents			
"Well, actually, I cannot speak for everyone, I can only speak for myself. But that was my biggest fear. If I was going to ask for help." (W10)	Surveillance	Access to care	Access to care and visibility	
""I think that's another thing, I think I got stuck in that cycle, as well, of having a team of people around me. Whether it be Social Services or the drug and alcohol midwife. And then, when they were leaving,	Navigating care			

I'd panic and do something stupid, where they'd have to come flying back in. Because I think I'd become dependent on it. And it has taken me a while to get out of that mentality." (W11)				
"Because you don't know. You can sit on a toilet somewhere and it could be dirty, and you could catch something." (W13)	Information/ Misinformation			
"I've said I know there's a lot of women in drug addiction who will have baby after baby after baby because they're scared to go to the doctor's and ask for contraceptives, or do you know for an abortion and stuff like that, because they're addicted to drugs, and it will all flag up in the system and they might have other children." (W02)	Healthcare interaction			
"I wanted to go- I was looking into all that higher power stuff, I wanted to go to church. I went to a couple of different ones and I felt like it was a cult, it was weird." (W18)	Mutual aid			
"…because I felt like that because I think I felt that I wasn't- I could never be a good enough mother anyway. I gave up." (W07) "Never appreciated a blasé attitude to becoming a parent…I have seen women abusing the privilege of motherhood" (SP09).	Bad mother	Visibility		

“I love them to bits, they're my life, and they're what has kept me here and going.” (W11)	Good mother			

Appendix G: Consent form

The reproductive health and social care needs of women who use drugs and alcohol: a qualitative study. Version 4

INTERVIEW CONSENT FORM

(ALL participants must read and agree before the interview can begin)

CASE ID:

Consent form completed:
Online ☐
In person ☐

Please **initial** the box if you agree:

1. I confirm that I have read and understood the study information leaflet (dated 12/4/22, version 4). ☐

2. I confirm that I have had the opportunity to ask any questions I may have about the study and any questions I have asked, have been answered to my satisfaction. ☐

3. I understand that my participation is **voluntary** and that I am free to withdraw at any time without giving any reason, without my legal rights being affected in any way. ☐

4. I understand my interview will be audio recorded (digital recording device/ Zoom/ Microsoft Teams), anonymised, and then transcribed by a transcription company with a signed confidentiality agreement with Newcastle University. ☐

5. I understand that any data from this study will be held in a locked cabinet or secure electronic server for ten years, after which it will be destroyed. ☐

6. All data will be kept confidential. Confidentiality will only be broken if there is a risk of harm to yourself or another person. ☐

7. I understand that findings from the study, including anonymised quotes from my interview will be used in the researcher's thesis and may be used ☐

in future presentations to academic and non-academic audiences and, in academic journal articles.

8. I understand that other authenticated researchers may use my data in publications, reports, web pages, and other research outputs, only if they agree to preserve the confidentiality of the information as requested in this consent process. ☐

9. I agree to take part in the interview. ☐

10. **Optional:** I would like to receive a summary of the findings of this research. ☐

Appendix H: Copy of Ethical Approval

22 September 2022

Faculty of Medical Sciences
Newcastle University
Medical School
Framlington Place
Newcastle upon Tyne
NE2 4HH

Claire Smiles
Population Health Sciences Institute

FACULTY OF MEDICAL SCIENCES: ETHICS COMMITTEE

Dear Claire

Title: Exploring the reproductive health and social care needs of women who use drugs: A qualitative study
Application No: 2356/24186/2021
Start date to end date: 21/07/2022 to 21/01/2023

On behalf of the Faculty of Medical Sciences Ethics Committee, I am writing to confirm that the ethical aspects of your proposal have been considered and your study has been given ethical approval.

The approval is limited to this project: **2356/24186/2021**. If you wish for a further approval to extend this project, please submit a re-application to the FMS Ethics Committee and this will be considered.

During the course of your research project you may find it necessary to revise your protocol. Substantial changes in methodology, or changes that impact on the interface between the researcher and the participants must be considered by the FMS Ethics Committee, prior to implementation.*

At the close of your research project, please report any adverse events that have occurred and the actions that were taken to the FMS Ethics Committee.*

Best wishes,

Yours sincerely

Marjorie Holbrough
On behalf of Faculty Ethics Committee

cc.
Professor Jan Deckers, Chair of FMS Ethics Committee
Mrs Kay Howes, Research Manager

*Please refer to the latest guidance available on the internal Newcastle web-site.

Appendix I: Debrief Information Sheet

Women's Sexual Wellbeing Study

Exploring the reproductive health and social care needs of women who use drugs.

Thank you

Thank you for taking part in our study. Your views and experiences are truly valued. Find below a list of organisations you might find useful:

Drug and Alcohol Support

Newcastle- Newcastle Treatment and Recovery (NTaR), (01912061117).

Gateshead- Change Grow Live/ Recovery Partnership (01915947821).

Sunderland- Change Grow Live/ Wear Recovery (0800 234 6798) *free to call*.

South Tyneside- South Tyneside Adult Recovery Service (01919171160).

Durham- County Durham Drug and Alcohol Recovery Services (03000 266 666).

North Tyneside- North Tyneside Recovery Partnership/ CNTW (0191 2408122).

Northumberland- Northumberland Recovery Partnership (01670798200).

Sexual and Reproductive Health Support

Newcastle- New Croft Centre (0191229299).

Claire Smiles
(lead researcher)

Tel:
07415768749

Email:
c.smiles2@newcastle.ac.uk

Available between 9am -5pm weekdays.

Newcastle University

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recording is given an identification number (ID) and names are removed. Only the research team will have access to the interview notes. Data from the study may be used in publications, reports, web pages, and other research outputs, and will preserve the confidentiality of the information requested in the consent process. You will not be named in any report. All the information collected will be treated as confidential and will only be disclosed to other agencies with your consent, except where required by law or where you or another person is at risk.

This study was approved by the Faculty of Medical Sciences Research Ethics Committee, part of Newcastle University's Research Ethics Committee. This committee contains members who are internal to the Faculty. This study was reviewed by members of the committee, who must provide impartial advice and avoid significant conflicts of interests.

What will happen with the results of this study?

A summary report will be produced. Findings from the study will be published in academic journals and will help to shape policy and practice. We can provide a summary of the findings of the research if you would find this of interest.

WHAT IF THERE IS A PROBLEM?

Any complaints or concerns about the study or how you were treated should be made within 7 days and in writing to: Dr. Ruth McGovern [r.mcgovern@newcastle.ac.uk]. If you remain unhappy and wish to complain formally, you can do this through Newcastle University complaints procedure; details of which can be obtained from 0191 2227045.

Appendix J: Poetry written by women for this study

Womanhood by Marie Warby

The road to womanhood wasn't so kind to me.

I look at infancy and I see abuse; I look at puberty and I see a noose.

A very painful past as I recall, I didn't allow it to stop me, I refuse to fall.

I felt like an adolescent, stuck in a woman's bod,

Screaming out hoping someone would hear, my body always stick in a constant state of fear/

Very submissive that's what I'd become, all I needed was a way to find home.

Without a map nor a tool, just a woman to teach me from her school,

A wealth of knowledge to show me the way, I know ill be powerful and independent one day.

My inner child is reaching out and ready to kneel, this little girl needs to heal.

With a blank sheet of paper where do I start, its time to mend my broken hear.

I look at my past with no regret, for every challenge of womanhood I've met.

To say it's been easy that would be wrong, and here I stand singing my song.

Shining a light for others to see, some days I can't believe its me.

Womanhood is such a beautiful place t o be, and now finally I can nurture Marie.

Needs to be everything by Kayleigh Cookson

The expectations of a mother is not easy,
I need superpowers and multi-tasking skills.
I have to be a role model and provide a clean tidy house,
I have to budget and pay all the bills.

I need to be very organised,
Always plan ahead every time I go shopping.
I have to be a cook, a Baker, I'm never out the kitchen,
And I am a professional at washing.

I need to be brilliant at cleaning,
Wash the dishes, hoover up, pick up mess.
I have to negotiate and play referee,
My patience constantly at test.

I need to be very responsible,
Be a doctor, nurse, Councillor, therapist.
I have to be handy at odd jobs round the house,
There's no problem that I cannot fix.

I need to be an expert encyclopaedia,
To answer all the why's, how's, what's, Where's and when.
I have to be fun and play lots of games,
Again and again and again.

I need to be a smart tutor,
Help with homework, teach right from wrong.
I have to be a PA, hair dresser, taxi driver,
And always put things back where they belong.

