



Synopsis

Models of perinatal care for women using drugs and their infants: synopsis of The Stepping Stones Study

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Abstract

Background: Women who use drugs during the perinatal period often have complex health and social care needs. Their infants can experience developmental and health problems. Despite United Kingdom's guidelines and policies on the care of pregnant women and mothers who use drugs, there is little evidence of the services that are available in the United Kingdom and whether they meet the needs of women and their infants.

This study sought evidence of (1) best practice models for care that have the potential to interrupt the transmission of adversity across generations and (2) the views and experiences of women and staff on different models of care and how services could be improved. The study involved systematic reviews, longitudinal qualitative research and coproduction. There were three phases.

In phase 1, an Expert Advisory and CoProduction Group was established to guide the research and to develop a theory of change for improved service models. The group comprised multidisciplinary stakeholders from health and social care and peer advisers.

Two reviews were undertaken:

1. A scoping review of UK guidance for perinatal care for women who use drugs included 111 documents, recommending integrated multidisciplinary working.
2. A mixed-methods systematic review of evidence of integrated models of perinatal care for women who use drugs and their babies reviewed 197 studies. Qualitative findings suggest that women appreciate collocated services that are easy to access. Quantitative findings found evidence that integrated programmes at the point of delivery decrease substance use during the perinatal period.

Phase 2 involved a qualitative longitudinal study in four sites, two in England and two in Scotland, that aimed to explore perinatal care pathways. Up to five interviews were conducted with 36 women, from early pregnancy up to 18 months post natal (131 interviews). Many women experienced stigma and were anxious about social services' involvement. Access to residential treatment and mental health support was uneven. Support for women who had lost care of their babies was poor.

Focus group interviews (79 staff) and individual interviews (21 staff) were conducted with health and social care practitioners. Staff reported that high caseloads, staff turnover and training gaps contributed to difficulties in providing care to this challenging group.

In phase 3, the Expert Advisory and CoProduction Group worked with the research team to develop a theory of change for recommendations for an optimised service model. The theory of change identified eight key recommendations and emphasised that a whole-system approach is required to meet the complex needs of this population.

Limitations: For the quantitative findings of the mixed-methods systematic review, the diversity of study types made it difficult to draw firm conclusions on the effectiveness of different approaches. Not all women recruited to the qualitative longitudinal study took part in all the anticipated interviews.

Future research: There is a need for high-quality research studies into effective interventions for pregnant women who use drugs. Implementation research is required to test and implement the theory of change for optimum services for women who use drugs in the perinatal period.

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Background

There is a growing recognition of the impact on children of parental drug use,^{1,2} with studies emphasising the enduring problems for children, beginning in utero with delays in physical, cognitive and socioemotional development.^{3,4} As a result of the increased risk of serious harms and poor outcomes, a high proportion of children of mothers who use substances become the subject of child protection procedures.^{5,6} The 'inverse care law', described nearly 50 years ago by Tudor Hart,⁷ occurs when 'the availability of good medical care tends to vary inversely with the need for it in the population served'. This circumstance particularly applies to pregnant women and mothers who use and are in treatment for using drugs because their complex health and social needs are related to histories of abuse, mental health problems, poor physical health, drug-related violence and crime, social exclusion, homelessness and poverty.⁸ These mothers and their infants are at risk of falling through the gaps during maternity care that is more focused on healthy pregnant women and women with physical or mental health problems. While women who use drugs and are in treatment for using drugs require normal maternity care, they also often have physical or/and mental health problems and do not 'fit' into standard care pathways. Substance use in pregnancy is thus a multifaceted public health problem, with many confounding factors and implications for the long-term health and wellbeing of both mothers and children.^{9,10} This study addressed an urgent gap in knowledge regarding the kinds of multidisciplinary support and care that can provide good outcomes for this group of women and their children in the first 18 months of life.

Rationale

There is little evidence of the lived experiences of women receiving multidisciplinary and integrated

treatment services in the UK and whether their needs and their infants' needs are met. We do not yet know if current services are acceptable to women and if they lead to better or worse outcomes for families. Existing recommendations for woman-focused care, co-ordinated multidisciplinary family support plans and integrated care pathways have been inconsistently implemented across the UK. Despite a proliferation of UK and international good practice guidance on managing drug dependence around childbirth,¹¹⁻¹⁶ there is little robust UK evidence about which models of care deliver the best outcomes for women and their children, and virtually there is no evidence that women who are dependent on drugs themselves have been involved in efforts to improve or redesign services.¹¹

Evidence of a rise of repeat removals of infants in England and Wales^{17,18} and in kinship care arrangements in Scotland,¹⁹ including from mothers who use and are in treatment for using drugs and who experience other complex needs, suggests that there is an urgent need to identify how services can work across disciplinary boundaries to consistently support this marginalised group of mothers to care for their children. UK evidence was thus required of (1) the best practice models for co-ordinated and integrated/multidisciplinary care that have the potential to interrupt the transmission of adversity across generations and (2) women's views and experiences of different models of care and how services could be improved.

Aim

The study aimed to investigate the range of care models and pathways for women who use and are in treatment for using drugs in the perinatal period and to understand how

health and social care services can best meet the needs of this group of women and of their babies.

Research questions

1. What are key candidate models of multidisciplinary care for women who use and are in treatment for using drugs from preconception through to 18 months post natal? (phase 1)
 2. What is best practice across health and social care for optimising outcomes and reducing inequalities for these women around childbirth? (phase 1)
 3. How do women who use drugs and who are in treatment for using drugs experience services and their care journey and how do these experiences impact on the engagement and outcomes for women and their infants? (phase 2)
 4. What is the optimal service model for women who use and are in treatment for using drugs (from preconception up to 18 months post natal) to foster good parenting and to provide a safe, stable and nurturing caregiving environment for the mother, infant and family as a whole? (phase 3)
 5. What is the optimal best practice guidance for the care of mothers who use and are in treatment for using drugs and their infants to maximise engagement with services, maternal and infant outcomes and to prevent out-of-home care placements? (phase 3)
2. Review the international evidence on models of care and care pathways for women who are dependent on drugs and their infants, from preconception through to 18 months post natal, and clinical and good practice guidance on the treatment and care of mothers who are dependent on drugs and their infants.
 3. Critically evaluate women's experiences of health and social care, their care journeys and outcomes for the family, from confirmation of pregnancy to 18 months post natal.
 4. Coproduce an optimal service model for women who are dependent on drugs, child and family-centred care and insights for future care and practice guidance to optimise outcomes for mothers, infants and the family.

Methods and results

The Stepping Stones Study consisted of three phases, as shown in [Figure 1](#). These included: the establishment of an EACPG, a scoping review of UK clinical and best practice guidelines and a mixed-methods systematic review of interventions for women who use and are in treatment for using drugs in the perinatal period (phase 1); a qualitative longitudinal study examining contrasting service delivery models in four sites (two in England and two in Scotland) (phase 2); and development of a coproduced theory of change (ToC) for an optimised service model and key recommendations for practice (phase 3).

Objectives

1. Establish an Expert Advisory and CoProduction Group (EACPG) to guide the conduct of the study and to coproduce the research outputs.

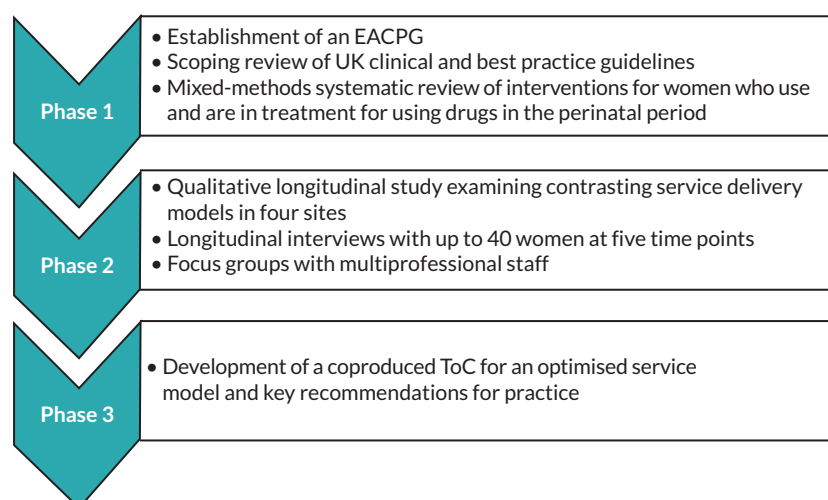


FIGURE 1 Study phases.

Phase 1, part 1: establishment of an Expert Advisory and CoProduction Group

An EACPG was established at the start of the Stepping Stones Study with a dual role: to guide the conduct of the study and to coproduce the ToC. We aimed to make the group as representative as possible, including a broad range of stakeholders from Scotland and England, including health and social care practitioners (midwives, public health practitioners, health visitors and social workers), service commissioners and policy-makers, staff of third-sector organisations that support women affected by substance use and experts by experience/peer advisers. Two peer advisers with lived experience of substance use treatment worked with the study team throughout the project, attending EACPG meetings and supporting the researchers to consult women with lived experience of substance use. Overall, the group comprised 25 members and 10 members of the Stepping Stones research team. Terms of reference, setting out the process and purpose of the group were agreed in the first meeting and reviewed at intervals through the project.

We used the term coproduction to describe our approach of working with a wide range of stakeholders, academics, health and social care professionals and third-sector staff and peer advisers to contribute to and shape the Stepping Stones Study and to interpret research findings and support dissemination. Our approach was adapted from the Coproduction Star (www.coproductionscotland.org.uk/resources/the-co-production-star/) that comprises a set of principles: sharing power, including a wide range of perspectives and skills, valuing and including all sources of knowledge, reciprocity and relationships. Embedded in the wider coproduction work was the focused task of developing the ToC²⁰ that outlines the hypothetical causal pathway for care in the perinatal period for women who use or are in treatment for use of drugs, with the aim of identifying processes and aspects of care that are effective, important to women and relevant and useable for staff.

Phase 1, part 2: scoping review and mixed-methods systematic review of interventions for women who use and are in treatment for using drugs in the perinatal period

Scoping review

This review aimed to map clinical guidelines, treatment protocols and good practice guidance across the UK for women who use drugs during the perinatal period. We wanted to identify the recommended best practice across health and social care for optimising outcomes and reducing inequalities for these women as well as identify potential gaps within guidance.

The Joanna Briggs Institute (JBI) guidance on scoping reviews²¹ and Preferred Reporting Items for Systematic Reviews and Meta-Analyses - Scoping reviews (PRISMA-Scr) extension²² were used, following a registered protocol,²³ with a clear search strategy, and inclusion and exclusion criteria (the open access paper, including the search strategy, can be found at: <https://bmcpregnancychildbirth.biomedcentral.com/articles/10.1186/s12884-023-06172-6>). Searches were iterative and mainly in grey literature, taking place between November 2021 and March 2022. Reviewers double-screened 25% of search results, discussing disagreements. Data were extracted using a predefined template and charted in tables. Recommendations for best practice were organised around agreed categories, and reported in a table, with narrative synthesis.

Mixed-method systematic review

Following a predetermined protocol²³ and the JBI guidance for mixed-method systematic review,²⁴ a segregated approach was adopted. Eight databases were searched: MEDLINE, Global Health, PsycInfo® (American Psychological Association, Washington, DC, USA), Web of Science, Cumulative Index to Nursing and Allied Health Literature, EMBASE, MIDIRS and Applied Social Sciences Index and Abstracts. Results were exported and screened in Covidence (Melbourne, VIC, Australia), with over 25% double-screened, and third reviewers were used to resolve disagreements. An updated search of the databases took place in January 2024, and the manuscript was submitted for review in April 2024.

An extraction sheet based on the Template for Intervention Description and Replication guidelines²⁵ was developed by the research team. This was used to record intervention characteristics, and qualitative and quantitative data were extracted separately. The Mixed-Method Appraisal Tool²⁶ was used to assess the risk of bias in the included studies. For each quantitative outcome, where possible, the effect size (Cohen's *d*) was calculated and results were presented in an effect direction table.²⁷ Qualitative data were analysed and synthesised thematically²⁸ using the themes and conclusions from included studies. Overall results of the review were synthesised narratively.

Phase 2, part 1: a qualitative longitudinal study examining contrasting service delivery models in four sites

We aimed to recruit 40 women from maternity services in four sites: a London borough (site 1), a northern English city (site 2), a conurbation in central Scotland (site 3) and a semi-rural part of southwest Scotland (site 4). Women were eligible to participate if they were: pregnant or up to 9 months post natal, used or were in treatment for opioids (e.g. heroin, codeine and tramadol), benzodiazepines,

cocaine/crack or amphetamines, over the age of 18 years and were able to communicate in English.

Researchers made weekly calls to midwives or attended weekly meetings with maternity care staff to facilitate recruitment. Potential participants gave midwives consent to be contacted by researchers. Researchers then called women to arrange meetings (in person or over the phone) to go through the participant information sheet. If women wished to be involved in the study, further appointments were made to elicit informed consent and to conduct the first interviews.

