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Navigating surveillance: The experience of prenatal women who use or who are in treatment for using drugs

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Abstract

There is little knowledge of how women who use and are in treatment for using drugs in the perinatal period experience multidisciplinary services prenatally. This study used qualitative longitudinal methods to explore women's experiences of care in four sites in England and Scotland. Thirty-six women who used and were in treatment for drug use (opioid, stimulants, and benzodiazepines) were recruited via maternity services. Framework analysis was used to manage the data and data were coded thematically. The profile of research participants included experiences of a range of cooccurring physical and mental health problems. Most women for whom this was not

their first maternity, had had previous children removed from their care. The findings focus on women's experiences of surveillance and uncertainty surrounding referrals to social services, social work assessments and possible removal of babies. Research participants reported managing the conceptual entanglement of treatment for opioid use with illicit drug use. Participants described being subject to multi-agency monitoring and there were few examples of trauma-informed care at the point of delivery. Findings have implications for how multi agency services engage with women who use drugs and call for approaches that are responsive to their needs and those of their babies.

Keywords: pregnancy; pre-birth assessment; qualitative; stigma; substance use.

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Introduction

Drug use in pregnancy is recognized as a multifaceted public health problem (Smiles et al., 2022) with implications for the long-term health and wellbeing of mothers and children (Forray 2016; National Institute for Health and Social Care Excellence 2018). A recent scoping review of UK good practice and clinical guidelines for women who use, and are in treatment for, drug use in the perinatal period (Gilmour et al., 2024) stated that the UK guidelines recommend 'an integrated model of care with a lead professional, clear referral pathways and information sharing between agencies' as does international guidance (Felker et al., 2024a). However, there is little known about how women who use and are in treatment for using drugs in the perinatal period experience multidisciplinary models of care.

A growing literature has highlighted the barriers to accessing services faced by women who use and are in treatment for drug use in the perinatal period. These are often related to feelings of shame and stigma related to drug use (Chandler et al., 2013; Tsuda-McCaie and Kotera 2022). Research has shown that fear of social service interventions, especially of child removal, is an important barrier to engaging with health and social care services (Alrouh et al., 2019; Hill, Gilligan, and Connelly 2020). The impact of infant and child removals on the mental health and wellbeing of women can be very harmful (Broadhurst and Mason 2020; Grant et al., 2023) with heightened risks of intentional and non-intentional deaths among women who have had babies removed from their care within 12 months of giving birth (Felker et al., 2024b).

This article thus addresses an urgent public health issue and is based upon a qualitative longitudinal research study funded by the National Institute of Health and Care Research (NIHR130619) that aimed to examine the experiences and care pathways for women who use and are in treatment for using drugs in the perinatal period in four sites in England

and Scotland. The study received ethical approval from the North of Scotland Research Ethics Service (22/NS/0047). The study was coproduced by an Expert Advisory and Coproduction Group that included maternity, substance use and health visitor practitioners, policy makers, academics and peer advisers. Peer advisers and researchers consulted women with lived experience of using drugs and maternity services, throughout the project on issues such as: the language used in participant information sheets, topic guides, approaches to recruitment, and responses to preliminary findings.

The article is concerned with the findings from Phase 2 of the study and draws on interview accounts from women in the four sites who describe navigating multidisciplinary services connected to drug use and treatment for drug use prenatally, a very under-researched area. First, we discuss the policy and practice background that informs professional involvement with the women concerned. We then provide further details of the overall study, its aims and methods and discuss our findings, highlighting key challenges and tensions for services and mothers.

Policy and practice context

Scottish and English statutory guidance for health and social care practitioners mandate that they work together and share information to safeguard children from a range of risks including parents' substance use. The most recent statutory guidance for multi-agency working to safeguard children in England reinforces a well-established consensus about the need to assess family circumstance presenting challenges for the child, such as drug and alcohol misuse, adult mental health issues, and domestic abuse (Department for Education 2023; Scottish Government 2023). In Scotland, the current guidance also references substance misuse as a risk factor for children and the importance of professionals working together.