I need to make lots of dreams come true,
I am Santa, the tooth fairy, Easter bunny.
I have to cure boredom on cold and wet rainy days,
Go out and make memories when it is sunny.

I need to be rich with empathy,
Be supportive, wipe away lots of tears.
I have to be a hero and never be scared,
And chase away all the nightmares and fears.

I need to be a care giver,
A good communicator and be able to detect lies.
I have to be an agony aunt and a shoulder to lean on,
I've got to know how to save lives.

I need to be an active listener,
Good at advice and have psychic abilities.
I have to be ready and always prepared,
To provide mental and emotional stability.

I need to be loving and caring,
Tend to wounds, scars, bumps, patch up scrapes.
I have to be a healer and always the best one,
To pick up pieces everytime a heart breaks.

I need to be strong, be a survivor,
Put on a brave face no matter the weather.
I have to paint on a smile, show no pain, head up high,
Always cope, always hold it all together.

I need to always have time,
There's no relax, no switch off, no escape.

I have to put everyone's needs above my own,
Ohh the guilt if I make a mistake.

I need to never be ill,
Cope with bleeding monthly and raging hormones.
I have to put up with mood swings, hot flushes and cramps,
Then not to mention the menopause.

I need to be forever perfect,
Can't shout or swear coz I'll face stigma and shame.
I have to never go out coz I'll be a bad mam and a slag,
Not worthy, always judged, the one to blame.

The expectations of a mother is not easy,
I need to also then be a friend, a partner, a wife.
I have to be a daughter, a sister, an aunty, a nana,
I am never just me, a woman living my life.

References

Abdul-Khabir, W., Hall, T., Swanson, A. N., & Shoptaw, S. (2014). Intimate Partner Violence and Reproductive Health Among Methamphetamine-Using Women in Los Angeles: A Qualitative Pilot Study. *Journal of Psychoactive Drugs*, 46(4), 310-316.

Adams, EA., Parker, J., Jablonski, T., Kennedy, J., Tasker, F., Hunter, D., Denham, K., Smiles, C., Muir, C., O'Donnell, A., Widnall, E., Dotsikas, K., Kaner, E., Ramsay, S.E. (2022). A Qualitative Study Exploring Access to Mental Health and Substance Use Support among Individuals Experiencing Homelessness during COVID-19. *International Journal of Environmental Research and Public Health*, 19(6), 3459.

Adewole, I. and Gavira, A. (2018). Sexual and reproductive health and rights for all: an urgent need to change the narrative. *The Lancet*, 391(10140), pp.2585-2587.

Advisory Council on Misuse of Drugs. (2003). Hidden Harm Report. London: Gov.uk; 2003. Available from: https://www.gov.uk/government/publications/amcd-inquiry-hidden-harm-report-on-children-of-drug-users [Accessed on 10.6.23].

Agenda Alliance & Changing Lives (2023). Dismantling Disadvantage. Available at: https://www.agendaalliance.org/documents/148/Transforming_Services_Final_Report.pdf [Accessed on 20.12.23].

Alderson, H., Spencer, L., Scott, S., Kaner, E., Reeves, A., Robson, S., Ling J. (2021).Using behavioural insights to improve the uptake of services for drug and alcohol misuse. *International Journal of Environmental Research and Public Health*, 18(13), 6923.

Alvesson, M., & Sandburg, J (2011). GENERATING RESEARCH QUESTIONS THROUGH PROBLEMATIZATION. *The Academy of Management Review*, *36*(2): 247–271.

Andrade C. (2020). The Limitations of Online Surveys. *Indian Journal of Psychology Medicine*;42(6): 575-576.

Andrews, N. C. Z., Motz, M., Leibson, T., Austin, Z., Ito, S., & Pepler, D. J. (2018). Reasons for substance use continuation and discontinuation during pregnancy: A qualitative study. *Women and birth: Journal of the Australian College of Midwives*, 32(1), e57-e64.

Angrosino, Michael. (2009) *"Focus on Observation" In Doing Ethnographic and Observational Research*, 53-66, Qualitative Research Kit. London: SAGE Publications Ltd,

Baker, P. L., & Carson, A. (1999). I take care of my kids: Mothering practices of substance-abusing women. *Gender and Society*, 13(3), 347-363.

Banwell C. & Bammer G. (2006). Maternal habits: Narratives of mothering, social position and drug use. *International Journal of Drug Policy*, 17, 504-513.

Baptista, C., Dourado, I., de Andrade, T., Brignol, S., Bertoni, N. and Bastos, F., 2017. HIV Prevalence, Knowledge, Attitudes, and Practices Among Polydrug Users in Brazil: A Biological Survey Using Respondent Driven Sampling. *AIDS and Behavior*, 22(7), pp.2089-2103.

Barnett, E.R., Knight, E., Herman, R.J., Amarakaran, K., Jankowski, M.K.(2021). Difficult binds: A systematic review of facilitators and barriers to treatment among mothers with substance use disorders. *Journal of Substance Abuse Treatment*, *26*, 108341.

Baumgarten, Britta., Ullrich, Peter. (2012). Discourse, power and governmentality: Social movement research with and beyond Foucault, WZB Discussion Paper, No. SP IV 2012-401, Wissenschaftszentrum Berlin für Sozialforschung (WZB), Berlin.

Bearak, J., Popinchalk, A., Ganatra, B., Moller, A.B., Tunçalp Ö, Beavin. C, *et al.* (2020). Unintended pregnancy and abortion by income, region, and the legal status of abortion:

estimates from a comprehensive model for 1990–2019. *The Lancet Global Health*, 8(9):e1152-e61.

Bedston, S., Philip, G., Youansamouth, L., Clifton, J., Broadhurst, K., Brandon, M. and Hu, Y. (2019). Linked lives: Gender, family relations and recurrent care proceedings in England. *Children and Youth Services Review*, 105, p.104392.

Benoit, C., Magnus, S., Phillips, R., Marcellus, L., & Charbonneau, S. (2015). Complicating the dominant morality discourse: Mothers and fathers' constructions of substance use during pregnancy and early parenthood. *International Journal for Equity in Health*, 14(1), 206.

Bentham, J. (2010). *Edited* by Philip Schofield. New York, N.Y.: Clarendon Press.

Bertin, J. (1995). Regulating reproduction. In Reproduction, Ethics and the Law: Feminist Responses. *Edited* by Callahan Joan. Bloomington: Indiana University Press, pp. 380–97.

Best, D., Segal, J., Day, E. (2009). Changing patterns of heroin and crack use during pregnancy and beyond. *Journal of Substance Use*, 14(2):124-32.

Bignall, S. (2008). Deleuze and Foucault on Desire and Power, Angelaki, 13:1, 127-147.

Black, K. and Day, C. (2016). Improving Access to Long-Acting Contraceptive Methods and Reducing Unplanned Pregnancy among Women with Substance Use Disorders. *Substance Abuse: Research and Treatment*, 10s1, p.SART.S34555.

Black, K., Stephens, C., Haber, P. and Lintzeris, N. (2012). Unplanned pregnancy and contraceptive use in women attending drug treatment services. Australian and New Zealand *Journal of Obstetrics and Gynaecology*, 52(2), pp.146-150.

Blythe, S., Wilkes, L., Jackson, D. and Halcomb, E. (2013). The challenges of being an insider in storytelling research. *Nurse Researcher*, 21(1), pp.8-12.

Bolen, M., McWey, L. and Schlee, B. (2008). Are At-Risk Parents Getting What They Need? Perspectives of Parents Involved with Child Protective Services. *Clinical Social Work Journal*, 36(4), pp.341-354.

Booth, A. (2016). Searching for qualitative research for inclusion in systematic reviews: a structured methodological review. *Systematic Reviews*, 5, 74.

Boyd, S.C. and Marcellus, L., *eds*. (2007). With child: substance use during pregnancy: a woman-centred approach. Vancouver: Fernwood.

Boyd, S.C. (1999). Mothers and illicit drugs: transcending the myths. Toronto: University of Toronto Press.

Brett, J., Staniszewska, S., Mockford, C., Herron-Marx, S., Hughes, J., Tysall, C., Suleman, R. (2014). Mapping the impact of patient and public involvement on health and social care research: a systematic review. *Health Expect*. 2014 Oct;17(5):637-50.

Broadhurst, K. and Mason, C. (2013). Maternal outcasts: raising the profile of women who are vulnerable to successive, compulsory removals of their children – a plea for preventative action. *Journal of Social Welfare and Family Law*, 35(3), pp.291-304.