Up to five qualitative longitudinal interviews were conducted with each woman. Interviews were audio-recorded and transcribed verbatim by professional transcription services and lasted between 25 minutes and 2 hours. Transcripts were anonymised by researchers. Participants were given notebooks to record significant events between interviews and were offered the option of recording audio diaries to share with researchers. However, participants were not able to find the time to keep written or audio diaries. Instead, researchers kept in touch with participants between interviews by SMS, WhatsApp or telephone calls, with participants often sending long WhatsApp messages and voice notes to researchers, which were all logged as research data. Women received £20 in shopping vouchers for each interview they took part in. Following an interview safeguarding protocol, interviews were conducted by one or two researchers in participants' homes and in public places or by telephone. Interviews focused on experiences and interactions with services at each stage of the perinatal period. Visual timelines were cocreated with women eliciting narration of life histories.

In 2 days of in-person meetings, the research team collaborated on the development of an analysis framework designed to divide the data across time points (background, pregnancy, labour and birth, 0–12 weeks post natal, 3–12 months post natal, 12 months+ post natal) using Microsoft Excel® (Microsoft Corporation, Redmond, WA, USA) spreadsheets to reflect up to five interviews per participant. Seven spreadsheets were created within Microsoft Excel to plot data for: (1) demographic information, (2) background (from the first interview), (3) pregnancy, (4) labour/birth and (5–7) three postnatal stages. Each column (in each spreadsheet) was titled with a key topic included in the semi-structured interview schedule, or an emerging theme, as agreed by the research team. Each row reflected the response of an individual participant throughout the seven worksheets and researchers used quotes and summarised responses related to the topics in each column. The columns of data were then imported into Microsoft Word (Microsoft Corporation, Redmond, WA, USA) documents for the

interpretation of the data coding and iterative generation of themes²⁹ across the cohort. Individual pathway documents were also created for each participant to enable analysis of the individuals' experiences over time. The research team tested out the framework on transcripts during the in-person meeting. 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 researchers (ES, SL, LG and LH) and PR subsequently independently coded two transcripts and discussed codes in online meetings. In addition, MUG and PR created case study flow charts for each participant, which plotted their care journeys and which were populated with quotes. These were then checked and amended by the researchers who had conducted the interviews.

Phase 2, part 2: focus groups with multiprofessional staff

Interviews with service leads and focus groups with a wide range of professionals were conducted in each site to test care pathways and models of care that were derived from interviews with women in each site. Firstly, we interviewed lead specialist midwives and service managers in each site and asked them to describe typical care pathways for women who use drugs, which would then be used at focus groups to aid discussion. Lead participants also helped by putting us in touch with key people across a range of services, enabling researchers to adopt snowball sampling approach to focus group recruitment.

Secondly, three focus groups were held in each site, between May and June 2023. Interviews and focus groups were held either online or in-person and were audio-recorded and transcribed by third-party services. Senior staff interviews and focus groups were analysed concurrently using deductive content analysis in NVivo (QSR International, Warrington, UK). Prior to coding, researchers developed a codebook which mapped onto main aims and outcomes of the interviews and focus groups (challenges, 'what works well' and suggested improvements) as well as key time points on the perinatal journey.

Phase 3: development of a coproduced theory of change for an optimised service model and key recommendations for practice

We used a coproduction approach to develop a ToC that sets out key requirements for the care pathways, a rationale for how/why they will work and intended outcomes. We integrated experiential knowledge with primary and secondary research evidence produced by the Stepping Stones Study in a series of coproduction workshops.

Theory of change is generated by first articulating (intended/ anticipated) the impact and medium-term outcomes, followed by backwards and forwards mapping to identify processes, activities and interventions necessary to achieve outcomes (and impact) along with a supporting logic and underpinning evidence for what is anticipated to work and why. While the overarching problem of poor outcomes for women who use drugs is clearly recognised, there may be different understandings and perspectives on the causal and modifiable factors underpinning the problem. Therefore, it was important that we also articulated ‘the problem’ to ensure consensus on the current context and that we included perspectives of those with lived experience.

Coproduction workshops

The EACPG met approximately every 3 months through the lifetime of the project (eight times in all). The first two meetings were concerned with research framing, group working arrangements, identifying relevant new members, agreeing terms of reference, discussing study plans and materials, reviewing search protocols for the literature reviews and learning about ToC. Subsequent meetings focused on developing the ToC. The meetings were chaired by an independent chair; however, the coproduction of ToC was facilitated by members of the research team.

All meetings were online using Microsoft Teams (Microsoft Corporation, Redmond, WA, USA) and lasted for approximately 2 hours. This enabled participants to take part without the need for travel; however, it may have limited the relational elements to some extent. The process of developing the ToC involved forwards and backwards mapping of the hypothesised causal pathways in relation to the articulated problems and idealised impacts and outcomes (the stages in development are described in Table 1). We used iterative design cycles of discussion, proposing ideas, rediscussion and refining. Break out ‘rooms’ and ‘Jamboards’ were used to facilitate discussion and inclusion of all members of the group. Between meetings,

members were asked to reflect and consult more widely with relevant stakeholders, including women with lived experience of drug use. Members of the research team used the discussion notes and Jamboards to synthesise workshop outputs and to draft stages of the ToC diagram.

In developing the ToC, the group was asked to draw on a wide range of knowledge and sources of evidence. We placed equal importance on all types of knowledge, combining primary and secondary research evidence, clinical knowledge and experiential knowledge. The woman’s voice was included in two ways – firstly by involvement of peer advisers and secondly through the emerging primary research (conducted within the Stepping Stones Study) of women’s experiences of involvement with services and their perinatal and life journey.

Results summary

Results of the Stepping Stones Study are reported in detail in the research papers listed in Table 2.

Scoping review: summary of findings

A total of 968 documents were screened, and of these, 111, published between 2000 and 2022, met the inclusion criteria. The documents included UK-wide (n = 26), specific to Scotland (n = 6), England (n = 9), Northern Ireland (n = 3) or (Wales n = 1), regional and organisational guidelines and policy documents. They varied in the degree in which they were relevant to women who use or are in treatment for drug use during the perinatal period, with some being specific to pregnant women who use drugs (n = 39), or having a specific section (n = 29), only containing a reference to pregnant women who use drugs (n = 22), or were universal documents that provided overall guidance on an issue such as vulnerable pregnancies that included pregnant women who use or are in treatment for drugs within their scope (n = 21).

TABLE 1 Stepping Stones publications

Phase	Title	Status
1	Scoping review: mapping clinical guidelines and policy documents that address the needs of women who are dependent on drugs during the perinatal period	<i>BMC Pregnancy and Childbirth</i> 2024;24(1):84. https://doi.org/10.1186/s12884-023-06172-6
1	Meeting the needs of women in the perinatal period, who use or are in treatment for using drugs: a mixed-methods systematic review	<i>Health Soc Care Deliv Res</i> 2025 [published online ahead of print August 20 2025] https://doi.org/10.3310/GJPR0321
2	Navigating surveillance: the experiences of prenatal women who use or who are in treatment for using drugs	<i>British Journal of Social Work</i> 2025;bcaf161 https://doi.org/10.1093/bjsw/bcaf161
3	Development of a co-produced theory of change for optimal care of women who use drugs or are in treatment for drug use during the perinatal period	Submitted – <i>BMC Health Services Research</i> , under review

TABLE 2 Stages in ToC development

Stage	Purpose	Method
1	Agreement on impact, outcomes and articulating the problems/problem context (two meetings)	Propose real-world impacts that should be achieved in the context of best care for women who use drugs/are in treatment for drug use in the perinatal period. Agree on short- and medium-term outcomes Make statements about the problems/gaps in services for women who use/are in treatment for substance use in the perinatal period Revisit and refine over subsequent meetings incorporating emerging primary and secondary data. Agree on list of impacts, outcomes and problems
2	Creating hypothesised causal pathways from problems to anticipated outcomes (four meetings)	Working backwards and forwards to agree the requirements and potential solutions necessary to reach the desired outcomes At each meeting, emerging evidence was presented and discussed The process was iterative and, at times, messy as all stages were revisited and revised as research findings emerged during the project
3	Refining the ToC	Between EACPG meetings, the research team finalised the format of the ToC, which was then presented for discussion to the EACPG and a wide range of participants in series of webinars and workshops before being finally refined by the research team

They were applicable in a range of settings, including hospital ($n = 21$), a community setting ($n = 13$), hospital and community ($n = 14$), prison ($n = 2$), and any setting in which a professional may be supporting pregnant women who use or are in treatment for drugs ($n = 60$). Documents were designed to be used by a wide range of users (maternity staff, healthcare professionals, social workers, substance use service staff and pharmacists, etc.), with some being relevant to more than one user group. There were 14 documents that stated that they could be used by patients or service users. Most were produced without patient or public involvement or any clear evidence base.

Overall, documents recommended an integrated model of care with a lead professional, clear referral pathways and information sharing between agencies. They suggested that referrals should be made to specialist midwives, drug and social care services. A holistic assessment and inclusion of fathers/partners were advised. More recent documents advocated a trauma-informed care approach. Where there was a need, opioid replacement therapy (ORT) was recommended throughout pregnancy. Potential gaps were identified around providing support for women postnatally, especially when their baby is removed from their care.

Mixed-methods review: summary of findings

Of a total of 15,655 articles identified, 197 met our inclusion criteria. The PRISMA diagram is shown in [Figure 2](#).

Of these 197 included articles, 119 were quantitative, 52 were qualitative and 26 articles were mixed-methods. Included articles were published between 1991 and 2023, with most from the USA ($N = 148$, 75.1%), followed by Canada ($N = 20$, 10.1%) and the UK ($N = 8$, 4%).

There were 217 separate interventions reported within the 197 included articles. Most interventions ($N = 151$) were delivered via more than one mode of delivery and were delivered in a range of settings, including outpatient clinics, hospitals, residential rehabilitation facilities, prisons, family courts or via telecommunication. There were 48 interventions colocated alongside other services. All 217 interventions had at least one psychosocial component. Overall, the interventions were complex, offering different arrangements and combinations of services. Alongside psychosocial components, the interventions included medication-assisted treatment (MAT) ($N = 83$), perinatal health care ($N = 144$), practical support ($N = 116$) and child welfare ($N = 41$). A small number of interventions ($N = 31$) were purely psychosocial, and the remaining 186 included two or more components.

The quantitative synthesis focused on three critical outcomes for women in the perinatal period: (1) improvements in engagement and retention in substance use treatment services, (2) reduction in illicit substance use and (3) improvements in engagement and retention in prenatal care. Meta-analysis was not possible due to the heterogeneity of studies. We offer these results cautiously since the studies varied in the interventions being tested,

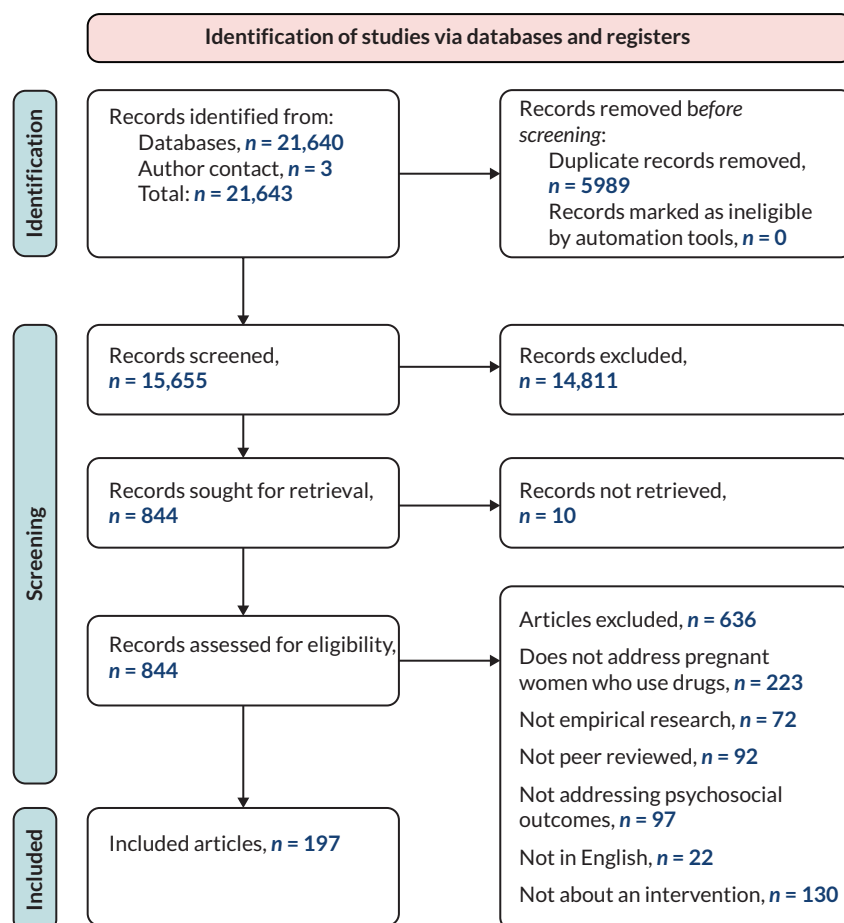


FIGURE 2 The PRISMA diagram.

the study design and sample sizes. Although we found some meaningful effect sizes, there was little consistency in terms of mode of delivery, setting or what part of the intervention was being tested.