Developing procedures, expert risk assessment protocols and multi-agency working have become central to protecting children (Featherstone et al., 2018). The prioritization of the protection of children has meant that maternity and substance use practitioners providing care to women have increasingly become enlisted in practices of risk assessment. Such developments have been the subject of critique not least because of the impacts on those in poverty and from marginalized backgrounds (see, e.g. Featherstone 2023). Notwithstanding these, a powerful consensus remains in place, prioritizing the protection of vulnerable children over supporting parents and families as a whole (Featherstone et al., 2018).

Biomedical developments in the late twentieth century parallel shifts seen in children's social care. Although in the UK, the foetus is not formally considered a person, prenatal imaging technologies and predictive biomedicine mean the foetus has become constituted as a vulnerable

patient (Lowe 2016) whose needs are considered separate from and sometimes in conflict with a mother (Lupton 2012) who uses or is in treatment for using drugs.

Key features of the current landscape can thus be summarized as follows; parents (usually mothers) are held accountable and responsible for their children's safety and well-being and multi-agency working is considered central to professional activities, with failures to share information or co-operate seen as key in harm to children.

The study

This longitudinal, qualitative study sought to investigate the care journeys and experiences of women who use and are in treatment for using drugs in the perinatal period and the impact of these experiences on engagement and outcomes for women and their infants. The sites included a London borough (site 1), a northern English city (site 2), a conurbation in west central Scotland (site 3), and a semi-rural part of southwest Scotland (site 4). Women who use and are in treatment for substance use often receive care from specialist midwives, the arrangements for which varied across the four sites in our study, with specialist substance use midwives providing direct care in three of the four sites while in the fourth site, 'safeguarding' midwives coordinated care for women in liaison with community midwives (see Table 1). Joint working relationships between maternity and substance use treatment services also differed in the four sites, varying between colocation of midwives in substance use treatment services, joint working, 'one stop shop' interventions, and information sharing/liaison. In each site regular multidisciplinary meetings were held with specialist midwives, social services and, in some sites, perinatal mental health clinicians, at which women's cases were discussed, and that, in some sites, were made up 'panels' of professionals who women also met. Sites differed as to whether referrals to children's social care services were made routinely or only where considered necessary and postnatal care pathways differed, so that in two of the three sites, residential mother and baby placements were available. Sites differed in the availability of 'transitional' beds for mothers whose babies were receiving inpatient treatment for neonatal abstinence syndrome (NAS) (the group of withdrawal symptoms that occur in babies who have been exposed to opioids, both illicit and prescribed) (Greater Glasgow and Clyde 2023).

Recruitment

It was aimed to recruit ten women from maternity services in each of the four research sites. Women were eligible to participate if they were

Table 1. Prenatal care pathways in four sites.

Site 1	Site 2	Site 3	Site 4
• Substance use midwife during pregnancy (care through hospital visits and outreach) • MDT meetings with perinatal mental health, substance use, and domestic violence orgs • Referred to Social service at 3 months (if necessary)	• Co-located substance use midwife and substance use case manager in substance use treatment service, specialist midwife provides prenatal service (clinic and outreach) • 26-week multiagency meeting led by specialist midwives, involvement of neonatal team and Health Visitor	• Specialist Midwives take case management role within hospital-based team. • Pre-birth SW Parenting Assessment conducted by Children & Families SW Team, 28 weeks pre-birth assessment • Residential rehab available	• Safeguarding midwife provides direct care (hospital and outreach) • Monthly Perinatal Multi-disciplinary addictions clinic: incl addictions, perinatal mental health team, social work and safeguarding midwifery team • Multi Agency Pre-birth Screening Group: Child protection decision made by 22 weeks • Residential rehab available • Maternity Care Assistant (visit between 25 and 28 weeks): assessment for baby equipment, clothes, etc. and one parent, antenatal education

pregnant or up to nine months postnatal, used or were in treatment for opioids (e.g. heroin, codeine, and tramadol), benzodiazepines, cocaine/crack, or amphetamines, over the age of 18 and able to communicate in English. Illicit drug use in the perinatal period raises issues concerning stigma and fear of child removals that arguably do not apply in the same way or to the same extent for alcohol or cannabis use. We thus excluded women from our study who only used alcohol, or cannabis as we were interested in women who are at the greatest risk of childcare proceedings and social services involvement (Weber et al., 2021).