Broadhurst, K., Alrouh, B., Yeend, E., Harwin, J., Shaw, M., Pilling, M., Mason, C. and Kershaw, S. (2015). Connecting Events in Time to Identify a Hidden Population: Birth Mothers and Their Children in Recurrent Care Proceedings in England. *British Journal of Social Work*, 45(8), pp.2241-2260.

Brudenell, I. (1997). A grounded theory of protecting recovery during transition to motherhood. *American Journal of Drug and Alcohol Abuse*, 23(3), 453-466.

Butina, Campbell & Miller., (2015). A Narrative Approach to Qualitative Inquiry. *American Society for Clinical Laboratory Science, 28*, 190 - 196.

Campbell, N.D. (2000). Using women: gender, drug policy, and social justice. London: Routledge.

Campbell, R. and Wasco, S.M. (2000). Feminist approaches to Social Science: Epistemological and methodological tenets. *American Journal of Community Psychology*, 28(6), 773-791.

Catalao, R., Mann, S., Wilson, C. and Howard, L. (2019). Preconception care in mental health services: planning for a better future. *The British Journal of Psychiatry*,1-2.

Chandler, A., Whittaker, A., Cunningham-Burley, S., Williams, N., McGorm, K., & Mathews, G. (2013). Substance, structure and stigma: Parents in the UK accounting for opioid substitution therapy during the antenatal and postnatal periods. *International Journal of Drug Policy,* 24(6), e35-e42.

Chandler, A., Whittaker, A., Wiliams, N., McGorm, K., Cunningham-Burley, S., & Mathews, G. (2014). Mother's little helper? Contrasting accounts of benzodiazepine and methadone use among drug-dependent parents in the UK. *Drugs: Education, Prevention and Policy*, 21(6), 470-475.

Chang, J. C., Tarr, J. A., Holl, , C. L., De Genna, N. M., Richardson, G. AArnold, R. M. (2019). Beliefs and attitudes regarding prenatal marijuana use: Perspectives of pregnant women who report use. *Drug and Alcohol Dependence*, 196, 14.

Chapkis, W. (2010). Productive Tensions: Ethnographic Engagement, Complexity, and Contradiction. *Journal of Contemporary Ethnography*, 39(5), pp.483-497.

Chatterjee, K. (2018). What Can We Learn About the Female Condom Online? An Analysis of Visual Representations of the Female Condom on the Internet. *The Atlantic Journal of Communication*, 26. 149-163.

Chou, J., Pierce, K., Pennington, L., Seiler, R., Michael, J., Mc Namara, D. and Zand, D. (2018). Social Support, Family Empowerment, Substance Use, and Perceived Parenting Competency during Pregnancy for Women with Substance Use Disorders. *Substance Use & Misuse*, 53(13), pp.2250-2256.

Clarke, J., Gold, M., Simon, R., Roberts, M. and Stein, L. (2012). Motivational Interviewing with computer assistance as an intervention to empower women to make contraceptive choices while incarcerated: study protocol for randomized controlled trial. *Trials*, 13(1).

Clergue-Duval, V., Robin, S., Fortias, M., Dupuy, G., Badin-de-Montjoye, B. and Vorspan, F. (2017). Use and knowledge of contraceptive methods by patients in two substance use disorders treatment centers in Paris. *Harm Reduction Journal*, 14(1).

Cleveland, L. M., Bonugli, R. J., & McGlothen, K. S. The Mothering Experiences of Women With Substance Use Disorders. *Advances in Nursing Science*, 39(2), 119-129.

Coleman, P. K., Reardon, D. C., & Cougle, J. R. (2005). Substance use among pregnant women in the context of previous reproductive loss and desire for current pregnancy. *British Journal of Health Psychology*, 10(2), 255-268.

Collins, C.S and Stockton, C.M. (2018). The central role of theory in qualitative research. International Journal of Qualitative Methods, 17 (1).

Cook, R., Cusack, S. and Dickens, B. (2010). Unethical female stereotyping in reproductive health. *International Journal of Gynecology & Obstetrics*, 109(3), pp.255-258.

Costa Padovani, R., Fidalgo, T. M., & Tucci, A. M. (2018). Women crack users, pregnancy and motherhood: Potential periods for health care. *Psicologia: Teoria e Pesquisa*, 34.

Costa, S. *et al.* (2015) 'Gestantes em situação de rua no município de santos, SP: Reflexões E desafios para as Políticas Públicas'. *Saúde e Sociedade*, 24(3), pp. 1089–1102.

Courvette, A., Plourde, C., & Brochu, S. (2016). Negotiating Identity: Three Events that Weaken the Maternal Identity of Addicted Law-Breaking Women. *Deviant Behavior*, 37(11), 1252-1263.

Deleuze, G. (1992). Postscript on the societies of control. October, 59, 3–7.

Diez M, Pawlowicz MP, Vissicchio F, Amendolaro R, Barla JC, Muñiz A, Arrúa L. (2020). Between invisibility and stigma: consumption of psychoactive substances among pregnant and postpartum women at three Argentine general hospitals. *Salud Colectiva*, 16:e2509.

Dixon-Woods, M., Fitzpatrick, R., & Roberts, K. (2001). Including qualitative research in systematic reviews: opportunities and problems. *Journal of evaluation in clinical practice*, *7*(2), 125–133.

Ecker J, Abuhamad A, Hill W, Bailit J, Bateman BT, Berghella V. (2020). Substance use disorders in pregnancy: clinical, ethical, and research imperatives of the opioid epidemic: a report of a joint workshop of the Society for Maternal-Fetal Medicine, American College of Obstetricians and Gynecologists, and American Society of Addiction Medicine. *American Journal of Obstetric Gynecology*. 2019;221(1):B5-B28.

Edelman, N., Patel, H., Glasper, A. and Bogen-Johnston, L. (2013). Understanding barriers to sexual health service access among substance-misusing women on the South East coast of England. *Journal of Family Planning and Reproductive Health Care*, 39(4), pp.258-263.

Edelman, N., Patel, H., Glasper, A. and Bogen-Johnston, L. (2014). Sexual health risks and health-seeking behaviours among substance-misusing women. *Journal of Advanced Nursing*, 70(12), pp.2861-2870.

Ellard-Gray, A., Jeffrey, N. K., Choubak, M., & Crann, S. E. (2015). Finding the Hidden Participant: Solutions for Recruiting Hidden, Hard-to-Reach, and Vulnerable Populations. *International Journal of Qualitative Methods*, 14(5).

FRSH. (2024). The FRSH Hatfield Vision. Available at: https://www.fsrh.org/Public/Public/News-and-Advocacy/the-fsrh-hatfield-vision.aspx . [Accessed on 07.04.24]

Fentiman, L.C. (2009). In the Name of Fetal Protection: Why American Prosecutors Pursue Pregnant Drug Users (And Other Countries Don't), 18 Colum. *J. Gender & L*, 647.

Finer, L., Henshaw, S. (2006). Disparities in rates of unintended pregnancy in the United States 1994 and 2001. *Perspectives on Sexual and Reproductive Health*, 38(90).

Finlay, L. (2012). "Debating phenomenological methods". In: F. Finlay (*ed*.) (2012). Hermeneutic Phenomenology in Education, New York: Springer, pp.17-37.

Flacks, S. (2019). Dangerous drugs, dangerous mothers: Gender, responsibility and the problematisation of parental substance use. *Critical Social Policy*, *39*(3), 477-497.

Flacks, S. (2023). Parental Substance Use as a Child Protection Problem: A Post-structural Interview Analysis. *Contemporary Drug Problems*, *50*(4), 475-490

Fonow, Mary Margaret & Cook, Judith A. (1991). Beyond Methodology: Feminist Scholarship as Lived Research. Indiana University Press.

Foucault, M. (1991a). Discipline and punish: the birth of the prison. London: Penguin.

Foucault, M. (1991b). The Foucault effect: studies in governmentality (*Eds*. G. Burchell, C. Gordon & P.Miller). Chicago: University of Chicago Press.

Foucault, M. (1998). The will to knowledge: the history of sexuality (Vol. 1). London: Penguin.

Foucault, M. (2002). Power: essential works of Foucault 1954–1984, Vol. 3 (*Ed*. Faubion, J.D). London:Penguin Books.

Foucault, M. (2006). Psychiatric power: lectures at the collège de France 1973–1974 (Ed. J. Lagrange). New York: Palgrave Macmillan.

Foucault, M. (2007). Security, territory, population: lectures at the collège de France 1977–1978 (*Ed*. Senellart, M). New York: Picador.