1. Nineteen studies measured outcomes relating to the amount of time in treatment. Of those studies, nine studies demonstrated that the intervention had a positive impact on the amount of time during which women were retained in treatment, and all studies included a practical support element. Two studies with large effect sizes were for contingency management;^{30,31} one was an intensive outpatient programme for women and children³² and one was testing methadone maintenance.³³
2. How reduction in illicit substance use was measured was often unclear, and we were only able to measure the effect size of 42 studies. Findings were inconclusive: 9 of 23 show reduction in illicit opioid use, and 11 of 22 show reduction in cocaine use. All integrated interventions ($N = 6$) that measured reducing illicit substance use were found to be effective.
3. Fourteen studies assessed engagement in prenatal care. Seven were inconclusive, while seven studies (with a range of sample sizes and study designs)

showed a positive improvement. There were no similarities in the studies that were inconclusive in terms of study type, sample size, type of intervention, setting or mode of delivery. The studies that included a large effect size included two studies that measured prenatal addiction treatment, contingency management and therapeutic child care,^{34,35} integrated addiction and obstetric care³⁶ and methadone maintenance.³³

From a total of 75 qualitative or mixed-methods studies that were included within the review, only 35 included direct views of women about the treatment or intervention that they received and were able to be included in the qualitative synthesis. These 35 studies reported on a range of intervention types, including: colocated or one-stop shops ($N = 15$, 42.8%), integrated models of care ($N = 4$, 11.4%), peer support ($N = 4$, 11.4%), psychotherapy ($N = 2$, 5.7%), telehealth ($N = 2$, 5.7%), group work ($N = 2$, 5.7%), case management/care-co-ordination ($N = 1$, 2.8%), trauma informed ($N = 1$, 2.8%) and miscellaneous ($N = 4$, 11.4%). Thematic analysis of the authors' themes and conclusions in these qualitative studies revealed that women found most interventions to be helpful, with more evidence to support colocated or one-stop shop models.

Key themes supporting this model were also present in other intervention types, including the importance of a non-judgmental approach, positive staff relationships, trauma-informed care, cultural sensitivity and flexible, individualised care. Approaches that boosted parenting confidence, knowledge and skills were valued as were those that helped women expand their support networks. Peer support was particularly appreciated, offering shared experiences and hope for recovery. Additionally, service accessibility and a welcoming environment were crucial for engagement. Fear of child removal was stated to be both a barrier to and a motivation for engagement.

This review found that there is a need for further high-quality mixed-method research that takes women’s views into account. Overall, the review findings suggest women are more likely to access and engage with substance use and prenatal support in integrated services that also offer practical support.

Longitudinal interviews: summary of findings

Thirty-six women were recruited to the study, 23 of whom were pregnant and 13 were up to 9 months post natal (Table 3). Six women were lost to contact after one interview.

Participants were aged between 23 and 46 years, with a mean age of 34 years. Most participants (n = 30) were White British/European, and most (n = 34) described themselves as heterosexual. Seventy-five per cent of participants were receiving treatment for heroin and/or polydrug use (including crack cocaine, alcohol and benzodiazepines). Women reported a range of co-occurring and inter-related physical and mental health problems and trauma (Table 4).

Prenatal pathways

Women appreciated clear information and support from midwives (see Table 5). They were frequently overwhelmed by appointments and appreciated colocated support services. Women told us they preferred in-person meetings but that these could be hard to get to, both for

women living in rural areas, and for women in large, urban areas who were dependent on public transport. Barriers included cost and the physical demands of making multiple journeys while pregnant and postnatally. Participants reported fear of being perceived as unable to cope if they shared anxieties with professionals. Access to perinatal mental health services was patchy across the four sites.

Women who were stably housed and/or had supportive family networks were more likely to have engaged in substance use treatment prior to or very early in their pregnancies and to have presented to maternity services within 10 weeks of pregnancy. Women who had used drugs during pregnancy often presented late for maternity services, fearing judgement and social services intervention.

Inpatient care

Women often felt singled out for stigmatising practice by nurses and hospital midwives. ORT dosing was often poorly managed. Advice concerning breastfeeding was not always evidence-based or skin-to-skin contact-facilitated. Access to inpatient postnatal beds when babies were in neonatal intensive care unit (NICU) was variable.

Postnatal pathways

Social work assessments sometimes took place late in pregnancy or post birth, and women were often unprepared for the removal of babies under interim care orders. Access to residential rehabilitation services and mother and baby placements was variable and required women, for example, to begin the process of reducing ORT dosage to become eligible. Women who retained care of their babies were often keen to detox from ORT to distance themselves from drug using identities but feared relapse. Loss of babies to care caused intense distress and anxiety, putting women at risk of relapse. Women often felt they had been treated unfairly or that communication had not been clear. Support for women who had lost care of their babies was poor or fragmented.

TABLE 3 Interviews in four sites

Sites	First interview	Second interview	Third interview	Fourth interview	Fifth 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

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TABLE 4 Sample description

Sample description	
Age range	23–46 years
Mean age	34 years
White British/European	30 (83%)
Black British/mixed heritage	6 (17%)
Heterosexual	34 (94%)
Drug treatment	
Heroin and/or polydrug use	27 (75%)
Over-the-counter or prescription opioid use	5 (14%)
Stimulant use (crack cocaine, cocaine or amphetamine use)	4 (11%)
Co-occurring adversities	
Mental health problems/diagnoses	29 (80%)
Previous suicide attempts	12 (33%)
Survived overdose	11 (31%)
Chronic physical health problems	15 (42%)
Childhood abuse	11 (31%)
Intimate partner abuse	23 (64%)
Previous children removed from care	21 (80% ^a)
^a Of 26 women for whom not first maternity.	

TABLE 5 Illustrative quotations from longitudinal interviews

Theme	Quotation
Support and clear information from specialist midwives	<p><i>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 judgment. O1–P1</i></p> <p><i>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. O3–P5</i></p> <p><i>[specialist midwife] always used to mention ... she 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. O2–P7</i></p>
Overwhelmed by numbers of professionals involved and appointments	<p><i>It's kinda overwhelming to be honest. I don't really like going and, like, they're judging me. O3–P7</i></p> <p><i>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. O4–P3</i></p> <p><i>It was just a lot. I had health visitors, midwife, these bloody people from the Family Support Unit. I felt very scrutinised and quite bombarded. O1–P3</i></p>
Distance to travel to contact visits and to appointments	<p><i>Two buses Well we set off from here at half past nine and we don't get there until just after twelve. O3_P1</i></p> <p><i>So I feel it was a total waste of time going all the way doon there. I mean we wouldn't have found it on the bus and that. It was miles away. It was away doon in [town]. But it wasn't the easiest place to get to. O4–P5</i></p>
Anxiety regarding social work decision-making	<p><i>About 10 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? O2–P1</i></p> <p><i>But I feel as though like they're bringing up a lot o things fae like a couple o years ago, and judging it on that and no judging what's gaun on the nou. O4–P8</i></p>

Focus groups: summary of findings

Across the sites, 21 interviews with site leads/service managers were conducted (Table 6), and 12 focus groups (Table 7) involving 79 participants took place.

Four separate sites with distinct care pathways were included in this research. Maternity care was provided by specialist midwives across all four sites, although in one region within site 3, maternity care was co-ordinated by hospital-based, specialist midwifery team and delivered by community midwives. In site 2, the specialist midwives were colocated in a third-sector substance use treatment service, working alongside substance use treatment care providers.

Arrangements for and the range of disciplines that were represented in routine information sharing forums varied. In site 1, multidisciplinary meetings were led by a third-sector substance use treatment provider and included maternity services, social services, perinatal mental health and antenatal care. In sites 2 and 3, maternity service providers liaised with and referred into a range of specialist health and statutory providers. In site 2, there was a multidisciplinary meeting led by a third-sector service provider. In site 3, the midwives also attended a regular multidisciplinary pregnancy liaison group chaired by social work. In site 4, perinatal mental health led a joint monthly clinic, including specialist midwives and social work practitioners, where they discussed women's cases prior to inviting the woman herself to join them in meetings. Site 1 provided the only 'one-stop shop', integrated, drop-in session from pregnancy until 2 years post natal.

All sites made referrals to children's social care where there were concerns that women were not engaging and/or continuing to use substances.

Postnatal inpatient care for women whose babies were being treated in NICU differed with access to transitional beds for women in site 2 and a high-dependency unit in site 1. In sites 3 and 4, women were able to remain in hospital with their babies for up to 5 days postnatally. Referral pathways for detoxification, stabilisation, residential rehabilitation and mother and baby foster care/assessment centres were available in sites 1, 3 and 4.

Challenges noted in staff focus group discussion included the challenge of meeting the needs of this population of women. Staff described lack of joined-up IT systems, high levels of staff turnover, staff shortages and the inconsistent availability of perinatal mental health services. Lack of space for confidential conversations about medication on maternity wards was noted as reinforcing stigma and retraumatising women. Practitioners highlighted the lack of postnatal care for women whose babies have been removed from their care. The fall-off in support for women who retain care of their babies was also noted, especially for those deemed to be 'doing well'. Joint clinics, one-stop shops and opportunities for known staff to meet women on the postnatal ward were suggested solutions. The need to make care more trauma-informed was emphasised, including specific staff training, a more trauma-informed approach to child protection meetings and the availability of space for private discussion on labour wards.

TABLE 6 Key informant interviews

Site	Participants
1	8
2	7
3	5
4	1
Total	21

TABLE 7 Focus group participants

Site	Focus group 1	Focus group 2	Focus group 3	Total
1	6	7	4	17
2	6	3	8	17
3	4	7	5	16
4	8	10	11	29
Total				79

Development of a coproduced theory of change for an optimised service model and key recommendations for practice

The ToC diagram is presented in [Figure 3](#). This brings together all the elements of our findings as recommended by the Checklist for Reporting Theory of Change,³⁸ and supporting evidence is presented in [Appendix 1](#). The ToC articulates the main problem areas within the scope of services in the perinatal period, medium-term outcomes, longer term impacts and eight key requirements within which there are one or more specific activities or interventions for services and practice. The requirements are described in three interdependent levels: system (policy and strategic planning and commissioning of services), service (local service planning, development and management, e.g. at NHS Board or Trust level) and staff (direct care staff). The ToC suggests that optimum services first require buy-in and shared understanding at the level of policy and system development (and across sectors). This will ensure that resources enable service level change, in particular, provision of training resources and support to staff as well as infrastructure and service design that enables women to access and engage with services more easily. Services need to be designed to meet the complex needs of this population, for example, accessible, colocated services, care co-ordination and advocacy. System- and service-level buy-in, which is also underpinned by trauma-informed training and care practices, can then support staff (and staff training), which enables them to provide relationship-based, person-centred, flexible care and ongoing support that this population requires.

Discussion/interpretation

Overview of findings

Our study has investigated the complexities involved in the provision of care and support for mothers and the infants of mothers who use and are in treatment for drug use in the perinatal period. These services operate across complex systems (maternity, social work, mental health and drug services); while each have own priorities and ways of working, child protection priorities have come to dominate approaches to care. The study has been coproduced with an EACPG at all stages. Peer advisers consulted women with lived experience of substance use and maternity care throughout the life cycle of the project.

The scoping review of the current policy landscape for the care of women in the UK recommended 'integrated' services with clear referral pathways. The mixed-methods systematic review also found some evidence that integrated programmes at the point of delivery decrease substance use during the perinatal period, although diversity

of studies, types of interventions and low quality of evidence limit certainty concerning overall effect size. While the quantitative findings of the review are inconclusive overall, it provides insights into interventions that are likely to be effective, for example, contingency management, MAT and peer support, with the latter finding aligning with the qualitative findings. And while some approaches (e.g. case management and home visiting) show some positive effect sizes in either access to substance use treatment, prenatal care or reductions in substance use, the studies were too limited in number to draw robust conclusions.

Important themes from the scoping and systematic reviews were revisited in our empirical longitudinal study that explored the care pathways in each site and the experience of 36 women.

The profile of women who took part in our study closely reflects the women described in the Confidential Enquiry, MBRRACE report,³⁹ who are particularly vulnerable to suicide and overdose in the year after giving birth. Referrals to social services for prebirth social work assessments and the possible removal of babies from their care dominated women's experiences of maternity care. Anxieties about child removal were particularly experienced by women who had had children removed from their care previously and for whom postnatal treatment options were highly variable. The qualitative longitudinal interviews revealed that, although there were examples of supportive care and clear information, particularly from specialist midwives, multi-agency networks of health and social care services were dominated by practices of assessment and surveillance.