Midwives in the participating maternity services gave women a leaflet that included a detailed depiction of the research process that had been designed in collaboration with peer advisers. The study leaflet also included a QR code link to the study website where women could watch a short video describing the study in more detail. If women were interested in hearing more about the research, midwives obtained permission to pass their contact details on to the research team. If the woman was hesitant about the researcher contacting them, they were given a business card that also included the QR code, and advised they could visit the website to find out more and contact the researchers directly. When women gave consent to be contacted, researchers called the potential participant to discuss further. Researchers' skills at building rapport with the research participants were crucial.

Interviews

Qualitative longitudinal research was employed allowing for a close examination of critical moments in the life course (Tuthill et al., 2020; Neale 2021). Interviews were conducted by four white female researchers with experience in qualitative research. The aim was to conduct up to five interviews with each woman. However, there were varying degrees of attrition across the sites with 36 first interviews conducted and 18 fifth interviews (see Table 2).

Since women were recruited at different points in their gestation, the interviews could not take place at fixed time points in the perinatal period but rather every 2–4 months where possible. To maximize retention,

Table 2. Interviews in four sites.

Sites	1st interview	2nd interview	3rd interview	4th interview	5th interview
1	10	9	8	8	7
2	8	6	6	6	5
3	8	7	5	2	2
4	10	8	7	5	4
Total	36	30	26	21	18

researchers kept in touch with participants between interviews. Participants were also provided with journals to record updates about health and social care appointments; however, many preferred to send text messages and voice notes to the researchers between interviews that were recorded in contact logs. Interviews lasted between 25 min and 2 h and were conducted in participants' homes and and/or in public places. Although most interviews were conducted in person, the researchers were also able to respond to participants' circumstances and wishes and 25/131 interviews took place over the phone or using Microsoft Teams. For one participant, all five interviews took place over the phone.

During initial interviews, participants were asked about their pregnancies, their experience of giving birth (if postnatal), and any services they had accessed, or were accessing, during the prenatal period. During follow-up interviews, participants were asked for any updates, and how they felt about the services they were receiving. Visual timelines were co-created with women to plot relevant events from their childhoods and lives hitherto, including substance use, previous pregnancies, contact and involvement with health and social care, and anything else the women wished to share. The timeline method facilitated narration of life histories and were not attempted in interviews that took place over the telephone, or if women did not want to revisit histories of trauma and abuse.

Analysis

Interviews were audio recorded and transcribed verbatim by professional transcription services.

Framework analysis was used to manage the qualitative longitudinal data (Neale et al., 2022). The whole research team (P.R., J.N., H.C., M.M., N.A., E.S., S.L., L.G., L.H., and B.F.) collaborated on the development of the analytic framework in two days of in person meetings. The framework was designed to divide data across timepoints (background, pregnancy, labour & birth, 0–12 weeks postnatal, 3–12 months postnatal, 12 months + postnatal) using excel spreadsheets to reflect up to five interviews per participant. Seven spreadsheets were created within excel to plot data for (1) demographic information, (2) background (from the first interview), interview, (3) Pregnancy, (4) Labour/Birth, and (5), (6), and (7), three postnatal stages. Each column (in each spreadsheet) was titled with a key topic included in the semi-structured interview schedule. Each row reflected the response of an individual participant throughout the seven worksheets and researchers used quotes and summarized responses related to the topics in each column. The columns of data were then imported into Word documents for interpretation and coding of the data, and iterative generation of themes across the cohort. Codes and themes were developed in discussion

with the research team, deductively from the interview topic guides and inductively by comparing responses within categorical columns as well as across the participant's longitudinal journey. The research team tested out the framework on transcripts during in-person meeting. Subsequently, the researchers (E.S., S.L., L.G., and L.H.) and P.R. independently coded two transcripts and discussed codes in online meetings. In addition, M.U.G. and P.R. created case study flow charts for each participant, that plotted their care journeys, and which were populated with quotes. These were then checked and amended by the researchers (E.S., S.L., L.G., and L.H.) who had conducted the interviews. This approach to analysis ensured that each participant's views and experiences maintained a connection to other aspects of their journey across the framework, maintaining the context of their story (Gale et al., 2013).