Frazer, Z., McConnell, K., & Jansson, L. M. (2019). Treatment for substance use disorders in pregnant women: Motivators and barriers. *Drug and Alcohol Dependence*, 205, 107652.
Furedi, F. 2008 . Paranoid parenting: Why ignoring the experts may be best for your child , London: Continuum

Galea S. The Social Epidemiology of Substance Use. *Epidemiologic Reviews*. 2004;26(1):36-52.

Galič, M., Tjerk, T., and Koops, B.J. (2017). Bentham, Deleuze and Beyond: An Overview of Surveillance Theories from the Panopticon to Participation. *Philosophy & Technology*, 30(1), 9-37,

Galligan, K. and Comiskey, C. (2019). Hidden Harms and the Number of Children Whose Parents Misuse Substances: A Stepwise Methodological Framework for Estimating Prevalence. *Substance Use & Misuse*, 54(9), pp.1429-1437.

Ghebreyesus, T. A., & Kanem, N. (2018). Defining sexual and reproductive health and rights for all. *Lancet (London, England)*, *391*(10140), 2583–2585.

Gilchrist, K., Iqbal, S. & Vindrola-Padros, C. (2022). The role of patient and public involvement in rapid qualitative studies: Can we carry out meaningful PPIE with time pressures?. *Resesearch Involvement and Engagement,* 8, 67.

Gillies , V. (2008) . Perspectives on parenting responsibility: Contextualising values and practices . *Journal of Law and Society*, 35 (1) : 95 – 112 .

Goel, N., Beasley, D., Rajkumar, V., and Banerjee, S. (2011). Perinatal outcome of illicit substance use in pregnancy – comparative and contemporary socio-clinical profile in the UK. *European Journal of Pediatrics*, 170:199-205

Goffman, E. (1959). The presentation of self in everyday life. Doubleday.

Gollub, E., Cyrus-Cameron, E., Armstrong, K., Boney, T. and Chhatre, S. (2013). Basic body knowledge in street-recruited, active drug-using women enrolled in a "body empowerment" intervention trial. *AIDS Care*, 25(6), pp.732-737.

Gomez, L.E. (1997). Misconceiving mothers: legislators, prosecutors, and the politics of prenatal drug exposure. Philadelphia: Temple University Press.

Gómez AM, Arteaga S, Villaseñor E, Arcara J, Freihart B. (2019). The Misclassification of Ambivalence in Pregnancy Intentions: A Mixed-Methods Analysis. *Perspect Sex Reprod Health*. Mar;51(1):7-15.

Gomm, R. (2008). Social Research Methodology: A critical introduction. New York: Palgrave Macmillian.

Gopalakrishnan, S., & Ganeshkumar, P. (2013). Systematic Reviews and Meta-analysis: Understanding the Best Evidence in Primary Healthcare. *Journal of family medicine and primary care*, *2*(1), 9–14

Goodman, D. J., Saunders, E. C., & Wolff, K. B. (2020). In their own words: a qualitative study of factors promoting resilience and recovery among postpartum women with opioid use disorders. *BMC pregnancy and childbirth*, 20(1), 10.

Gordon, A. C., Lehane, D., Burr, J., & Mitchell, C. (2019). Influence of past trauma and health interactions on homeless women's views of perinatal care: a qualitative study. *The British journal of general practice: the journal of the Royal College of General Practitioners*, 69(688), e760-e767.

HM Treasury. (2003). Every child matters- gov.uk. Available at: https://assets.publishing.service.gov.uk/media/5a7c95a4e5274a0bb7cb806d/5860.pdf [Accessed on 05.12.23].

Grant, T., Christopher Graham, J., Ernst, C., Michelle Peavy, K. and Brown, N. (2014). Improving pregnancy outcomes among high-risk mothers who abuse alcohol and drugs: Factors associated with subsequent exposed births. *Children and Youth Services Review*, 46, pp.11-18.

Grant, T., Ernst, C., Streissguth, A. and Stark, K. (2005). Preventing Alcohol and Drug Exposed Births in Washington State: Intervention Findings From Three Parent-Child Assistance Program Sites. *The American Journal of Drug and Alcohol Abuse*, 31(3), pp.471-490.

Gray, R., Brasier, C., Zirnsak, T.M., Ng, A.H. (2021). 'Reporting of patient and public involvement and engagement (PPIE) in clinical trials published in Nursing Science Journals: A descriptive study', *Research Involvement and Engagement*, 7(1).

Grix, J. (2002). Introducing Students to the Generic Terminology of Social Research. *Politics*, *22*(3), 175-186.

Gutierres, S. and Barr, A. (2003). The relationship between attitudes toward pregnancy and contraception use among drug users. *Journal of Substance Abuse Treatment*, 24(1), pp.19-29.

Haaker, M. (2021) 'The power of the pregnant body: Perspectives of Agency and autonomy in pregnancy', *Genealogy*, 5(1), p. 13.

Haggerty, K. (2006). Tear down the walls: on demolishing the panopticon. In D. Lyon (*Ed*.), Theorising surveillance: The panopticon and beyond (pp. 23–45). Portland: Willan Publishing.

Hall, J. L., & van Teijlingen, E. R. (2006). A qualitative study of an integrated maternity, drugs and social care service for drug-using women. *BMC pregnancy and childbirth*, 6, 19.

Hannes, K., Goedhuys, J., and Aertgeerts, B. (2012). Obstacles to implementing evidence-based practice in Belgium: a context-specific qualitative evidence synthesis including findings from different health care disciplines. *Acta Clin Belg* 67(2): 99-107.

Hathazi, D., Lankenau, S. E., ers, B., & Jackson Bloom, J. (2009). Pregnancy and sexual health among homeless young injection drug *users. Journal of Adolescence*, 32(2), 339-355.

Hawker, S., Payne, S., Kerr, C., Hardey, M., & Powell, J. (2002). Appraising the evidence: reviewing disparate data systematically. *Qual Health Res*, 12(9), 1284-1299.

He, A., Traube, D. and Young, N. (2014). Perceptions of parental substance use disorders in cross-system collaboration among child welfare, alcohol and other drugs, and dependency court organizations. *Child Abuse & Neglect*, 38(5), pp.939-951.

Hennink, M., & Kaiser, B. N. (2022). Sample sizes for saturation in qualitative research: A systematic review of empirical tests. *Social science & medicine (1982)*, *292*, 114523.

Heil, S., Jones, H., Arria, A., Kaltenbach, K., Coyle, M., Fischer, G., Stine, S., Selby, P. and Martin, P. (2011). Unintended pregnancy in opioid-abusing women. *Journal of Substance Abuse Treatment*, 40(2), pp.199-202.

Hesse, M., Vanderplasschen, W., Rapp, R., Broekaert, E. and Fridell, M. (2014). Case management for persons with substance use disorders. *Cochrane Database of Systematic Reviews*.

Higgins, J., Thomas, J., Chandler, J., Cumpston, M., & Li, T., Page, M.J.,Welch, V.A. (2019). Cochrane Handbook for Systematic Reviews of Interventions (*Second ed*.). UK: The Cochrane Colation & John Wiley & sons ltd.

Holt, K. and French, G. (2019). Exploring the Motherhood Experiences of Active Methamphetamine Users. *Crime, Law, and Social Change*, *73*, 297–314.

Hotham, E. D., Ali, R. L., & White, J. M. Analysis of qualitative data from the investigation study in pregnancy of the ASSIST Version 3.0 (the Alcohol, Smoking and Substance Involvement Screening Test). *Midwifery*, 34, 183-197.

Howard, H. (2015). Reducing stigma: Lessons from opioid-dependent women. *Journal of Social Work Practice in the Addictions*, 15(4), 418-438.

Howard, H. (2016). Experiences of opioid-dependent women in their prenatal and postpartum care: Implications for social workers in health care. *Social Work in Health Care*, 55(1), 61-85.

Howlett, H., Mackenzie, S., Strehle, E., Rankin, J. and Gray, W. (2019). A Survey of Health Care Professionals' Knowledge and Experience of Foetal Alcohol Spectrum Disorder and Alcohol Use in Pregnancy. *Clinical Medicine Insights: Reproductive Health*, 13, p.117955811983887.

Humphreys. D. (2005). Issues in reproductive health and empowerment in perinatal women with substance use disorders. *Journal of Addictions Nursing*, 16(3), 97-105.

Humphries, D. (1999).Crack mothers: pregnancy, drugs, and the media. Columbus: Ohio State University Press.

Interventions (Second ed.). UK: The Cochrane Collaboration & John Wiley & sons ltd.