The point at which women presented to maternity services was important in terms of their experience of care. Women who had engaged in substance use treatment prior to or very early in their pregnancies, and who had presented to maternity services at or around the recommended window of 10 weeks for the booking appointment, had contrasting experiences from those women who had found they were pregnant later in their pregnancies, had used drugs throughout their pregnancies and/or were not engaged in drug treatment. While women who presented early to treatment and maternity services may also have had co-occurring mental health problems, including depression and anxiety, and may have had previous children removed from their care, they were often stably housed and/or had networks of family support. The second group of women often reported using cocaine, cannabis benzodiazepines and/or drinking hazardingly in addition to heroin use. Postnatally, women had highly variable experiences and opportunities to engage with support services, both between and within the different sites. The outcomes for women with the most complex needs who had presented

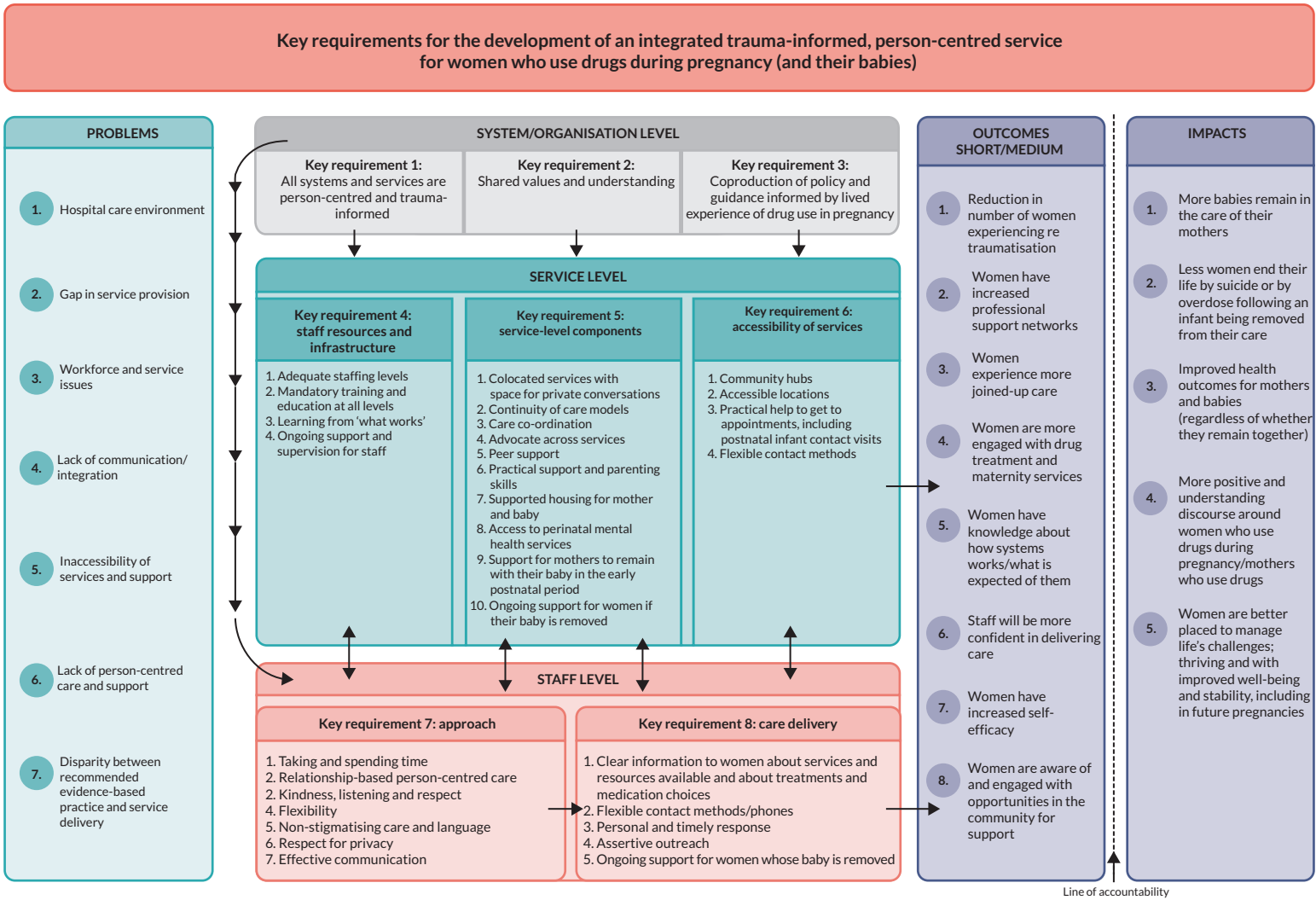


FIGURE 3 Theory of change.

late to services were thus dependent on the opportunities for treatment that were made available to them.

Best practice guidance evidenced in our scoping review for pregnant women to be prescribed ORT was at odds with the wider cultural association of treatment for heroin use with drug use itself. As other authors have described,⁴⁰⁻⁴² 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, the impact of ORT on their babies and the close association of treatment with drug use itself risked undermining and jeopardising efforts to separate themselves from the stigmatising figure of the drug-using mother. While some women went against medical advice to detox, others like the women interviewed by Ostrach and Leiner,⁴³ expressed the desire to detox from ORT as soon as they had had their babies. Postnatally, women often reported implicit encouragement from children's social care professionals to detox from ORT. Although they were often keen not to be considered as drug-using mothers, they also expressed fear of relapsing to drug use and anxiety about loss of support from community substance use treatment services.

While other authors have found that fear of children's social care involvement represents both barriers for some women, for others, there was an impetus to engage in substance use treatment and maternity services;^{44,45} these have tended to be cross-sectional studies in individual clinics. The use of longitudinal qualitative methods in our study has afforded rich qualitative data that have generated insights into women's experience and outcomes across their perinatal journey.

There is considerable research on treatment and interventions as well as guidance and protocols relating to this population. Many of the elements within the ToC are already widely recommended for practice and are implemented in some areas. The Stepping Stones Study found many examples of good practice. Yet, too often services are fragmented and fail to meet women's needs. The study found that women who use drugs during and after pregnancy often have complex lives, characterised by a history of long-term and ongoing trauma. Yet, during and after pregnancy, they are often expected to navigate a multitude of inflexible appointments, assessments and services that appear to be designed to meet the requirements of the services rather than the needs of the women. Women reported feeling set up to fail, as services too often seemed to be placing barriers rather than making it as easy as possible for them to engage with services. While the study found many areas of high-quality

specialist services and staff 'going the extra mile', the benefit could be lost where ill-informed casual remarks or impersonal care could negatively impact an already highly disadvantaged population.

Our findings need to be understood in the context of policies in recent decades in England and Scotland, which have reduced funding for family support services and prioritised the assessment of risk in individual parents.⁴⁶ Maternity and substance use practitioners have increasingly become enlisted in practices of risk assessment. In addition, since 2010 in England and 2015 in Scotland, there have been significant funding cuts to drug treatment services^{47,48} Scarcity of specialist family residential rehabilitation services for women postnatally and (especially in England) complex arrangements and short-term commissioning cycles mean that these services have effectively been rationed. Services to address women's wider needs for support are limited and tend to be delivered by third-sector organisations that are oversubscribed and funded via short-term commissioning cycles. In some sites in our study, eligibility criteria for referral to mother and baby residential rehabilitation services required women to demonstrate motivation to detox from opioid replacement treatment, making these services especially out of reach for women whose lives are more complex. We have also seen the closure and threat of closure of women's specific residential rehabilitation services in England in the last year (while family services have opened in Scotland) and conversion of Jasmine Women's Recovery into an assessment centre. A paper on the postnatal care pathways of women is in preparation.

Strengths and limitations

This study has been conducted with the strong support and involvement of our EACPG to ensure that the questions we have asked at all stages (in our systematic reviews and our qualitative studies) have been grounded in what is important to those with lived experience (as recipients of services as well as health and social care practitioners and providers). The involvement of the EACPG ensured that the study focus was on providing findings that are of use to practitioners and policy-makers.

A further strength of this study is the rich longitudinal data that captured women's journeys through the care pathways, their reflections on this care and its impact on them. The study used many different methods for capturing women's experiences (timelines, interviews and text messaging), ensuring that aspects of their life stories and their current circumstances were also taken into account. This was also valuable for understanding their framing of services and their 'rational' responses to

professional and service-related decisions surrounding their care and the care of their babies.

The analysis of longitudinal interview data across different locations can have significant challenges. The research team made substantial efforts to conduct data coding and analysis as one. Significant time went into discussing and creating the templates for coding data extracts with continual discussion and review of the content of the codes. The team came together (face to face) to conduct many of the tasks, and the high-level qualitative expertise by many of the coinvestigators on the study ensured that data management and analytical processes were robust.

Not all women recruited to the study took part in all the anticipated interviews or were able to take part in interviews at equal intervals throughout the study. The rate of attrition was fairly even between each interview phase (17%, 13%, 19% and 14%). Our retention of 50% of the sample throughout the study is in line with other longitudinal qualitative research, with people who use and in treatment for using drugs,⁴⁹ with researchers using a range of strategies to keep in contact with the study participants between interviews and half of the sample completing five interviews. We were reliant on specialist midwives to let women know about the study. We were aware that midwives were less likely to refer women who were struggling to engage with services. Although we may speculate therefore that women with more complex needs who were not engaged with maternity and substance use treatment services were not recruited or retained in the study, a subsample of women who had presented late to services was recruited to the study, and we were able to retain five women whose babies had been removed from their care in the study. Flexibility regarding time between interviews also meant that we were able to capture the experiences of women who had disengaged, relapsed and returned to services.

This provides lessons for conducting research with participants who are often marginalised and who live in difficult circumstances – it requires more flexibility in research design and an acceptance of ‘missing data’ that is not seen as a weakness of design or robustness of the data that are gathered.

Reflections/challenges

We aimed to understand women's experiences of services and support available during the perinatal period, through up to five qualitative longitudinal interviews. This required considerable effort from the researchers in engaging with the women to build trust and to retain participants

throughout the study. Many of our participants had experienced multiple and complex trauma, and some were living in precarious situations involving domestic violence. This required sensitivity and flexibility on the part of researchers. It became clear, for example, that participants would not be able to prioritise keeping written or audio diaries between interviews, but they were often happy to keep in touch with researchers through regular SMS, WhatsApp messages and voice notes instead. Using the timelines for data collection was not always appropriate with women, where there was an acute risk of retraumatisation or if their mental health was fragile. Careful risk assessment was also essential to ensure the safety of researchers, with debriefing and ongoing support to protect their emotional well-being.

Attempts in the systematic review to identify the characteristics of interventions that improve engagement and retention in substance use treatment, engagement and retention in prenatal care and reduce women's illicit substance use prenatally were inconclusive largely due to the heterogeneity of included studies. A further limitation of the mixed-methods review was that most of the studies were based in the USA, which has a very different healthcare and substance use treatment policy landscape, poorer access to ORT and widespread measures to criminalise pregnant and post partum women who use drugs.

Patient and public involvement

Throughout the study, concurrent coproduction and patient and public involvement (PPI) activities took place, which supported and informed project activities.

From the project's inception, two peer advisers with experience of substance use (one based in England and one in Scotland) worked collaboratively with the research team on designing tasks and supporting wider PPI engagement. Peer advisers offered essential expertise in designing and developing recruitment materials that were appropriate and accessible for potential study participants. This involved co-designing and offering consultation on the design of a business card, a comic strip, a participant website, a calendar, an animation and recruitment leaflet. Peer advisers, with support from the research team, led expert-by-experience consultations on the study topic guide and resource list prior to the commencing of interviews. Researchers also facilitated a workshop session with experts by experience to seek their views on how best to engage with and speak with women

who use drugs during pregnancy and developed a 'top tips for researchers' resource.

Throughout the study, researchers maintained contact with peer advisers and wider experts by experience outside of regular quarterly EACPG meetings to update on the progress of the study, share experiences from fieldwork and provide feedback on preliminary results for discussion.

One of the key things I'd take away is the profound sense that collaborative research not only enriches my own knowledge and skills but also empowers individuals from diverse backgrounds, ensuring their perspectives are valued, leading to a truly engaging and impactful project where constant feedback and flexibility are integral. This experience has underscored the importance of inclusivity, diverse perspectives, and a supportive team environment in research collaboration.

Mel (London peer adviser)

Equality, diversity and inclusion

This study was focused on women who use and are in treatment for drug use during pregnancy and up to 18 months post natal. We used this person-first language throughout our study and in study outputs. This is a population that is known to have complex health and social needs, often stemming from adverse life circumstances. They are a highly vulnerable population, often experiencing homelessness and poverty. The methods employed in this study were developed to be inclusive and to give voice to these women who experience inequalities in most areas of their lives. Although the recruited sample was predominantly White and of UK origins, it was also representative of the female population with problematic drug use in the UK. Six out of 36 women recruited (mainly from the London site) were of Black or minority ethnic background. This ethnic profile reflects the profile of patients in the sites from which women were recruited.

In addition to the women recruited to this study, we engaged/consulted with other women with experience of adverse life circumstances and drug use, such as a group of women attending services provided by The Salvation Army.