Findings

Sample description

Thirty-six women were recruited across the four sites, and 131 interviews were conducted overall. In our presentation of quotations from the qualitative interviews, we refer to the number of the site (01–04), followed by the anonymous identifier for the participant (P1, etc.).

Participants were aged between 23 and 46 years, with a mean age of 34 years. Most participants ($n = 30$) were white British and most ($n = 34$) described themselves as being in, or having been in, a heterosexual relationship. At recruitment, 23 women (64 percent) were between 12 and 36 weeks pregnant while 13 women (36 percent) were between one week and 9 months post-natal. All women in the sample were receiving treatment for drug use at the point at which they were recruited to the study. Most of the sample ($n = 32$) were receiving Opioid Replacement Treatment (ORT) including twenty-seven women who were receiving treatment for heroin use, and five women who had developed dependent use of codeine in over the counter and prescription medication. All drug use was not always disclosed to the researchers, but it was clear that many of the women receiving ORT, also used or had a history of using crack cocaine, cannabis, benzodiazepines, and alcohol. A small number of women ($n = 4$) were receiving treatment for stimulant use (cocaine, crack cocaine, or amphetamine) alone. Participants often also combined illicit/or illicitly acquired drug use with prescribed psychopharmacological medication:

> I've always been on benzos and pregabalin, diazepam and pregabalin, or clonazepam and pregabalin, but I came off my benzos when I was pregnant with him. (01-P5)

While two thirds of the study participants reported receiving sickness and out-of-work benefits, 12 participants (33 percent) reported current and past employment or education, sometimes in a series of jobs. Some women reported having always worked despite using drugs, others said that their drug use had resulted in them losing their jobs: 'when I got a habit, it all crashed down, I couldn't hold down a job' (04_P5), and others explained how they 'fell into bad habits' (01-P7) after losing their jobs.

Co-occurring adversities

Twenty-nine (80 percent) of the women who took part in the study reported having experienced mental health problems including depression and anxiety, in addition to diagnoses of bipolar and personality disorders. Twelve women (33 percent) reported previous suicide attempts, and eleven women described having survived drug overdoses. In additional to mental health problems, fifteen (42 percent) described experiencing a range of long-standing physical health conditions. Some women described managing conditions linked to injecting drug use including hepatitis C and HIV and lymphedema.

Eleven women (31 percent) reported having experienced childhood abuse and seven women reported experiences of the care system as children. Twenty-three women (64 percent) reported having experienced acts of physical and sexual abuse in their intimate relationships as adults. Of the thirty-six women who took part in the study, for twenty-six this was not their first maternity and of these, twenty-one (80 percent) had had children previously removed from their care (including into kinship care, local authority care, and to adoption). As will be discussed, many women for whom this was not their first maternity had well-founded fears of child removal.

While some women had engaged with drug treatment services some years before ($n = 21$) or early in this pregnancy ($n = 6$), presenting to maternity services for booking appointments at or around ten weeks gestation; others did not engage with substance use treatment or health services until near or after the births of their babies ($n = 9$).

Judgement and support

Participants often anticipated a negative and judgmental response from health professionals, sometimes borne of previous experiences. For example, 03-P7, described being made to feel judged and 'let down' in a previous attempt to seek help from her GP for her drug use, an act that she said required considerable courage on her part:

> I went to the doctors at the time, and she was so judgemental, it was awful, she really put me off. I thought I was being brave by going to the doctor and saying I've got a problem, like, admitting it. and the way she made me feel, I was like, I could've walked away and never went back and never referred myself. So I think I was … not failed in a sense but I felt let down. [03-P7]

Anticipating judgement, women often reported feeling pleasantly surprised, however, by the support and empathy they had received from specialist midwives:

> As soon as they passed me to [name of specialist midwife], I know I'm going to be okay . [she was] empathetic to my situation. no judgement [01-P1]

They reported appreciating receiving 'normal' midwifery care, for example describing the reassurance of the normalizing rituals of the midwife's stethoscope, sounding the baby's heartbeat, and the generation of ultrasound images:

> I'm always pleased to go, when you hear the wean's [little one's] heartbeat, and your scan, that's always a good day 03-P15

Women described being grateful for the provision of clear information from specialist midwives about the impact of drug use and ORT medication on the foetus and new-born; and the benefits of breast feeding for babies who may be experiencing NAS (the collection of symptoms linked to withdrawal from opioid medication).