Islam, S. *et al.* (2021) '"we are not hard to reach, but we may find it hard to trust" …. involving and engaging "seldom listened to" community voices in Clinical Translational Health Research: A social innovation approach', *Research Involvement and Engagement*, 7(1).

Jackson, A., & Shannon, L. (2012). Barriers to receiving substance abuse treatment among rural pregnant women in Kentucky. *Maternal and child health journal*, 16(9), 1762-1770.

Jackson, A., & Shannon, L. (2012). Examining Barriers to and Motivations for Substance Abuse Treatment Among Pregnant Women: Does Urban-Rural Residence Matter? *Women and Health*, 52(6), 570-586.

Jansson LM, Patrick SW. (2019).Neonatal Abstinence Syndrome. *Pediatric Clinics of North America*, 66(2):353-67.

Jessup, C.; Humphreys, J. M. A., Brindis, C.D., Lee, K. A. (2003). Extrinsic barriers to substance abuse treatment among pregnant drug dependent women. *Journal of Drug Issues*, 33(2), 285-304.

Kalo, Z. (2019). Szerhasználó Várandós és kisgyermekes nők Anyaság - Fogalmának Feltárása', *Mentálhigién és Pszichoszomatika,* 20(3), pp. 239–266

Kearney, M. H., Murphy, S., & Rosenbaum, M. (1994). Learning by Losing: Sex and Fertility on Crack Cocaine. *Qualitative Health Research*, 4(2), 142-162.

Keen, J. (2001). Drug misusing parents: key points for health professionals. *Archives of Disease in Childhood*, 85(4), pp.296-299.

Khan, M., Hazra, A., Kant, A. and Ali, M., 2016. Conditional and unconditional cash transfers to improve use of contraception in low- and middle-income countries: A Systematic Review. *Studies in Family Planning*, 47(4), pp.371-383.

King, K. E., Ross, L. E., Bruno, T. L., & Erickson, P. G. (2009). Identity work among street-involved young mothers. *Journal of Youth Studies*, 12(2), 139-149.

Klee, H. (1998). Drug-using parents: analysing the stereotypes. *International Journal of Drug Policy*, 9(6), pp.437-448.

Klimas, J., Field, C., Cullen, W., O'Gorman, C., Glynn, L., Keenan, E., Saunders, J., Bury, G. and Dunne, C. (2014). Psychosocial interventions to reduce alcohol consumption in concurrent problem alcohol and illicit drug users: Cochrane review. *Drug and Alcohol Dependence*, 140, e106.

Kouimtsidis, C., M. Reynolds, M. Hunt, J. Lind, J. Beckett, C. Drummond and H. Ghodse (2003). Substance use in the general hospital. *Addictive Behaviors*, 28(3): 483-499.

Kramlich, D., Kronk, R., Marcellus, L., Colbert, A., & Jakub, K. (2018). Rural Postpartum Women With Substance Use Disorders. *Qualitative Health Research*, 28(9), 1449-1461.

Kunitz, S. J. (2008). A case of old wine in re-labeled bottles? A commentary on Aronowitz. *Social Science & Medicine*, 67(1), 10e13.

Kuo, C., Schonbrun, Y. C., Zlotnick, C., Bates, N., Todorova, R., Kao, J. C. W., & Johnson, J. (2013). A Qualitative Study of Treatment Needs Among Pregnant and Postpartum Women with Substance Use and Depression. *Substance Use & Misuse*, 48(14), 1498-1508.

Labate, B. C. Consumption of Ayahuasca by Children and Pregnant Women: Medical Controversies and Religious Perspectives. *Journal of Psychoactive Drugs*, 43(1), 27-35.

Latkin, C. and Friedman, S., 2012. Drug Use Research: Drug Users as Subjects or Agents of Change. *Substance Use & Misuse*, 47(5), pp.598-599.

Latuskie, K., Andrews, N., Motz, M., Leibson, T., Austin, Z., Ito, S. and Pepler, D., 2019. Reasons for substance use continuation and discontinuation during pregnancy: A qualitative study. *Women and Birth*, 32(1), pp.e57 e64.

Lee, N., & Boeri, M. (2017). Managing Stigma: Women Drug Users and Recovery Services. *Fusio : the Bentley undergraduate research journal*, *1*(2), 65–94.

Lee E., Macvarish J., Bristow J. (2010). Editorial: Risk, health and parenting culture. *Health, Risk & Society*, 12(4), 293–300.

Leppo, A. (2012). " Subutex is safe": Perceptions of risk in using illicit drugs during pregnancy. *International Journal of Drug Policy*, 23(5), 365-373.

Letherby, G. (2007). Feminist Research in Theory. 2nd ed. Buckingham: Open University Press.

Lewis, S., Klee, H., & Jackson, M. (1995). Illicit Drug Users' Experiences of Pregnancy. An Exploratory Study. *Journal of Reproductive and Infant Psychology*, 13(3), 219-227.

Liamputtong, Pranee (ed.) (2019). Handbook of Research Methods in Health Social Sciences. Springer Singapore.

Lincoln, Y., & Guba, E. G. (1985). Naturalistic inquiry. Newbury Park, CA: Sage.

Longhurst, R. (2005) '(ad)dressing pregnant bodies in New Zealand: Clothing, fashion, subjectivities and Spatialities', *Gender, Place and Culture*, 12(4), pp. 433–446.

Lopez, V & Whitehead, D 2013, Sampling data and data collection in qualitative research. in *Nursing & Midwifery Research: Methods and Appraisal for Evidence-Based Practice.* 4th edn, Elsevier Mosby, pp. 123-140.

Lui, S., Terplan, M. and Smith, E. (2008). Psychosocial interventions for women enrolled in alcohol treatment during pregnancy. *Cochrane Database of Systematic Reviews*.

Lupton, D. (2012) 'Precious cargo': foetal subjects, risk and reproductive citizenship, *Critical Public Health*, 22:3, 329-340

Lyon, D. (2004). Surveillance Technology and Surveillance Society. *Modernity and Technology,* 161-184.

Marshall H., Woollett A. (2000). Fit to reproduce? The regulative role of pregnancy texts. *Feminism & Psychology*, 10(3), 351–366.

MacKenzie, H., Dewey, A., Drahota, A., Kilburn, S., Kalra, P., Fogg, C., & Zachariah, D. (2012). Systematic reviews: what they are, why they are important, and how to get involved. *Journal of Clinical and Preventive Cardiology*, *1*(4), 193-202.

Mason, C., Taggart, D., Broadhurst, K. (2020). Parental Non-Engagement within Child Protection Services—How Can Understandings of Complex Trauma and Epistemic Trust Help? *Societies*. 10(4):93.

Mattocks, K. M., Clark, R., & Weinreb, L. (2017). Initiation and Engagement with Methadone Treatment among Pregnant and Postpartum Women. *Women's Health Issues*, 27(6), 646-651.

Mburu, G., Ayon, S., Mahinda, S., & Kaveh, K. (2020). Determinants of Women's Drug Use During Pregnancy: Perspectives from a Qualitative Study. *Maternal and child health journal*, 24(9), 1170-1178.

Mburu, G., Ndimbii, J., Ayon, S., Mlewa, O., Mbizvo, M., Kihara, C. and Ragi, A. (2018). Contraceptive Use Among Women Who Inject Drugs: Motivators, Barriers, and Unmet Needs. *Women's Reproductive Health*, 5(2), pp.99-116.

McCracken, K., Priest, S., FitzSimons, A., Kelly, B., Torchia, K., Parry, W., & Stanely, N. (2017). Evaluation of pause. Department for Education.

McGovern, R., Addison, M., Newham, J., Hickman, M. and Kaner, E. (2017). Effectiveness of psychosocial interventions for reducing parental substance misuse. *Cochrane Database of Systematic Reviews*.

McGovern, R., Gilvarry, E., Addison, M., Alderson, H., Geijer-Simpson, E., Lingam, R., Smart, D. and Kaner, E. (2018). The Association Between Adverse Child Health, Psychological, Educational and Social Outcomes, and Nondependent Parental Substance: A Rapid Evidence Assessment. Trauma, *Violence, & Abuse*, p.152483801877285.

McGovern, R., Newham, J.J, Addison, M.T, Hickman, M., Kaner, E. (2021). Effectiveness of psychosocial interventions for reducing parental substance misuse. *Cochrane Database of Systematic Reviews*, Issue 3.

McGrane, N., Dunbar, P. and Keyes, L.M. (2023). To summarise the approach to and findings of the PPIE undertaken as part of a programme of secondary research with a vulnerable, hard to reach population during the COVID-19 pandemic. *Research Involvement and Engagement*, 9(1).