Our approach to PPI throughout the project was a direct attempt to include women with experience to redress the imbalance they often experience in dealing with services and professionals. Our methods of engaging

and communicating with women, including the use of arts-based approaches, demonstrates our commitment to inclusion and redressing educational/communication inequalities among the women we worked with.

Impact and learning

As a result of taking part in the EACPG, specialist substance misuse midwives from across England have formed an information sharing and support group that meets online. We are involved in work with this group of midwives to incorporate findings from the Stepping Stones Study into routine staff training.

Related work

Working in partnership with theatre charity Tortoise in a Nutshell (TIAN) and supported by a University of Stirling Impact Accelerator Grant, researchers from University of Stirling developed a workshop format to creatively and more widely share the results of the study with student midwives and social workers. The workshops told stories of women who participated in the study using visual elements from TIAN's show 'Concerned Others', which explored experiences of the communities supporting people who use drugs.

Anonymised vignettes represented moments in women's journeys where they experienced stigma, judgement or fear within health and social care services. Lightboxes illuminated small models depicting snapshots into a woman's experience, with text from the vignettes projected behind that was accompanied by a soundscape. Participants were invited to take part in creative activities, reflection and a short evaluation.

Over September and October 2024, six workshops were delivered to 60 students at Robert Gordon University, University of the West of Scotland and University of Stirling. Evaluation data highlighted that the participants felt they gained a deeper understanding of the complexities of women's experiences, they appreciated the space to discuss their experiences and feelings related to the topic and that it was a useful and valuable workshop.

Collaboration with Outside Edge Theatre Company

The theatre company will develop a theatre production based on the Stepping Stones Study's research and deliver up to six performances of this production across up to three venues. Outside Edge Theatre Company focuses on creating work that raises awareness about issues

related to addiction. A professional playwright will create a short play (30–45 minutes) for three actors, which will be rehearsed and then performed for audiences. The content of the script will respond to the Stepping Stones Study findings and will contribute to dissemination and awareness raising.

Dissemination

The findings from the Stepping Stones Study have been widely disseminated to policy-makers, multiprofessional practitioners and women with lived experience of drug use through workshops, seminars and webinars

(Table 8). Academic conference presentations are listed in the [Additional information](#) section.

Implications for decision-makers

The implications for decision-makers are principally linked to the ToC. As the ToC developed, it became clear that the majority of the key requirements for good care must be developed and supported at strategic/organisational and service levels rather than at the level of individual staff members.

TABLE 8 Stepping Stones Study dissemination activity

Date	Audience	Event/channel/format	Title/description
November 2024	Midwives	Royal College of Midwives (Scotland) conference. Interactive workshop	Challenging stigma towards women who use drugs during and after pregnancy
November 2024	Academics	PARCKAs PARLEYS seminar series	Shared findings of Stepping Stones study with PARCKA team at University of Utah
October 2024	Student midwives and student social workers	Six interactive workshops	Challenging stigma towards women who use drugs during and after pregnancy: accelerating the societal and future workforce impact of the Stepping Stones study
September 2024	Practitioners/policy decision-makers/academics	Stepping Stones in-person conference. Kings College London	Improving care for women who use drugs during the perinatal period – findings from the Stepping Stones Study
April 2024	Policy/decision-makers	Supporting Women Reducing Harm (Scottish Government Short Life Working Group)	Findings of the Stepping Stones Study and discussion of implementation
April 2024	Practitioners/carers/people with lived and living experience	Scottish families affected by Alcohol and Drugs Stigma seminar	Care pathways for women who use and/or are in treatment for drug use during the perinatal period and their babies
April 2024	Practitioners/policy-makers/academics/people with lived and living experience	Scottish Drugs Forum: insights event	How women who use substances during the perinatal period experience integrated care pathways: findings of a qualitative longitudinal study
March 2024	Practitioners/service providers/policy and decision-makers/people with lived and living experience	Two UK-wide webinars	Stepping Stones Study – two-hour event. Series of short presentations providing an overview of the study and key findings followed by a panel discussion
March 2024	Homerton hospital dissemination event	In-person dissemination event	Evaluating models of care, best practice and care pathways for women who are dependent on drugs and their infants, from preconception to 18 months post natal
March 2024	Practitioners/service providers/policy and decision-makers	In-person dissemination event in site 4	Stepping Stones Study – half-day event. Series of short presentations providing an overview of the study and key findings followed by a panel discussion
March 2024	Practitioners/service providers/policy and decision-makers	In-person dissemination event in site 3	Stepping Stones Study – half-day event. Series of short presentations providing an overview of the study and key findings followed by a panel discussion
August 2023	Public	Panel discussion – in person Edinburgh festival fringe	Concerned others: panel discussion

TABLE 8 Stepping Stones Study dissemination activity (*continued*)

Date	Audience	Event/channel/format	Title/description
June 2023	Policy/decision-makers	Presentation of the Stepping Stones Studies to an invited audience, including the Scottish Government Chief Nurse, Chief Midwife and Lead Allied Health Professions officer for Scotland	Presentation of study outline and emerging findings
June 2023	Student health visitors	Stirling University (online) Health Visitor Child Protection Masterclass	Engaging women who use drugs during the perinatal period
April 2023	Academics	British Sociological Association Conference	Structures of stigma and sites of surveillance; women who use substances during the perinatal period and their experiences of accessing health and social care
March 2023	Academics	University of Stirling Faculty of Health Research Seminar	Research with marginalised populations

- The study indicates that there is a need for person-centred and trauma-informed approaches to extend to policy-makers, senior management/decision-makers and service development managers across health and social care settings.
- Multidisciplinary team training is required to address organisational culture and improve support for women. This training should include all staff from senior management to frontline staff to promote shared values and understanding. Training should include trauma-informed and person-centred care, strategies to address judgemental and stigmatising attitudes towards women who use drugs or are in treatment for drug use during the perinatal period.
- Further coproduction of policy and services and informed by lived experience of drug use in pregnancy is required. Gathering feedback on women's experiences at national and local levels will enable continuous improvements to be made to services. This study has been a start in that process, but this should continue within and across services.
- This study has highlighted challenges and 'emotion work' encountered by staff involved in the care of women who use or are in treatment for drug use in the perinatal period and their infants. Services must provide ongoing support and regular supervision of staff who are involved in their care.
- At service level, the evidence from this study strongly indicates the need for an integrated approach from services; however, this integration had to serve the women's needs. The study found that services co-operated and shared information regarding safeguarding of the baby, but this was less evident in relation to the needs of the women and how services might help them to keep custody of their baby. Service integration also meant colocation and community hubs or 'one-stop-shops' for easy access to a range of services at one time.
- Models of care that enable continuity of care must be developed and supported at service and strategic levels. Staff working within a rigid service infrastructure, that did not facilitate the flexibility needed for person-centred care, including organisational structures such as flexible clinic spaces, cannot not sustain relational-based care.
- For women in more vulnerable circumstances, for example, where there was a lack of any family support or problems with homelessness or unsafe accommodation, the option for supported accommodation specifically designed to support the multiple needs of mothers with drug use and their babies should be available. There are good models of such provision (e.g. Aberlour, Jasmine Women's Recovery), which could be extended elsewhere with planning and resources.
- The study found that there is still considerable variation in access to perinatal mental health services across England and the devolved nations, and this is even more so for women with multiple disadvantages, including deprivation, trauma experience and discrimination. The Maternal Mental Health Alliance has already identified key recommendations for delivering perinatal mental health services across the UK, many of which (such as addressing short- and long-term workforce issues, making equity a priority, enabling women's experiences to shape change, joining up the care women and families receive and delivering a trauma-informed approach to perinatal mental health care) resonate entirely with the findings and recommendations from this study.⁵⁰

- The accessibility of services was a key issue, particularly if women had additional costs for travel or were restricted in other ways (e.g. due to child care or work commitments). Retaining women in services in the perinatal period is crucial in improving outcomes, therefore assertive outreach delivery options are a better way of meeting the women's needs and should be an option within all services.
- There is a need to deliver interventions that enable and support women in looking after their baby, including practical parenting support and skills and support for mothers to remain with their baby in the early postnatal period.
- Clear information should be provided about services and resources available; about treatments and medications, options and choices. Staff should use flexible contact methods (including texting) and should provide women with personal and timely responses.
- A care co-ordinator who could communicate with the women and understand where and when women may have difficulties in attending or accessing or complying with services would be helpful. This role could also be provided by an advocate, provided they had credibility with the services for negotiating the women's difficulties and ensuring that missed appointments or failure to provide information or comply with requests was understood from the woman's perspective.
- The study found that lack of attention to the needs of the women who experience real trauma from decisions, in particular, to have babies removed from their care, may exacerbate further drug use, poor self-care and mental health problems. A specific programme of support should be developed, tailored for and delivered to these women, ideally spanning the period prior to the decision to remove the child being communicated to the women as well as beyond.

Research recommendations

The Stepping Stones Study provides rigorous evidence regarding the care experiences of women who use drugs, or are in treatment for drug use in the perinatal period, regarding staff who provide care and services and regarding the potential for optimal service redesign. We propose the following priority areas for research:

Coproduced patient reported experience measures

The ToC proposed seven short- and medium-term outcomes relating to women's experiences of perinatal services. Further research is now required to develop a set of robust patient-reported experience measures (PREMs)

capable of assessing experiences of care and services with appropriate sensitivity and applicability to women who use drugs or who are in treatment for drug use. The PREMs would be coproduced with services users and stakeholders, ensuring that the PREMs produced are valid and acceptable, and this will also help to determine the optimal timing for implementation.

Evaluation of women-centred interventions and supported accommodation service models

There is a need for up-to-date, high-quality research studies into interventions for pregnant women who use and/or are in treatment for drug use. Robust evaluation is required of women-centred and supported accommodation service models, including research evaluating the costs/benefits of such models of care for their impact on women and their infants.

Implementation and evaluation of the theory of change

The Stepping Stones Study has coproduced an evidence-based ToC for optimum services for women who use drugs or who are in treatment for drug use in the perinatal period. Implementation research will be required to develop and implement redesigned services in one or more pilot sites and to conduct robust theory-informed evaluation, for example, realist evaluation to determine how and where processes and outcomes are improved/not improved.

Conclusions

The Stepping Stones Study was an ambitious mixed-method study that scoped UK policy and best practice and reviewed international evidence for optimising outcomes for women who use drugs and are in treatment for using drugs in the perinatal period. A qualitative longitudinal study explored the extent to which best practice models and recommendations were implemented in the care of women in four diverse sites in England and Scotland. Peer advisers with lived experience of substance use treatment were part of the study team, and coproduction ran throughout. A ToC for an optimal service model was coproduced with members of a study EACPG that included practitioners, policy-makers and other experts in the field, ensuring that the perspective of practitioners, policy-makers and service users was coproduction in the conduct of the study, dissemination of the study findings and in knowledge mobilisation.

The UK scoping review of policy and best practice guidelines for the care of women who use and are in treatment for using drugs referred to established protocols

for drug treatment, with recommendations for 'integrated' health and social care services, with clear referral pathways. These recommendations were supported in the findings of the mixed methods systematic review of studies of interventions, that also found the inclusion of practical support helped women to engage in substance use treatment and maternity care. Support for trauma-informed and person-centred care was evidenced in more recent studies of interventions; and, in studies that consulted users of these services, there was support for peer-led members and peer navigators.

The profiles of the 36 pregnant and post partum women who took part in the qualitative longitudinal study included high levels of co-occurring trauma, mental health disorders, intimate partner violence, poverty and disadvantage. Information sharing and liaison within multiagency networks of health and social care professionals (maternity care, substance treatment services and children's social care) in the four sites prioritised child protection. This meant that women sometimes felt their needs for support were overlooked or were afraid to raise problems, which suggested that they were not able to cope and care for their babies. Women valued non-judgemental support and clear information from specialist midwives, but fear of children's social care services involvement and the removal of babies dominated their experience of healthcare services prenatally and this was a barrier to engaging in services for some women. Apparent attempts to conceal drug use on the part of late presenters frequently triggered child protection referrals and assessment practices. Multiagency practice was thus frequently experienced as surveillance rather than support.

Prescribing and dosing of opioid replacement treatment was not always dealt with sensitively in hospital. Women's accounts of social care assessments indicated that they were encouraged to become abstinent, including from ORT, suggesting that children's social care practitioners did not always understand that ORT allows women to live stable lives and should not be time-limited. Where there were referrals available to specialist treatment services postnatally, they were sometimes conditional on demonstrated commitment to reductions and detox from ORT. For women who retained care of their babies, detox from ORT medications represented an escape from the stigma of treatment regimens, yet risked loss of contact with support services and relapse. These findings must be seen in the context of policies in the last decades, which have seen cuts to whole-family support services, the retargeting of professional intervention to individual parents for the assessment of risk and reductions in substance use treatment budgets in England and Scotland. The key

requirements for optimised service models described in the coproduced ToC are system- and organisational-level measures to improve the co-ordination, continuity and integration of care and include a call for kindness, listening and respect. Key requirements for measures that address addiction stigma, poverty and for the refunding of family and specialist treatment services are pointed out by our study.