> The midwife was the person to explain interactions with methadone and the baby, if it would harm the baby, when is safe to reduce, that some bairns [babies] do and some don't … it was good to kinda learn 03-P5

> She [specialist midwife] encouraged (breastfeeding) … you know, like, didn't push it, but she said it was better for her, because of the medication, and it'd be a bit easier for her, if she did have any symptoms 02-P7

Not all women felt supported however, with some feeling judged and criticized by midwives who were 'too busy trying to pick out fault' [04-P5]. While specialist midwives were reported to be well-informed about the impact of drug use and ORT in pregnancy, this was not always the case with other health care professionals whom women encountered prenatally. For example, participant 02 in site 1 described the tacit links that she felt a sonographer had made between her ORT medication, and a drug user identity. Such professional responses could be experienced as 'microaggressions' and had the potential to rock women's confidence and to injure their sense of purpose as would-be mothers.:

> Just seeing the medication you're on, not that you've been stable on it and you're not using or anything like that, they just see that and it's like automatically they [professionals] look at you or treat you in a different way. 01-P2

Navigating ORT medication and its impact on the baby

In this section, we describe women's accounts of navigating stigma associated with ORT medication. The conceptual entanglement of ORT with heroin use, not only had the potential to stigmatize women who were receiving ORT during pregnancy; the impact of this medication on their babies was also a source of concern. For many women, the possibility of giving birth to a baby who may experience NAS was at odds with their desire to do the very best for their unborn child. Many expressed feelings of guilt for potentially harming their foetus, and embarrassment at being seen as the kind of mother who would cause her baby harm. For this reason, many women expressed a desire to 'be off' their medication:

> I want to be completely off them [ORT medication], as soon as possible. [02-P7]

> I find I'm, like, I've got a lot of guilt… because I'm like God, for all that time that I've been using and I've not felt her moving, there's obviously certain times I did feel but she's very, very active… and I do sometimes, like, 'God what have I done to this baby when I have been pregnant' (04-P4)

03-P7 who had 'always wanted to be a mum' revealed that not only she, but also her partner, had been worried about the impact ORT medication might have on their baby:

> [Partner] was really quite nervous about that [effects of medication on baby], and he was constantly—like he doesn't really say much on appointments. But that was his main focus. What is going to be wrong with her? Like how's she going to—like is she going to suffer? Like he was quite concerned about that. [03-P7]

For some women, medical advice that detoxing from ORT in pregnancy represented a risk of miscarriage meant they felt in a catch twenty-two situation. Women thus described feeling that they had little choice but to follow medical advice to continue ORT, sometimes increasing dosage as their pregnancies progressed. For some women adhering to this advice demonstrated their commitment to motherhood:

> I couldn't stop because I was told I'd probably miscarry. It's Catch-22 really. So yeah, like some people really don't care. But I suppose I showed my commitment. I showed how much I loved him, and they were very supportive after that. [01-P6]

> See if I could come off my tablets and not harm the baby I would've, like, I would've just told them to ram it. But obviously it's going to be more risk so I'm stuck. [04-P7]

Other women felt that professional advice against detoxing from ORT during pregnancy undermined their right to choose the best course for

their baby. Some reported that they had ignored medical advice not to detox, leaning towards discourses in which the expertise of the mother is preferred over that of health care professionals:

> I feel like as a pregnant woman you should be able to say 'listen, I don't want to take this now. [03-P6]

> They told me at first actually not to reduce 'cos it brings on miscarriage you know. I was to stop reducing for the first trimester and going into my second they've kind of still been a wee bit iffy about it but because of how determined I was they've had to do it anyway cause obviously it's my decision. … As I say, just the more determined I was, they didn't really have a choice [laugh] didn't really have a choice at all, so they just went that way. [04-02]

Pregnancy for these women embodied a paradox in which medication that was prescribed both as an alternative to illicit drug use, and to prevent their own withdrawal symptoms, risked inflicting harm in the form of withdrawal symptoms to their new babies.