McGrath, J., Lhussier, M., Crossley, S., Forster, N. (2023). "They Tarred Me with the Same Brush": Navigating Stigma in the Context of Child Removal. *Int. J. Environ. Res.Public Health*.

McHugh, R.K., Wigderson, S., Greenfield, S.F. (2014). Epidemiology of substance use in reproductive-age women. *Obstetrics Gynecology Clinics of North America*, 41(2):177-89.

McNaughton D. (2011). From the womb to the tomb: Obesity and maternal responsibility. *Critical Public Health*, 21(2), 179–190.

Miles, M. B., Huberman, A. M., & Saldana, J. (2014). Qualitative data analysis: A methods sourcebook (3rd ed.). Los Angeles, CA: Sage.

Moher, D., Liberati, A., Tetzlaff, J., Altman, D. G., & PRISMA Group (2009). Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. *PLoS medicine*, *6*(7), e1000097.

McQueen, K.A., Murphy-Oikonen, J., Desaulniers, L. (2015). Maternal Substance Use and Neonatal Abstinence Syndrome: A Descriptive Study. *Maternal Child Health Journal*, 19(8):1756-65.

Mejak, V., & Kastelic, A. (2016). The experience of pregnancy, childbirth and motherhood of drug-using women. *Heroin Addiction and Related Clinical Problems*, 18(5), 33-42.

Miller, S. M. (1995). Case Studies: Profiles of Women Recovering from Drug Addiction. *Journal of Drug Education*, 25(2), 139-148.

Milligan, K., Niccols, A., Sword, W., Thabane, L., Henderson, J. and Smith, A. (2011). Birth outcomes for infants born to women participating in integrated substance abuse treatment programs: A meta-analytic review. *Addiction Research & Theory*, 19(6), 542-555.

Milligan, K., Niccol's, A., Sword, W., Thabane, L., Henderson, J., Smith, A. and Liu, J. (2010). Maternal substance use and integrated treatment programs for women with substance abuse issues and their children: a meta-analysis. *Substance Abuse Treatment, Prevention, and Policy*, 5(1).

Mitchell, K.M. (2017) 'Academic voice: On feminism, presence, and objectivity in writing', *Nursing Inquiry*, 24(4). doi:10.1111/nin.12200.

Moriarty, J. (2011). *Qualitative Methods Overview*. (SSCR Methods Reviews). National Institute for Health Research School for Social Care

Morris, K. (2012). Troubled families: vulnerable families' experiences of multiple service use. *Child & Family Social Work*, 18(2), pp.198-206.

Murtagh, M. J., & Hepworth, J. (2003). Menopause as a long-term risk to health: implications of general practitioner accounts of prevention for women's choice and decision-making. *Sociology of health & illness*, *25*(2), 185–207.

Myra, S. M., Ravndal, E., Torsteinsson, V. W., & Wiig, E. M. (2016) Pregnant substance-abusing women in involuntary treatment: Attachment experiences with the unborn child. *Nordic Studies on Alcohol and Drugs*, 33(3), 299-316.

National Institute for Health and Care Excellence. (2021) Antenatal care.United Kingdom: Royal College of Obstetricians and Gynaecologists; 2021. Available from: https://www.nice.org.uk/guidance/ng201/resources/antenatal-care-pdf-66143709695941 [Accessed on 25.10.21]

Ndimbii, J., Ayon, S., Abdulrahman, T., Mahinda, S., Jeneby, F., Armstrong, G., & Mburu, G. (2018). Access and utilisation of reproductive, maternal, neonatal and child health services among women who inject drugs in coastal Kenya: Findings from a qualitative study. *Sexual and Reproductive Healthcare*, 18, 48-55.

Neale, J., Allen, D. and Coombes, L. (2005). Qualitative research methods within the addictions. *Addiction*, 100(11), pp.1584-1593.

Neale, J., Nettleton, S. and Pickering, L. (2010) 'Recovery from problem drug use: What can we learn from the sociologist Erving Goffman?', *Drugs: Education, Prevention and Policy*, 18(1), pp. 3–9..

National Health Service (2020). Causes infertility. Available at https://www.nhs.uk/conditions/infertility/causes/#:~:text=Illegal%20drugs%2C%20such%20as%20marijuana,and%20make%20ovulation%20more%20difficult. [Accessed on 21/07/2020].]

NICE. (2010). Pregnancy and complex social factors: a model for service provision for pregnant women with complex social factors. Available at:

https://www.nice.org.uk/guidance/cg110/resources/pregnancy-and-complex-social-factors-a-model-for-service-provision-for-pregnant-women-with-complex-social-factors-pdf-35109382718149 . [Accessed on 28.02.23]

NIHR (2020) Improving inclusion of under-served groups in clinical research: Guidance from the NIHR-INCLUDE project. UK: NIHR. Available at: https://www.nihr.ac.uk/documents/improving-inclusion-of-under-served-groups-in-clinical-research-guidance-from-include-project/25435 [Accessed on: 10.10.23].

NIHR (2021). Briefing notes for researchers. UK: NIHR. Available at: https://www.nihr.ac.uk/documents/briefing-notes-for-researchers-public-involvement-in-nhs-health-and-social-care-research/27371 [Accessed on: 10.10.23].

Nordenfors, M., & Hojer, I. (2017). Mothers with substance and alcohol abuse support through pregnancy and early infancy. *Social Work in Health Care*, 56(5), 381-399.

North East ADCS. Northeast Submission to the Independent Review of Children's Social Care 2021. 2021. Available at: https://adcs.org.uk/assets/documentation/NorthEastSubmissiontotheIndependentReviewofChildrensSocialCare2.pdf [Accessed on 5.11.23].

Mann, S., & Stephenson, J. (2018). Reproductive Health and wellbeing- addressing the unmet need. British Medical Association. Available at: https://www.bma.org.uk/media/2114/bma-womens-reproductive-health-report-aug-2018.pdf . [Accessed on: 22.04.23].

Morse, J.M. (2000). Determining sample size. *Qualitative Health Research,* 10(1):3-5.

O'Connor, A., Harris, E., Hamilton, D., Fisher, C., & Sachmann, M. (2020). The experiences of pregnant women attending a specialist service and using methamphetamine. *Women and Birth*, 107.

Office for National Statistics. (2020). Drug use, alcohol and smoking. United Kingdom. Available at: https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/drugusealcoholandsmoking [Accessed 23/11/2020].

Oliva G, Rienks J, McDermid M. (1999)/ What high-risk women are telling us about access to primary and reproductive health care and HIV prevention services. *AIDS Education Prevention*, 1999, 11(6), pp513-24.

Olsen, A., Banwell, C., & Madden, A. (2014). Contraception, punishment and women who use drugs. *BMC Women's Health*, 14(1).

Oni, H.T., Buultjens, M., Blandthorn, J., Davis, D., Abdel-Latif, M., Islam, M.M. (2020).Barriers and facilitators in antenatal settings to screening and referral of pregnant women who use alcohol or other drugs: A qualitative study of midwives' experience. *Midwifery*, 81.

Ouzzani, M., Hammady, H., Fedorowicz, Z. and Elmagarmid, A. (2016). Rayyan—a web and mobile app for systematic reviews. *Systematic Reviews*, 5(1).

Ovens, M., & Prinsloo, J. (2018). Maternal attitudes towards pre-natal substance abuse, medical care, and treatment in a historically disadvantaged South African community. *Journal of Psychology in Africa*, 28(6), 498-503.

Padgett, D. K. (2017). Qualitative Methods in Social Work Research (2nd ed.). Thousand Oaks, CA: Sage.

Page, B. J., and Merrill, S. (2011). Comprehending Drug Use: Ethnographic Research at the Social Margins. *Contemporary Sociology*, 40(3), 370.

Paris, R., Herriott, A.L., Maru, M., Hacking, S.E., Sommer, A.R. (2020). Secrecy Versus Disclosure: Women with Substance Use Disorders Share Experiences in Help Seeking During Pregnancy. *Matern Child Health J*, 24(11):1396-1403.

Parker G., and Pausé C. (2019). Productive but not constructive: The work of shame in the affective governance of fat pregnancy. *Feminism & Psychology*, 29(2), 250–268.

Paterno, M. T., Low, M., Gubrium, A., & Sanger, K. (2019).Mothers and Mentors: Exploring Perinatal Addiction and Recovery Through Digital Storytelling. *Qualitative Health Research*, 29(4), 545-556.

Paulhus, D. L. (1984). Two-component models of socially desirable responding. *Journal of Personality and Social Psychology, 46*(3), 598–609.