Additional information

CRedit contribution statement

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Data-sharing statement

Individual participant-level data are not available as participant anonymity cannot be ensured, but authors can provide research materials, analytic codes and sample-level data and information upon reasonable request.

Ethics statement

NHS Research Ethical approval for the Stepping Stones Study was obtained from the North of Scotland Research Ethics Committee, NHS Grampian Reference Number 22/NS/0047, date: 9 May 2022.

Information governance statement

King's College London and University of Stirling are committed to handling all personal information in line with the UK Data Protection Act (2018) and the General Data Protection Regulation (EU GDPR) 2016/679. Under Data Protection legislation, King's College London and University of Stirling are the Data Controllers; Huddersfield University is the Data Processor. And they process personal data in accordance with their instructions. You can find out more about how we handle personal data, including how to exercise your individual rights and the contact details for our Data Protection Officers www.stir.ac.uk/about/professional-services/student-academic-and-corporate-services/policy-and-planning/legal-compliance/data-protectiongdpr/ and www.kcl.ac.uk/professional-services/business-assurance/data-protection-introduction-data-losses-and-reporting#section-4.

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Publications

Gilmour L, Honeybul L, Lewis S, Smith E, Cheyne H, Aladangady N, *et al.* Scoping review: mapping clinical guidelines and policy documents that address the needs of women who are dependent on drugs during the perinatal period. *BMC Pregn Childbi* 2024;**24**:84.

Smith E, Lewis S, Gilmour L, Honeybul L, Cheyne H, Aladangady N, *et al.* Meeting the needs of women in the perinatal period, who use or are in treatment for using drugs: a mixed methods systematic review [published online ahead of print August 20 2025]. *Health Soc Care Deliv Res* 2025. <https://doi.org/10.3310/GJPR0321>

Radcliffe P, Smith E, Gilmour L, Lewis S, Honeybul L, Gonzalez Utrilla M, *et al.* Navigating surveillance: the experiences of prenatal women who use or who are in treatment for using drugs. *Br J Soc Work* 2025;bcaf161. <https://doi.org/10.1093/bjsw/bcaf161>

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for the reader; please be aware this may not have been peer reviewed:

Cheyne H, Maxwell M. Development of a co produced Theory of Change for optimal health and social care services for women who use drugs or are in treatment for drug use during the erinatal period. *BMC Health Serv Res* 2025. <http://hdl.handle.net/1893/37168>

Conferences

The Stepping Stones Study academic conference presentations are presented in [Table 9](#).

Study registration

This study is registered as CRD42021288571 and Open Science Framework. The study protocol V3 October 2023 was approved by the NIHR and is available at: <https://fundingawards.nihr.ac.uk/award/NIHR130619>

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This synopsis provides an overview of the research award *Evaluating Models of care, best practice and care pathways for women who are dependent on drugs and their infants, from preconception to 18 months postnatal*. For other articles from this thread and for more information about this research, please view the award page (www.fundingawards.nihr.ac.uk/award/NIHR130619)

About this synopsis

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TABLE 9 Stepping Stones Study academic conference presentations

Date	Conference/event	Title
October 2024	Lisbon Addictions Conference	Meeting the needs of women who use or are in treatment for using drugs during the perinatal period: a mixed-methods systematic review
		The care pathways of women who use drugs in the perinatal period: findings of a qualitative longitudinal study
November 2023	Society for the Study of Addictions 2023 Conference	The care pathways of women who use drugs in the perinatal period: findings of a qualitative longitudinal study
April 2023	British Sociological Association Conference	Structures of stigma at sites of surveillance; women who substances during the perinatal period and their experiences of accessing health and social
February 2023	University of Oslo Centre for Addiction	The care pathways of pregnant women who use drugs and their babies in the perinatal period: implications for social work practice
September 2023	The European Scientific Association on Residential and Family Care for Children and Adolescents University of Sussex	The care pathways of pregnant women who use drugs and their babies in the perinatal period: implications for social work practice
October 2023	European Working Group on Drugs Oriented Research	Services and care for women who use drugs in the perinatal period: findings of a qualitative longitudinal study
November 2023	Society for the Study of Addiction	The care pathways of women who use drugs in the perinatal period: findings of a qualitative longitudinal study
June 2024	The International Society for the Study of Drug Policy (ISSDP)	Scoping review: mapping clinical guidelines and policy documents that address the needs of women who are dependent on drugs during the perinatal period

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List of abbreviations

EACPG	Expert Advisory and CoProduction Group
JB I	Joanna Briggs Institute
MAT	medication-assisted treatment
NICU	neonatal intensive care unit
ORT	opioid replacement therapy
PPI	patient and public involvement
PREM	patient-reported experience measure
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
TIAN	Tortoise in a Nutshell
ToC	theory of change

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Appendix 1 Key recommendations for services for women who use drugs or are in treatment for drug use in the perinatal period: supporting evidence examples

Requirement	Evidence source and illustration
System level	
System level refers to policy and strategic planning, commissioning of services	
Key requirement 1: all systems and services are person-centred and trauma-informed	
Everyone involved in perinatal services policy, development and delivery should have a shared understanding of how trauma and addiction impacts on an individual. Those in strategic planning and leadership positions must work together to plan and deliver effective services that avoid causing further harm or traumatisation.	Most of the women in our study had experienced multiple and complex trauma. They shared positive care experiences and also numerous instances where services failed to meet their needs and often appeared to be setting them up to fail. In particular, casual ill-informed comments and judgemental attitudes could be retraumatising.
Training about addiction and trauma-informed care and the needs of women who use substances during and after pregnancy, and their infants, should be provided for all those with responsibility for planning, funding and prioritising perinatal services, including commissioners, policy-makers and service providers. ^{51,52}	You’ve been banging on about past traumas, and yet all you seem to be doing, at the moment, is bringing on these traumas in me. P01_02_IV4 referring to contact with social worker- Focus groups with staff also highlighted that although many of the specialist services do practice trauma-informed care, this can be undermined by ill-informed workers, practices and systems that do not respect women’s trauma histories. Child protection’s important, but so’s () humanity, and looking at that person as an individual with a history, with a story, with a trauma. Not just an addiction and the fact that they’ve lost their child. Site 3, focus group

Requirement	Evidence source and illustration
Key requirement 2: shared values and understanding	
All those involved in policy, planning and delivering services that impact on women who use or are in treatment for using drugs during the perinatal period must understand the particular challenges faced by women, who used drugs or are in treatment for drug use, and the staff providing care. At all levels, it is recognised 'why this population matters'.	<p>The EACPG noted that all staff who come into contact with women who use drugs during pregnancy should be trained in trauma-informed care and that services overall should be trauma-literate. They recommended that people across the spectrum of care, including commissioners, policy-makers and service leaders, are taught about 'why this population matters' and also that training should recognise the challenges that staff are going through, often working in stressful and challenging environments with short-term funding and job insecurity.</p> <p><i>It comes from the top, it's a management/leadership-led approach. Being kind, being thoughtful, being – you know, reflective all the time. We are working hard on that, but if there's poor practice up there it just feeds right through. Site 3, focus group</i></p>
Key requirement 3: coproduction of policy and guidance informed by lived experience	
Policy and guidance should be coproduction and informed by women with lived experience of drug use in pregnancy.	<p>The scoping review⁵¹ found that only 13% of reviewed documents included consultation with women with lived experience of use of drugs during pregnancy.</p> <p>Our study found that there were considerable gaps between policy and guidance and service capacity and care delivery, women with living and lived experience had valuable insights into what worked/did not work and their voices should inform and shape policy and service development.</p> <p>The EACPG noted that lived experience should be embedded into services, with individuals with living and lived experiences being able to contribute to and shape service development.</p>
Service level	
<i>Service level refers to local service planning, development and management for example at NHS Board or Trust level (UK)</i>	
Key requirement 4: staff resources and infrastructure	
4.1 Adequate staffing levels	
Services must be appropriately staffed to allow practitioners to provide care in line with both their organisations and national recommendations regarding care schedules and proceedings.	<p>From our EACPG, staff interviews and focus groups, we heard how across all services, challenges of staff shortage, high turnover and lack of consistent third-sector funding impact on staff capabilities and capacity and meant that care delivery is inconsistent. Women recognised that services were understaffed and underfunded and experienced high turnover of practitioners, which impacted their care experiences, for example, making it harder to contact staff and appointments being cancelled.</p>
Third-sector and specialist services require secure and ongoing funding to allow them to provide continued support to women as well as maintain and develop staff expertise.	<p><i>I don't think there's enough support in place. ...I know they're understaffed and that. That's probably the problem, why you don't get enough help. Cause like I don't see anybody.</i> 04_P1_d woman's interview</p> <p>In focus groups, staff described the impact of staff shortages on their ability to develop trusting relationships with women and on their own mental health.</p> <p><i>I spent a lot of my own time as well, running around, chasing things, going home late, taking food parcels at six o'clock at night, when I actually finish work at half four. So how do you sustain that? we don't get the time, even to reflect on those cases. Or have any time to think about the impact that it is having on your own mental health, and your own family life. Site 3, staff focus group</i></p> <p><i>Staff need time to work with that family, to build up relationships Especially if there's some kind of issue or crisis happened within that family it can be really difficult. And we need to be afforded the time for that really intensive piece of work to go ahead. And unfortunately we're not afforded the time. Site 3, focus group</i></p>
4.2 Mandatory training and education at all levels	
Training should be developed within organisations to ensure all staff understand the experiences and complex needs of women who use drugs during the perinatal period and trauma informed care. Training should include the below details:	<p>From all sources of evidence that were gathered during the study, the need for training was highlighted as being essential for improved care delivery and outcomes.⁵¹ Women described how they often encountered stigmatising and/or unsupportive attitudes and care practices within services, in particular, involving intrapartum and in-hospital services where specialist drug services may not be available. However, casual interactions, for example, general practitioner receptionists, social workers could also communicate a lack of awareness, understanding and compassion.</p>

Requirement	Evidence source and illustration
<ul style="list-style-type: none"> Communication skills/empathy 	<i>They weren't very kind. I felt very judged by some of them. The way some of them checked on [baby] was very unfriendly and a few comments here and there, which just weren't very nice, and yeah. Just it made me feel very, very uncomfortable and very stressed.</i> P01_03_IV1
<ul style="list-style-type: none"> Person-centred care 	Women spoke about staff on the labour and postnatal ward having a lack of knowledge about addiction and prescribing of OST.
<ul style="list-style-type: none"> Trauma-informed approaches 	<i>Went to breastfeed ... they stopped me ... 'you've got opiates in your system' 'didn't know dihydrocodeine was an opiate ... everyone else on the ward had had an opiate so why could they breastfeed, and I couldn't?' P03_01_IV1</i>
<ul style="list-style-type: none"> Domestic abuse 	Focus group interviews with staff also highlighted the need for regular education, including disciplines and areas, such as medical staff and scan departments.
<ul style="list-style-type: none"> Stigma 	<i>Understanding and knowing what the pathway is that that mum, that pregnant lady will have been through before she has given birth, the meetings that she will have been through.</i> Site 2, focus group
<ul style="list-style-type: none"> Addiction and opioid substitution treatment and implications of treatments during the perinatal period, including breastfeeding 	<i>Training can't be a one-off, it's a philosophy isn't it for understanding addiction through trauma.</i> Site 2, focus group
All midwives and medical staff should receive training on the identification and care of neonatal abstinence syndrome and neonatal opioid withdrawal syndrome (EACPG).	

4.3 Learning from what's working well

Service leads and those responsible for developing services should seek to learn from examples of good practice.

EACPG recommends that services seek to learn from examples of services that are working well.

Maternity services' quality improvement work has typically focused on deficit-based approaches such as analysis of adverse events. Lessons from safety in other healthcare environments suggest that the principles of Safety-II, such as learning from successes and taking a positive strengths-based approach, will have applicability in maternity care.

4.4 Ongoing support and supervision for staff

All staff providing care for women who use or are in treatment for use of drugs during the perinatal period should have access to appropriate regular clinical supervision that helps them to reflect upon their experiences and the emotional impact of their work.

The EACPG discussed experiences of staff's secondary trauma and the emotional intensity of providing compassionate care to women who use or are dependent on drugs throughout the perinatal period, stressing the importance of mentoring, supervision and counselling.

During focus groups, staff shared examples of being impacted by the vicarious trauma of managing and supporting complex and challenging cases and of the benefits of support and supervision.

I feel like we are really well supported, like we have things like restorative supervision, and I know that if I was struggling, I could go to someone. Community PH midwife, site 1

The child was removed within the meeting ... and Mum was on the floor, and she was upset, and she was screaming and crying. And [addictions worker] came out and she just burst into tear, and I thought, we need to recognise that it's challenging for parents at the meetings, but it's also challenging for a worker to witness. Site 3, focus group

Key requirement 5: components and interventions

5.1 Colocated services with space for private conversations

Colocated and one-stop-shop models of care should be offered for maternity and drug treatment services, where women can also access a range of other practical and community supports, such as child care, benefit advice, parenting support and education and peer support groups.