Experiences of multi-agency surveillance

Whether or not they had presented 'early' and had engaged in maternity care and substance use treatment before or early in their pregnancies or not, women often described a focus in midwifery appointments on the collection of evidence (often in the form of urine tests) to ascertain whether they had used illicit drugs:

> [When asked if she could provide a urine test]" I told her I'd just already been, and she was like 'well I'll come in and supervise you and I'll squeeze one out of you'. She intimidated me." [03_P1]

> I do get a bit annoyed with [specialist midwife] every time I go in there and she's like, "Oh, are you going to be clean … I'm not some raving cokehead. [01_P2]

Although formal social work assessments were rarely initiated until the last third of pregnancy, social work scrutiny was often perceived as a threatening, covert aspect of midwifery appointments with a sense that information was being collected for assessment and evaluation of a woman's motivation and engagement. Anticipating professional scepticism about their record of negative urine tests, some women requested more frequent urine testing as proof for social services that they were not using illicit drugs:

> I asked her for weekly testing, because I was worried social services were going to turn round and say, 'Ah, but she's only been tested once a month, or once every three months. [02_P6]

Although many women expressed the need for mental health support prenatally, enquiries in midwifery appointments about their mental health could feel intrusive rather than oriented towards support. Indeed, for many women, it was considered that such practices of surveillance and scrutiny led to poor mental health:

> Like, it's the way the … like, my midwife does it as well, there's no like 'oh how are you?' or whatever, it's straight like 'how's your mental health?' it is honestly it's 'how's your mental health?' I find that very— because my mental health was fine till I fell pregnant, I planned this we'an [little one], my drugs and all that was done and by with everything, and I just felt that it's quite condescending, it's quite offensive at all 'how's your mental health?', like, ask me how my day is. [04-P10]

Multi-agency assessment could also be experienced as exhausting: 'it's always having to meet new people and say the same things' [03_P5]. 'Panel meetings' where women were confronted with a room full of health and social care professionals were described as 'overwhelming':

> It's kinda overwhelming to be honest. I don't really like going and, like, they're judging me. [03-P7]

> I mean, if I had any issues, I would have to talk about it in front of four people which I don't feel comfy doing, so most of the time when they ask how I am I just say I'm fine, whether I am or not. [04-P3]

Women's strategies for engaging with services

Many women reported not having planned pregnancies and, for some, finding they were pregnant was the impetus for accessing substance use treatment. A participant whose three older children had been placed in kinship care, reported in an interview that took place after she had given birth, that she had sought to engage in substance use treatment (for heroin and crack use) as soon as she had learned of her pregnancy. She described an active process of countering any perception that she might have something to hide, by always responding to professionals' phone calls, always answering the door and always telling them about any 'slip-ups' with her drug use:

> Researcher: what kind of involvement did you have with [children's services] throughout the pregnancy?

> IV: Just engaging with them with appointments and never cancelling any appointments. If they rang and there was a missed call, I'd always ring them back and it was just keeping that contact with them because I think as soon as you start ignoring doors and things like that, you've got something to hide. My drug of choice at the time that I was struggling

> with was crack cocaine and if I had a slip up, I'd always tell them because I thought the truth always comes out in the end anyway. [02-P1]

Despite her positive strategy for managing professional involvement, she had not known whether she would be given care of her baby until late into her pregnancy:

> About ten days before I was getting induced … it was a bit nerve-wracking because I was thinking, 'I'm nearly at the end of it. Is he going to be coming home or are they going to take him? [02-P1]

This participant's belief in the importance of transparency with professionals was not shared by all, with some arguing that being open about lapses in drug use in pregnancy would likely lead to removal of children:

> And I bet if you ask everyone that's ever been involved with social services, everyone will tell you the same thing. Every drug user will tell you, 'I don't tell them that I've messed up, because they're going to take my baby. [02-P6]

Women who had presented 'late' to services, that is beyond the ten weeks gestation that is considered optimum for maternity care booking appointments, often reported feeling that they were the objects of suspicion and mistrust. One described having missed midwives' calls and at least one appointment. At her first midwife appointment, at five month's gestation, she reported that her attempts at honesty were met with the response that social services would be 'concerned', a response that she said caused her to relapse:

> I told her I had drugs and alcohol in my history. She wrote it down, then she goes, 'You know the social services are going to be concerned about your pregnancy.' I was like, 'Really? I've already detoxed.' That made me relapse. [01-P7]

However, honest 01-P7 had attempted to be about her history, presenting late to maternity services seemed to signal an attempt to deceive professionals about her drug use. Participants' reported attempts to manage disclosures of substance use/treatment also seemed to provide grounds for suspicion and for social services referral prenatally. For example, one woman who had had previous children removed, reported that fear of social services involvement had led her to neither tell substance use treatment services that she was pregnant nor tell her community midwife that she was receiving treatment for heroin use:

> I didn't tell anyone [at drug service] I was pregnant, because I was scared. My midwife at [community clinic] I was going to my appointments, and everything was fine, but I just didn't tell them that I was on methadone … and, because I didn't tell her, she phoned me up one Monday morning, and she was like, 'I've seen you've got heroin in your system, I'm phoning the social services'. [02-P2]

This woman had a sense of the provisional status of her motherhood, commenting that 'it just feels like I'm surrogate' [02_P2] emphasizing her sense of being perceived as a separate being from that of her baby. Participant 2's (Site 2) anticipation of the removal of her baby into the care system highlighted the limited opportunities open to her to demonstrate her fitness as a mother. Although she had expressed a desire for a referral to a residential rehabilitation treatment service, this did not appear to have been an option. Other women in this site and elsewhere who had presented late to services also expressed frustration that they were being denied the opportunity to stabilize or detox from substances in residential rehabilitation treatment postnatally:

> I'll move. I'll do anything. I'll go into rehab. I just want a chance with my child.' [02-P5]

> We've been asking for them to put us into a rehab ever since [baby] was born to get us off the methadone so we could be fully stable parents and they're saying that we ain't ready for that yet [03-P1].

We are not party to the range of evidence on which decisions made by social workers and in childcare courts were based. It was notable, however, that postnatal referral pathways and options for treatment for women who presented late to services differed in the four sites. The outcomes for women with the most complex needs, and that of their infants, were thus dependent on the opportunities for treatment that were made available to them.

Discussion and conclusions

Policy and guidelines recommend that women who are identified as using illicit substances are automatically referred both for specialist midwifery care and for child protection assessment (Gilmour et al., 2024). Although it is also recognized in policy that drug use does not necessarily infer inability to provide 'good enough' parenting (Scottish Government 2013; Public Health England 2021), within most mainstream and universal services this caveat is poorly understood. The use of illicit drugs (such as opioids) tend to be associated with greater child protection involvement than licit substances for a range of reasons, including their status in law, the higher risk of harm to the mother and child, and societal norms and attitudes (Weber et al., 2021).

Our sample describes a group of women who have experienced a range of co-occurring and interrelated physical and mental health problems, intimate partner violence and histories of child abuse. Women frequently reported feelings of guilt and shame concerning their drug use, anxiety concerning the impacts of drug use and treatment on their babies and uncertainty concerning social care decisions about whether they

would retain care of their babies. They described valuing non-judgemental support and appreciated receiving clear information from specialist midwives regarding the impact of their medication and/or drug use on their foetus and baby. This is consistent with other research that has shown that non-judgemental support and clear information is valued by people who use drugs when accessing health and social care services, including within inpatient treatment settings (Neale et al., 2024).