Pearson, M., Moxham, T. and Ashton, K. (2011). Effectiveness of Search Strategies for Qualitative Research About Barriers and Facilitators of Program Delivery. *Evaluation & the Health Professions*, 34(3), pp.297-308.

Perry, A., Neilson, M., Martyn-St James, M., Glanville, J., Woodhouse, R. and Hewitt, C. (2015). Interventions for female drug-using offenders. *Cochrane Database of Systematic Reviews.*

Petchesky, R. (1984). Abortion and Women's Choice: The State, Sexuality and Reproductive Freedom. New York: Longman.

Phillips, R. (2004). Caring for children exposed to parental substance misuse. London: BAAF.

Phillips, D., Thomas, K., Cox, H., Ricciardelli, L., Ogle, J., Love, V. and Steele, A. (2007). Factors That Influence Women's Disclosures of Substance Use during Pregnancy: A Qualitative Study of Ten Midwives and Ten Pregnant *Women. Journal of Drug Issues*, 37(2), 357-375.

Pollitt, K. (1990). Fetal Rights, Women's Wrongs. In Reasonable Creatures: Essays on Women and Feminism. New York: Vintage Books, p. 169–86

Pollitt, K. (1998). “Fetal rights”: A New Assault on Feminism. In The Politics of Women’s Bodies: Sexuality, Appearance and Behavior. Edited by Weitz Rose and Kwan Samantha. New York: Oxford University Press, p. 278–87.

Priscilla, K., Coleman, D., Reardon, C., Strahan, T., Cougle, J.R. (2005). The psychology of abortion: A review and suggestions for future research. *Psychology & Health*, 20:2, 237-271.

Project Prevention. (2011). Project Prevention. Available at: http://www.projectprevention.org [Accessed 10/12/20]

Public Health England. (2019). Adult substance misuse treatment statistics 2018-2019: report. England. Available at: https://www.gov.uk/government/publications/substance-misuse-treatment-for-adults-statistics-2018-to-2019/adult-substance-misuse-treatment-statistics-2018-to-2019-report [Accessed 10/07/2020].

Public Health England. (2020). Misuse of illicit drugs and medicines: applying All Our Health. England. Available at: https://www.gov.uk/government/publications/misuse-of-illicit-drugs-and-medicines-applying-all-our-health/misuse-of-illicit-drugs-and-medicines-applying-all-our-health) [Accessed 10/07/20].

Public Health England.(2020). Adult substance misuse treatment statistics 2019 to 2020: report. London: Gov.uk; 2020. Available at: https://www.gov.uk/government/statistics/substance-misuse-treatment-for-adults-statistics-2019-to-2020/adult-substance-misuse-treatment-statistics-2019-to-2020-report [Accessed on 25/10/21].

Radcliffe, P. (2009). Drug use and motherhood: Strategies for managing identity. Drugs and Alcohol Today, 9(3), 17-21.

Radcliffe, P. (2011) ‘Motherhood, pregnancy, and the negotiation of identity: The moral career of drug treatment’, Social Science and Medicine, 72(6), pp. 984–991.

Ramazanoglu, C. & Holland, J. (2002). Feminist methodology: Challenges and choices. London, England: SAGE

Ramiro, F., Padovani, R., Fidalgo, T. and Tucci, A. (2018). Women Crack Users, Pregnancy and Motherhood: Potential Periods for Health Care. *Psicologia: Teoria e Pesquisa*, 34.

Rehm, J., Shield, K., Gmel, G., Rehm, M., Frick, U. (2013). Modeling the impact of alcohol dependence on mortality burden and the effect of available treatment interventions in the European Union. *European Neuropsychopharmacology*, 23(2):89-97.

Renbarger, K. M., Shieh, C., Moorman, M., Latham-Mintus, K., & Draucker. (2020). C. Health Care Encounters of Pregnant and Postpartum Women with Substance Use Disorders. *Western Journal of Nursing Research*, 42(8), 612-628.

Roberts, S. C. M., & Pies, C. (2011). Complex calculations: how drug use during pregnancy becomes a barrier to prenatal care. *Maternal and child health journal*, 15(3), 333-341.

Robinowitz, N., Muqueeth, S., Scheibler, J., Salisbury-Afshar, E. and Terplan, M. (2016). Family Planning in Substance Use Disorder Treatment Centers: Opportunities and Challenges. *Substance Use & Misuse*, 51(11), 1477-1483.

Rolova,G., Gavurova,B., Petruzelka, B. (2021). Health Literacy, Self-Perceived Health, and Substance Use Behavior among Young People with Alcohol and Substance Use Disorders. *Int. J. Environ. Res. Public Health*,18,4337.

Rose, G. (1983) Deciphering Sociological Research. London: Sage.

Rose, G. (1997). Situating knowledges: positionality, reflexivities and other tactics. *Progress in Human Geography*, 21(3), pp.305-320.

Rubin, H. J., & Rubin, I. S. (2005). Qualitative interviewing *(2nd ed.): The art of hearing data*. SAGE Publications, Inc.

Ruckenstein, M., & Granroth, J. (2020) Algorithms, advertising and the intimacy of surveillance, *Journal of Cultural Economy*, 13:1, 12-24.

Ruhl, L. (1999) Liberal governance and prenatal care: risk and regulation in pregnancy. *Economy and Society*, 28:1, 95 117.

Russell, L., Gajwani, R., Turner, F., & Minnis, H. (2022). Gender, Addiction, and Removal of Children Into Care. *Frontiers in psychiatry*, *13*, 887660.

Sadeghi, S. *et al.* (2021) 'Life experience of pregnancy among Iranian homeless women', *International Social Work*, 64(1), pp. 24–39..

Salmon, A. (2004). 'It takes a community': constructing aboriginal mothers and children with FAS/FAE as objects of moral panic in/through a FAS/FAE prevention policy. *Journal of the Association for Research on Mothering*, 6 (1), 112–123.

Salmon, A. (2011) Aboriginal mothering, FASD prevention and the contestations of neoliberal citizenship, *Critical Public Health*, 21:2, 165-178.

Salonen, D., McGovern, R., Sobo-Allen, L., Adams,E., Muir,C., Bourne, J., Herlihy, J., Tasker, F., Hunter, D., Kaner E. (2023) Being and becoming a father in the context of heavy drinking and other substance use—a qualitative evidence synthesis, *Drugs: Education, Prevention and Policy*.

Sandelowski, M. and Barroso, J. (2002). Finding the Findings in Qualitative Studies. *Journal of Nursing Scholarship*, 34(3), 213-219.

Seers K. (2015). Qualitative systematic reviews: their importance for our understanding of research relevant to pain. *British journal of pain*, *9*(1), 36–40.

Sharma, V., Sarna, A., Tun W., Saraswati, L. R., Thior, I., Madan, I., Luchters, S. (2017). Women and substance use: a qualitative study on sexual and reproductive health of women who use drugs in Delhi, India. *BMJ Open,* 7:e018530.

Sharpe, T. T. (2015). Sex-for-Crack-Cocaine Exchange, Poor Black Women, and Pregnancy. *Qualitative Health Research*, 11(5), 612-630.

Shaw, R., Booth, A., Sutton, A., Miller, T., Smith, J., Young, B., Jones, D. and Dixon-Woods, M. (2004). Finding qualitative research: an evaluation of search strategies. *BMC Medical Research Methodology*, 4(1).

Sherman, S. and Latkin, C. (2001). Intimate relationship characteristics associated with condom use among drug users and their sex partners: a multilevel analysis. *Drug and Alcohol Dependence,* 64(1), pp.97-104.

Shieh, C., & Kravitz, M. (2002). Maternal-fetal attachment in pregnant women who use illicit drugs. *Journal of obstetric, gynecologic, and neonatal nursing* : JOGNN / NAACOG, 31(2), 156-164.

Spencer L, Alderson H, Scott S, Kaner E, Ling J. (2023). 'The Addiction Was Making Things Harder for My Mental Health': A Qualitative Exploration of the Views of Adults and Adolescents Accessing a Substance Misuse Treatment Service. *International Journal of Environmental Research and Public Health*, 20(11), 5967.

Silva, S. A., Pires, A. P., Guerreiro, C., & Cardoso, A. (2013). Balancing motherhood and drug addiction: the transition to parenthood of addicted mothers. *Journal of health psychology*, 18(3), 359-367.

Smiles, C., McGovern, R., Kaner, E., Rankin, J. (2023) 'Drug and Alcohol Use in Pregnancy and Early Parenthood', in Perspectives on Midwifery and Parenthood. Springer International Publishing.