Our study found that there was evidence of benefits associated with colocated services. The mixed-methods systematic review⁵² found that women reported improvements on their own, and their child's health and well-being and colocated services were associated with a self-reported reduction in substance use. Women also reported maintaining or regaining custody of their babies because of the integrated support offered in colocated service models.

Requirement	Evidence source and illustration
At a minimum, multiagency/non-siloed approach with clear communication channels and information sharing systems between agencies and to women should be provided.	<p>Practitioners in our study focus groups identified one-stop shops as supporting engagement and destigmatising seeking care for women.</p> <p><i>There is something about being colocated. Somewhere that's accessible to the maternity service, that is really meaningful. a lot of the time we find that women with substance misuse or alcohol issues might have comorbid medical or obstetric conditions that are quite tricky, quite complex. So being able to be in a place where you can get them that care and work around that at the same time is good. Site 1, focus group</i></p>
5.2 Continuity of care and carer (all services)	
Continuity of care from those supporting women prior to pregnancy and throughout (relationship building), where possible, a named worker.	<p>Our study found that fragmented care leads to women having to repeat their stories and medical experiences to different professionals which is confusing, frustrating, time-consuming and can be retraumatising. The scoping review⁵¹ found that continuity of care is recommended to support effective communication between services during multidisciplinary working.</p> <p><i>I never had the same midwife twice. They'd often forget things. They'd get my name wrong. The nearly gave me the wrong injection once. 01_P3_a</i></p> <p><i>She [specialist midwife] was at the panel meeting, and I'm thinking to myself, I've seen you for five minutes What input have you got into this? I don't see the point in that. 03_P7_e</i></p> <p>Staff in focus groups highlighted the importance of practitioners being engaged with women across the span of their care and having a named worker who they could rely on.</p> <p><i>We make the women aware that myself, and whoever the social worker is, we work closely with each other, and just try and support them as much as we can. I think that's a huge benefit, that they know (us) – and there's not all different workers coming in. Site 3, focus group</i></p>
5.3 Care co-ordinator	
One named worker takes a lead role in co-ordinating all care and support being offered to a woman. They will have an overview of all the women's needs, the agencies involved and their role.	<p>The EACPG highlighted the need for one named practitioner to act in a co-ordinating role to link across services and streamline care for women and their babies.^{51,52}</p> <p>Staff reported that they would ideally like one point of contact to co-ordinate care between agencies involved.</p> <p><i>Sometimes it feels like women are being flung around to different agencies and expected to be the middleman for this. (ES + women)</i></p>
5.4 Advocate	
Women should have access to a trained professional advocate, independent to her care team who can help to support her to understand and negotiate the complexity of the care system and, if needed, can attend meetings with her and speak on her behalf.	<p>The EACPG and mixed-methods systematic review⁵² highlighted that there is a need for an independent, trained advocate who can assist women navigating the system and support them through challenging experiences (case conferences, social work involvement, etc.). They noted that systems and processes can be retraumatising, confusing and stressful and having an independent person with specific training could support and advocate for women.</p> <p>Staff in focus groups also highlighted the benefits and specific role of advocacy.</p> <p><i>Recently, we got (a woman) an advocate because they were quite vulnerable. ... they were able to go out and meet her a couple of times before and really discuss what she wanted out of this meeting rather than us sort of saying 'What sort of things do you want?' and giving her some suggestions. They were able to come up with some really different stuff, so that worked quite well. Site 2, focus group</i></p> <p><i>The other thing where I think there's a real gap is the advocacy of the woman herself. The social worker is actually for the baby but my personal view is that the woman should have her own social worker as well because the interest of the unborn shouldn't necessarily trump the interest (of the woman). Site 1, addictions psychiatrist</i></p>

Requirement	Evidence source and illustration
5.5 Peer support	
Social support either through one-to-one mentoring or group work facilitated by someone who has experience of using or being in treatment for drugs during the perinatal period.	<p>EACPG</p> <p>The EACPG felt that peer support was an effective and important way of supporting women through a potentially challenging, busy and difficult time. Peer support was considered to be helpful as it was inspirational/aspirational rather than instructive and authoritarian. It was noted that it is essential to include formal support structures within services for peer support staff.</p> <p>In our study, staff in focus groups suggested that there may be benefit in providing inspiration or role models within the context of formal support structures for peer support staff.</p> <p><i>We need to get away from the negativity and start showing these people who have turned their lives around and who are in a better place now.</i> Site 4, focus group</p> <p>Women in our study also reported benefit in having contact with women with similar lived experience but who have gone on to have positive outcomes.</p> <p><i>I don't actually know what her role, her job was but just kinda spoke of her experiences and basically she went through the same thing as me and it was just nice to hear that and now she's doing good for herself, she's got her kids back into her care and now she's working and helping other people, it's just something I want to do.</i> 04_P1_c_LH</p>
5.6 Parenting skills and support	
In-person parenting skills education and support tailored to the women's needs should be offered. This may be provided in the woman's home or in a community venue or multiagency setting.	<p>The qualitative element of the mixed-methods systematic review⁵² found that, in various interventions, women reported that being offered parenting skills and education was valued, increasing parenting confidence and supporting engagement with services.</p> <p>The study interviews with women also found that women valued parenting support</p> <p><i>[Specialist education midwife] came out to the house and just showed me, like, how to bath properly, how to feed properly, the sleeping things, because I wouldn't have known half the stuff.</i> 04_P7_c</p> <p>Staff in focus groups also highlighted this as important to build the woman's confidence in parenting.</p> <p><i>It's about working with people and trying to enhance life skills, you know they might not have had positive experiences of parenting when they were a child, and they've no really got a real idea of where they're going, ... so just having somebody there to reassure them, to say, 'We can work with you, we can look at skills, we can look at other things that you might be able to get into' and giving them options.</i> Site 3, focus group</p>
5.7 Supported housing for mother and baby	
Supported housing options should be available for mothers and their babies, which should include the below details:	<p>The EACPG agreed that there is a need for more supported housing where women and their babies can receive care and a range of supports while still maintaining their independence. Residential places are not always appropriate or necessary, but many women are also navigating challenging public housing systems and need stability and support.</p> <p>Overall, our study found that women experienced a lack of stable, supported housing options for women who are pregnant and using drugs. Women who experienced supported accommodation found it valuable.</p> <p><i>It's like supported accommodation, so it's like staff there during the day on a week day, but you've got their phone numbers and stuff if you've got anything wrong, and they used to help with sorting out permanent housing and benefits and anything like that really.</i> 01-05ESa</p> <p>Staff in focus groups also highlighted the frustration of lack of supported housing options.</p> <p><i>They're in horrible housing situations and they just don't want to be there. I wish there was a safe place that we could take people when they're not surrounded by other people that are using drugs, or other people that are maybe influencing their choices.</i> Site 1, safeguarding midwife</p>
<ul style="list-style-type: none"> • Mother and baby rehabilitation units 	
<ul style="list-style-type: none"> • Supported tenancies for mother and baby and family units in the community 	

Requirement	Evidence source and illustration
	<i>It seems nonsensical to send a woman so vulnerable back out into the community without her baby and then make her wait for six weeks in inadequate housing in a very vulnerable situation around all of the kind of the things in the first place that maybe had driven her towards being in that situation. Site 1, focus group</i>
5.8 Perinatal mental health support	
Women who use or are in treatment for drug use during the perinatal period should be offered perinatal mental health support and interventions independent to their drug treatment support.	Our EACPG highlighted different models and capacity for delivering mental health care and support. However, access to perinatal mental health and longer-term, trauma-informed mental health care (for women who want this) was seen as essential.
This should include tailored psychological assessment and treatment, including assessment of potential for intimate partner violence and post-traumatic stress disorder as well as the women's social support systems.	<p>Our study found that while perinatal mental health teams were in place across the country, access to support was patchy. Some women could not access mental health support because they were receiving drug treatment services and had an allocated drug worker. Drugs services were often limited specifically to drug treatment rather than mental health and well-being overall.</p> <p>Staff in focus groups reported that there was often no perinatal mental health support for women who have lost custody of children, and in some areas, very little mental health support in general.</p> <p><i>Who looks after her from a mental health perspective if the baby is going to be removed and she can't actually access perinatal mental health because she has had a child removal? Site 1, focus group</i></p> <p><i>There's too great a gap between perinatal mental health and perinatal substance misuse. I think that there is a strong argument that there should be some overlap or combination. ... I think that there's a gap in the provision of maternity-specific psychological interventions before birth that could have a positive impact on women in terms of anxiety, depression, post-traumatic stress disorder and grounding techniques. Site 1, addictions psychiatrist</i></p>
5.9 Support for mothers to remain with their baby in the early postnatal period	
Mothers should be supported to remain with their baby in the early postnatal period where possible.	<p>The EACPG agreed that early postnatal care in the hospital postnatal ward can provide opportunities for women to develop parenting skills and confidence, including education for breast-feeding support and provision of emotional support to the mother when an infant is given neonatal abstinence syndrome diagnosis and treatment.</p> <p>The interviews with women identified both positive and negative experiences of postnatal hospital care.</p> <p><i>'They didn't want me to bond with her', 'I was getting conflicting information' re skin to skin. 'they're assuming I'm a drug addict ... even if I was, I've got a right to bond with my child' very judged 'Not blatantly' but other moms encouraged to bond. 07Esa</i></p> <p><i>It was really nice you know, they supported me' helped her with learning about baby's care. 09Esa</i></p> <p>Staff in focus groups also highlighted the importance of supporting mothers in early postnatal ward care.</p> <p><i>'I think women get really good care antenatally and there is lots of services available to them. I think where it falls down is postnatally. Site 2, specialist midwife</i></p> <p>Focus groups found that midwives in different sites provide this (support) differently – but felt <i>'this was really important to build the woman's confidence in parenting'</i>. Site 3, focus groups</p>

Requirement	Evidence source and illustration
5.10 and 8.5 Ongoing support for women whose babies are taken into care	
All services must provide ongoing support for women whose babies have been removed, independent of the baby, and this includes individualised care planning and tailored treatment addressing psychological needs.	<p>Women who experience removal of their baby are at greater risk of suicide or accidental drug overdose.³⁹ The scoping review found that there was a lack of guidance and recommendations around the specific support to be provided to women whose babies are taken into care.</p> <p>Our EACPG and evidence from the focus groups with practitioners identified that service involvement with women whose babies have been taken into care is primarily focused upon the needs and protection of the baby and not on the women's health and mental well-being. Women in the study whose babies were taken into care reported relapsing, suicidal ideation, and attempts.</p> <p><i>What's the next thing I try? I don't want to wake up, d'you know what I mean. And I'm not wanting that happening ... I was on the bridge. I just felt so hopeless.</i> 03_P12_LGc</p> <p><i>What they [social work] say to me is, 'We're not there for you, we're there for [daughter]'. So it's like, 'Well, what support have I got?' I have none now.</i> 02_P5_SLe</p> <p>Staff in focus groups confirmed the women's perceptions and expressed concerns about gaps or potential gaps in services for these women.</p> <p><i>I think women get really good care antenatally and there is lots of services available to them. I think where it falls down is postnatally, especially for those women who go through care proceedings and their babies, for whatever reason, are removed into foster care, I think still, very much services seem to follow the baby and the woman just you know, gets well (dropped).</i> Site 2, specialist midwife</p> <p><i>(There is a) distinction between women who lose their babies and women who keep them. Whereas, one set can access perinatal mental health and the others don't. Also, once a woman has delivered, she is considered vulnerable if she keeps her baby and would have a right to housing. With the other person, four days after pregnancy, you're just number 27 on the homeless (list).</i> Site 1, addictions psychiatrist</p>
Key requirement 6: accessibility	
6.1 Community hubs	
Women should be able to access a range of services and professionals in one easily accessible location	<p>There is evidence that having services accessible in one place could improve access to different services and support engagement⁵²</p> <p>Our study found that women are overburdened with appointments during pregnancy, and they reported that transport and work schedules are not considered by staff.</p> <p><i>I don't think they really get how tired I actually am and how exhausting it is to have an appointment every single day of the week so, there is no day I can just rest [yeah], that is overwhelming.</i> 01-P8_a</p> <p>Staff also highlighted the benefits of locations which provide a range of services, including additional supports which are also destigmatising spaces.</p> <p><i>We kind of try and make this place as trauma-informed as possible, so it almost feels like a house. So we have like showers here, we have a washing machine, a tumble dryer, a living room area, a pantry area. They can get pyjamas, clean underwear, any kind of selfcare, toiletries that they might need as well. We'd always tell women to come in and get something to eat.</i> Service manager, site 3, focus group</p>
6.2 Accessible locations	
Women's care should be provided in accessible locations (facilitated by 6.1). Staff should take into account women's schedule of appointments and locations when planning appointments	<p>Women told us they prefer in-person meetings, but these can be hard to get to – especially for women living in rural areas and also for women in large, urban areas. Barriers included cost, and the physical demands of making multiple journeys while pregnant and postnatally.</p> <p>Staff in focus groups recognised this problem.</p> <p><i>Just being flexible with them. And sort of assertive outreach, as well. You have to be able to sort of meet with them where is convenient for them, a lot of the time.</i> Site 2, focus group</p>