ORT presented a 'Catch 22' scenario for women in pregnancy, where those who had adhered to treatment advice faced the prospect of giving birth to babies who might experience withdrawal symptoms, while detoxification from ORT in pregnancy risked miscarriage—and relapse to illicit drug use. These findings reflect those of the pregnant women receiving ORT who were interviewed by Chandler et al. (2013). Women in Ostrach and Leiner's study (Ostrach and Leiner 2019) also reported the desire to cease ORT as soon as possible after they had given birth. Some women in our study, however, maintained their right to choose to detox from ORT emphasizing their own expertise as mothers in the face of medical advice (Baker and Walsh 2023).

Although engaging with treatment prior to and early in their pregnancies was a way that women could demonstrate motivation, responsibility, and readiness to be mothers (Chandler et al., 2013), the impact of treatment on their babies and the close association of treatment with drug use itself risked undermining and jeopardizing efforts to separate themselves from the stigmatizing figure of the drug using mother. While women found ways, narratively, to present that adhering to treatment and choosing to detox demonstrated their responsibility for their baby's health and their commitment to motherhood, professionals did not always endorse such narrative presentations. As we have described, whether or not specialist midwives were supportive and encouraging of engagement, it was the assessment practices led by social work practitioners that determined outcomes.

It has become a cliché to suggest that pregnancy for women who use and are in treatment for drug use is a 'window of opportunity' for engagement with drug treatment services and support (Frazer, McConnell, and Jansson 2019; Rutman et al., 2020). While for some participants in our study, pregnancy had indeed been the impetus for engaging with substance use and maternity services, fears of social services involvement and previous experiences of child removals had led them to present late to services or to attempt to conceal their substance use, reinforcing findings from other studies (Frazer, McConnell, and Jansson 2019; Ostrach and Leiner 2019) regarding barriers to engagement. While anxieties surrounding social work assessments and the possible removal of babies from their care, were found across the sample, such anxieties were particularly apparent among women who had previously experienced the traumatic removal of children from their care. Some women described

strategies of engaging with substance use treatment and antenatal care such as second guessing any accusations of efforts to conceal substance use and always making themselves available to professional scrutiny. Attempts by other women to negotiate surveillance by avoiding professional contact, and managing disclosures both of pregnancy and of drug use frequently served to increase distrust by professionals. As Broadhurst and Mason (2020) have argued, recurrent removal of children for marginalized women can result in 'cumulative and enduring collateral consequences' (p. 19). For women with a history of substance use, we know that removal of infants increases risk of relapse, overdose and suicide (Felker et al., 2024b). Our findings illustrate that multi-agency, child protection led, assessment and surveillance can retraumatize already anxious women prenatally and are experienced as intrusive and overwhelming. Optimal models of care (Cheyne et al., 2025) emphasize the development of non-stigmatizing approaches to care prenatally that acknowledge experiences of trauma, that counter adversity and facilitate access to treatment and services.

A limitation of the study is that midwives as gate keepers in some sites may not have referred women with more complex needs to researchers because they did not want to jeopardize their engagement with maternity care more generally. However, our sample does include women who had continued to use drugs and presented late to services in pregnancy. Although this article has focused on the women's experience prenatally, the longitudinal character of the data has enabled insight into the arc of women's experiences through their perinatal journey. A further strength of our study is that while other studies have focused on the experience of women who use and are in treatment for substance use attending services in one site, our data across four sites has enabled comparative exploration of care pathways in four sites.

The implications of the child protection-dominated approach to multi agency care have difficult, if not actively counter-productive, implications for this group of mothers. The tensions here are not unique to the area of drug use by mothers. Researchers exploring how domestic abuse is dealt with within the child protection sector reinforce the findings here about mothers' fears and feelings of distrust (Featherstone, Gupta, and Morris 2025).They also question whether the emphasis on multi-agency working works to reinforce professionally led understandings of safety and risk at the expense of engaging those impacted and learning from their experiences (Featherstone, Gupta, and Morris 2025).This research concerns a highly vulnerable and stigmatized group of women whose voices are often absent from policy and practice discussions about the safeguarding issues for their children. By attending in a rigorous and sensitive way to their fears and hopes and highlighting the structural challenges that they face, the research contains important pointers for

practices that do not further reinforce their marginalization and promote humane and socially just approaches.

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