Söderström, K. (2012). Mental preparation during pregnancy in women with substance addiction: a qualitative interview-study. *Child and Family Social Work*, 17(4), 458-467.

Stengel, C. (2014). The risk of being 'too honest': drug use, stigma and pregnancy. *Health, Risk & Society,* 16(1), 36-50.

Stone, R. (2015) Pregnant women and substance use: fear, stigma, and barriers to care. *Health & Justice*, 3(1), 1-15.

Sun, A. (2004). Principles for Practice with Substance-Abusing Pregnant Women: A Framework Based on the Five Social Work Intervention Roles. *Social Work*, 49(3), 383-394.

Taplin S. (2017). Prenatal reporting to child protection: Characteristics and service responses in one Australian jurisdiction. *Child Abuse Negl*.,65:68-76.

Taplin, S. and Mattick, R.P. (2014). 'The nature and extent of child protection involvement among heroin-using mothers in treatment: High rates of reports, removals at birth and children in care'. *Drug and Alcohol Review*, 34(1), 31–37.

Taylor, L. *et al.* (2012). 'Clinical features and correlates of outcomes for high-risk, marginalized mothers and newborn infants engaged with a specialist perinatal and Family Drug Health Service', *Obstetrics and Gynecology International*,1–8.

Teijlingen, E. R. (2006). A qualitative study of an integrated maternity, drugs and social care service for drug-using women. *BMC pregnancy and childbirth*, 6, 19.

Terplan, M., Hand, D., Hutchinson, M., Salisbury-Afshar, E. and Heil, S. (2015). Contraceptive use and method choice among women with opioid and other substance use disorders: A systematic review. *Preventive Medicine*, 80, 23-31.

Terplan, M., Ramanadhan, S., Locke, A., Longinaker, N. and Lui, S. (2015). Psychosocial interventions for pregnant women in outpatient illicit drug treatment programs compared to other interventions. *Cochrane Database of Systematic Reviews*.

Thomas, J. and Harden, A. (2008). Methods for the thematic synthesis of qualitative research in systematic reviews. *BMC Medical Research Methodology*, 8(1).

Tolland, E., Kouimtsidis, C. and Reynolds, M. (2003). Substance Misuse among Women Attending Family Planning Clinics in a Rural Area in Britain: prevalence and associated problems. *Drugs: Education, Prevention and Policy*, 10(2), 195-202.

Tong, A., Flemming, K., McInnes, E., Oliver, S. and Craig, J. (2012). Enhancing transparency in reporting the synthesis of qualitative research: ENTREQ. *BMC Medical Research Methodology*, 12(1).

Torchalla, I., Linden, I. A., Strehlau, V., Neilson, E. K., & Krausz, M. (2014). "Like a lots happened with my whole childhood": Violence, trauma, and addiction in pregnant and postpartum women from Vancouver's Downtown Eastside. *Harm Reduction Journal,* 11(1), 34.

Trew, S. *et al.* (2022). 'Parents' experiences with child protection during pregnancy and post-birth', *Child and Family Social Work*, 28(2), 549–562.

Troya, M.I. *et al.* (2019). 'Patient and public involvement and engagement in a doctoral research project exploring self-harm in older adults'. *Health Expectations*, 22(4), 617–631.

Tyndall, M.W., Patrick, D., Spittal, P., Li, K., O'Shaughnessy, M.V., Schectn, M.T. (2002). Risky sexual behaviours among injection drug users with high HIV prevalence: implications for STD control. *Sexually Transmitted Infections*, 78 (1).

United Nations, Department of Economic and Social Affairs, Population Division. (2019). Contraceptive Use by Method: Data Booklet. 2019; (ST/ESA/SER.A/435).

United Nations Office on Drugs and Crime. (1971). Convention on psychotropic substances 1971. Available at : https://www.unodc.org./pdf/convention_1971_en.pdf .[Accessed on 23.04.2024]

Valentine, G., & Sporton, D. (2009). `How Other People See You, It's Like Nothing That's Inside': The Impact of Processes of Disidentification and Disavowal on Young People's Subjectivities. *Sociology*, *43*(4), 735-751

Van Scoyoc, A., Harrison, J. A., & Fisher, P. A. (2017). Beliefs and Behaviors of Pregnant Women with Addictions Awaiting Treatment Initiation. *Child and Adolescent Social Work Journal*, 34(1), 65-79.

Vanthuyne, A., Mundt-Leach, R., Boyd, A., Broughton, S. and Pittrof, R. (2016). Sexual and reproductive healthcare provided onsite in an inner-city community drug and alcohol service. *Journal of Family Planning and Reproductive Health Care*, 42(2), pp.152-154.

Varty, K., & Alwyn, T. (2011). Women's experiences of using heroin substitute medication in pregnancy. *British Journal of Midwifery*, 19(8), 507-514.

Ward, J. and Bailey, D. (2013). A participatory action research methodology in the management of self-harm in prison. *Journal of Mental Health*, 22(4), pp.306-316.

Warin M., Zivkovic T., Moore V., Davies M. (2012). Mothers as smoking guns: Fetal overnutrition and the reproduction of obesity. *Feminism & Psychology*, 23(3), 360–375.

Weber, L. (1998). A conceptual framework for understanding race, class, gender, and sexuality. *Psychology of Women Quarterly, 22*(1), 13–32

Weber, C. (2023). Rural Pregnant Women's Experiences with Substance Use Disorder: A Qualitative Study. *Dissertations*, 1167.

Weir, A. (1996) Sacrificial logics: Feminist theory and the critique of identity. New York: Routledge.

Wellings, K., Jones, K., Mercer, C., Tanton, C., Clifton, S., Datta, J., Copas, A., Erens, B., Gibson, L., Macdowall, W., Sonnenberg, P., Phelps, A. and Johnson, A. (2013). The prevalence of unplanned pregnancy and associated factors in Britain: findings from the third National Survey of Sexual Attitudes and Lifestyles (Natsal-3). *The Lancet*, 382(9907), pp.1807-1816.

Whittaker A, Williams N, Chandler A, Cunningham-Burley S, McGorm K, Mathews G. (2016). The burden of care: a focus group study of healthcare practitioners in Scotland talking about parental drug misuse. *Health & Social Care in the Community*, 24(5):e72-e80.

Whittaker, A., Martin, F., Olsen, A., & Wincup, E. (2020). Governing Parental Drug Use in the UK: What's Hidden in "Hidden Harm?". *Contemporary Drug Problems*, *47*(3), 170-187.

Wilson, C., Janes, G., & Williams, J. (2022). Identity, positionality and reflexivity: relevance and application to research paramedics. *British paramedic journal*, *7*(2), 43–49.

Wolf J. (2011). Is breast best? Taking on the breastfeeding experts and the new high stakes of motherhood. New York University Press.

Wolfe, D. (2007) 'Paradoxes in antiretroviral treatment for injecting drug users: Access, adherence and structural barriers in Asia and the former Soviet Union', *International Journal of Drug Policy*, 18(4), pp. 246–254.

Woollett, A., & Boyle, M. (2000). Reproduction, Women's Lives and Subjectivities. *Feminism & Psychology*, *10*(3), 307-311.

World Health Organisation, Department of Reproductive Health and Research. (2002). Defining sexual health. WHO: Geneva. Available at:

https://www.who.int/reproductivehealth/publications/sexual_health/defining_sh/en/ [Accessed 23/09/2020].

Wronksi, J.L., Pavelski, T., Guimaraes, A.N., Zanotelli, S., Schneider, J., Bonilha, A.(2016). USO DO *CRACK* NA GESTAÇÃO: VIVÊNCIAS DE MULHERES USUÁRIAS.Revista de Enfermagem UFPE On Line. Recife. Vol. 10, n.4 (abr. 2016), p. 1231-1239.

Yotebieng, K. A., Agot, K., Rota, G., Cohen, C. R., & Syvertsen, J. L. (2016). A Qualitative Study of Substance use during Pregnancy: Implications for Reproductive Healthcare in Western Kenya. *African journal of reproductive health*, 20(4), 51-59.

Young, I.M. (1984) 'Pregnant embodiment: Subjectivity and alienation', *Journal of Medicine and Philosophy*, 9(1), 45–62.

Yuill, C. *et al.* (2020) 'Women's experiences of decision-making and informed choice about pregnancy and birth care: A systematic review and meta-synthesis of qualitative research', *BMC Pregnancy and Childbirth*, 20(1).

Zolkefli, Z.H., Mumin, K.H. and Idris, D.R. (2020a) 'Autonomy and its impact on midwifery practice', *British Journal of Midwifery*, 28(2), 120–129.