Requirement	Evidence source and illustration
	<p>Women who needed residential rehabilitation were often offered placements, which were located far away from their home which could be logistically and culturally difficult (from focus groups and from women).</p> <p>For example, a woman in our study, who was discharged from a residential rehabilitation service, was housed in a hotel within a large urban area several hours away by public transport from her child care and the substance use service she was court-mandated to attend (and found useful). This resulted in her traveling upwards of 5 hours each day just to attend her recovery group. This was eventually rectified, and she was rehoused, but this took several months. She felt she was being 'set up to fail'.</p>
6.3 Practical help to get to appointments	
<p>Practical assistance should be given where necessary, including transport fares to attend appointments</p>	<p>Providing support (transport fares or vouchers, appointment reminders) can be helpful to support engagement and acknowledge that often this group is also struggling financially. The systematic review⁵² found that interventions which include additional practical support (transport vouchers, food vouchers, etc.) supported an increased engagement in treatment as well as reduced substance use during the perinatal period.</p> <p>Women in our study reported various difficulties in attending appointments, including lack of finances for bus/taxi fares, and often the logistical challenge of having to negotiate several buses/modes of transport as a pregnant woman or with a new baby. Where support was provided either by the provision of a bus pass, or taxi fares, women found this helpful. Additionally, some women were supported in person to attend appointments, including child protection meetings and supporting their engagement.</p> <p><i>I have got a social worker and they pay for cabs for me to get there and back [yeah] so, that's also an option so, yeah, pretty easy. Yeah, no excuses not to go unless I am sick or something, yeah. 01_P8_a</i></p> <p>Staff in focus groups agreed.</p> <p><i>And half the time, once we were able to give them maybe, a bus pass, or help them with their benefits, they become – d'you know, like it was totally night and day. Site 4, focus group</i></p>
6.4 and 8.2: flexible contact methods	
<p>Services should enable staff to offer a range of ways for women to get in touch and maintain contact. Appointments and important information should be communicated verbally and/or by text as well as in writing to ensure that women have this information and understand what they can expect</p>	<p>Staff recognised the importance of providing options for women to make attending appointments easier. They highlighted that text reminders can be useful and that asking women how they prefer to be contacted is essential. This was also recommended by our scoping review.⁵²</p> <p>Women reported receiving letters about appointments after the appointments have happened and forgetting about that. Women receiving calls or texts between appointments appreciated this, were more responsive, and it supported engagement.</p> <p><i>I tend to find that the letters don't come until after you actually have your appointment, ... I just missed one with the perinatal team. 04_P8_LGa</i></p> <p><i>That one I've got just now she's really, really nice and I couldn't speak high about her enough, like, she always texts me to check up on me and she'll phone me every week just to make sure I'm getting on alright and I'm taking my iron tablets and my vitamins and stuff, she is really nice. 04_P7_LGa</i></p>
Staff level	
Staff level refers to direct care staff	
Key requirement 7: approach	
<p>'Approach', in this context, is defined as being the way in which practitioners engage with women and how care is delivered. Many domains are overlapping, but an underlying culture and ethos of practice, whereby the person's experiences and their social and emotional context is central to care delivery.</p>	

Requirement	Evidence source and illustration
7.1 Taking and spending time	<p>(Enabled by resources provided at strategic and service levels.) Practitioners need to have time available to spend with women to get to know them and to allow them to adopt a relationship-based and trauma-informed approach</p> <p>In focus groups and interviews with practitioners, it was noted that being able to spend time getting to know women, their families and their circumstances enable practitioners to develop stronger relationships and deliver more person-centred care that is centred on individual needs.</p> <p><i>We don't think that detox and rehab that narrative needs to be for everybody and we want to give them as much options and the discussion to happen over time. Site 1, focus group 1</i></p> <p>Women also appreciated where staff were able to give time, enabling person-centred care.</p> <p><i>She came back out and seen me again after and she was finished with me, she even come back out. She's phoned me a few times as well to make sure that everything's still going alright and that, aye she has been really good. ... (she kept saying) we need to make sure not just [baby]'s alright but you're alright' ... she wasn't just a midwife to look after the wean, she says 'I'm here for you, to support you as well and make sure you're getting the support you need'. O4_P4_LGa</i></p>
7.2 Relationship-based and person-centred	<p>Staff should prioritise provision of continuity of relationship-based care for this group of women</p> <p>The scoping review⁵¹ found that many documents suggested a named worker or lead professional should be allocated (such as a specialist midwife, health visitor or doctor) who is easily accessible/contactable. It was suggested that this could improve engagement in some documents.</p> <p>The qualitative papers included in the mixed-methods systematic review⁵² reporting on a range of treatment approaches and models of care consistently stated that relationship-based practice was fundamental. Within certain interventions (specialist substance use treatment, integrated model of care), a person-centred, individualised approach to care was recommended.</p> <p>Interviews with women revealed that when they did have a named worker who got to know them and provided consistency throughout, it improved engagement and their experience of the service. Where this relationship was lacking, women reported negative experiences of care provision.</p> <p><i>I'm comfortable with her because she's always been the same worker, d'you know what I mean, I've never had anyone else stand in for her and she's known me through my worst as well. So I feel comfortable with her. O3_P6_b</i></p> <p>Staff also identified the importance of building and continuing a relationship with mothers and babies.</p> <p><i>I think relationships are key. It's kind of what you're all highlighting, that relationship, being able to build with that person, and how safe they are able to feel with you. The benefits of consistency, containment, knowing that you have some element of control over what's going to happen to your care and the care of your baby as well. ... that is what lends itself to more positive outcomes and keeping families together. Site 4, focus group</i></p>
7.3 Kindness and listening	<p>Practising kindness and holding the women in positive compassionate regard not only supports engagement but also a greater understanding of the woman and her needs, ensuring that support can be tailored to her circumstances. Listening to the woman's experience and point of view will also help to ensure that a trauma-informed approach is taken and that care is delivered in a person-centred way</p> <p>The EACPG noted that kindness and listening are essential factors in providing care to this population, as evidenced in multiple maternity care reviews.</p> <p>In this study, women reported feeling more confident to engage with services when practitioners and staff were kind and empathetic.</p> <p><i>Especially with [specialist midwife]. She does listen to me and has suggestions for stuff that I'll be comfortable with. Yeah, I definitely feel listened to. O1_P12_c</i></p> <p>Women had negative experiences when they felt unheard or that they were not listened to.</p> <p><i>I don't think I've been listened to at all ... I'm just seen as the drug addict who harmed her baby, I get that. O2_P3_d</i></p>

Requirement	Evidence source and illustration
	<p>Staff in the focus group interviews also recognised the importance of kindness and empathy</p> <p><i>It's being able to think, 'I wonder what it's like to sit in mum's shoes? I wonder what this is like for her. And will this help any of the healing process if we actually think about what this is like for mum a bit more?' and I don't think they are thought about enough. I think that very much gets lost in the process. Site 2, specialist HV</i></p>
7.4 Flexible	
<p>Practitioners need to provide care that is responsive to a woman's needs and situation: being able to offer appointments at short notice or change their time or format if needed⁵¹</p>	<p>The mixed-methods systematic review⁵² found that in integrated and multidisciplinary models of care, women noted that a flexible, individualised approach benefitted them.</p> <p>In this study, women reported not feeling that their needs were properly listened to or accounted for and that providers could often be inflexible in their responses.</p> <p><i>She's very resistant to helping me find a solution to the problem that I'm having. Yeah, she's not very flexible. She's just like, 'I'm not doing that' sort of thing. Yeah, there's no sort of compromise. Yeah, she's not helpful at all really. 01_P8_ESd</i></p> <p><i>She wanted me to go all the way up to the [local sexual health clinic], but I could hardly walk and it's miles. 04_P5_LHd</i></p> <p>However, when women were offered different ways to get in contact, or felt that their provider was able to be accommodating, they felt supported and secure.</p> <p><i>I missed a lot of appointments because I had so many for my physical health so, my maternity appointments sort of went, took a back seat for a little while which was concerning, obviously, I missed like a couple of scans and stuff, but [specialist midwife] sort of like yeah, she made sure that everything got done swiftly. 01_P8_ESa</i></p> <p>Staff in focus groups also highlighted the importance of flexibility.</p> <p><i>But also just being aware that, you know, sometimes these women are having to engage with so many different professionals, so many different appointments, and they can really struggle with that. You know? And I think it's about us ensuring that we're flexible with them, and trying to get the best outcome for them and their baby, as much as possible, really. Site 2, focus group</i></p>
7.5 Non-stigmatising care and language	
<p>The way in which support is provided should not stigmatise the woman. All services should be respectful of their privacy and dignity</p>	<p>The scoping review included many documents that recognised that women will often have experiences of stigma within healthcare settings and that this may impact on their presentation and engagement in antenatal care. Documents also highlighted the importance of challenging stigma within services and providing non-judgmental, stigma-free care to women and their families.^{51,52}</p>
<p>For example:</p>	
<ul style="list-style-type: none"> • Appointments should not solely be available within buildings and spaces associated with drug treatment 	<p>In our study, women reported feeling judged and stigmatised by services, which made them fearful.</p>
<ul style="list-style-type: none"> • Conversations about drug treatment should only be held in private spaces where a woman's right to confidentiality can be respected 	<p><i>Some nurses were lovely ... a lot of nurses were judgemental because of baby's meds, (I was) made to feel guilty. 03_P6_a</i></p>
<ul style="list-style-type: none"> • Practitioners should be careful 	<p><i>Very judged, yeah. And maybe sometimes that makes it a bit harder, because I get really worried that whatever I do is going to be seen in a negative light. 02_P3_SLC</i></p>
<ul style="list-style-type: none"> • About their choice of language and not assume prior knowledge of a woman's situation or history based on her substance use history or drug treatment 	<p>Staff in focus groups also recognised the importance of ensuring women's privacy.</p> <p><i>(staff are) advocating for side rooms when it's safe for a woman to have that so that they have their privacy and that they can have these meetings (case meetings) like in a separate way where they're not being listened to. Site 1, focus group</i></p>

Requirement	Evidence source and illustration
Key requirement 8: care delivery	
8.1 Effective communication	
Accessible information must be available for women about services and resources available, treatment and medication options, choices and expectations, child protection proceedings and about wider social support agencies ⁵¹	<p>The EACPG suggested that services should provide a booklet/information for pregnant women who use drugs on key stages of pregnancy and about the different staff that will be involved in their care and their role as well as definitions of key issues [NAS/Neonatal Opioid Withdrawal Syndrome (NOWS), etc.]</p> <p>Women in this study appreciated clear and honest communication, especially in relation to child protection proceedings</p> <p><i>This is my main midwife for now. She's lovely, she makes sure that she tells you every single detail and you know what's going to happen next and you know what's happening down the line and she's really nice. 04_P7_a</i></p> <p><i>Just transparency, really. I would have appreciated that and also, better communication between the people who were dealing with my care. 03ESa</i></p> <p>Staff in focus groups also highlighted the importance of provision of clear information</p> <p><i>And as long as they know kind of what the plan's going to be, and there's no kind of – they're not going to get blindsided and they think someone's going to take their baby away, cause that's what they always think when you go out for that first visit. So I think you need to be honest from the very beginning, and setting expectations is key. Site 4, focus group</i></p>
8.3 Personal and timely response	
Communication to women who use drugs during pregnancy should be timely as women's circumstances may change quickly. Services should develop protocols for appropriate responses and response times for women who call seeking advice/support/appointments	Interviews with women revealed that they were often calling services to ask to speak to their worker or healthcare professional and being told they were unavailable. They were left waiting on a call back that sometimes did not happen, or was days later, or was from someone who knew nothing about their case/care plan and could not offer any support
This approach will also be supported by continuity of care and a care co-ordinator	<i>It's just the frustrating part of not being able to get a hold of them for so long cause like I feel it kinda knocked me back about ten steps. 04_P8_LGa</i>
8.4 Midwifery care – assertive outreach	
Staff should adopt an assertive outreach approach to engage with the woman	<p>Members of the EACPG highlighted examples within their own practice of assertive outreach and working hard to engage women. They noted that this is time-consuming and challenging but often yields positive results</p> <p>Staff in focus groups described benefits of assertive outreach</p> <p><i>Assertive outreach, as well. You have to be able to sort of meet with them where is convenient for them, a lot of the time. Site 2, focus group</i></p> <p><i>I have spent the best part of the last year, and for the Children and Family social worker that was involved in the case, just chasing one person around the city. All over the city, not just in the south, sometimes she was in other places with- like weekends, evenings, taking food parcels. Accessing grants and things and trying to engage the person in that way. Site 3, focus group</i></p>

