



South West
Academic Health
Science Network



Apollo Health
Innovations

Factors impacting equity of access and patient outcomes for patients (and potential patients) of perinatal services in the UK

Literature Review

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Factors impacting equity of access and patient outcomes for patients (and potential patients) of perinatal services in the UK

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Executive Summary

Background

Apollo have been commissioned by the SW AHSN to support the development of a programmatic approach to user-led design and engagement for regional health equity programmes (particularly perinatal health). This document provides a scoping review of the academic and grey literature exploring the factors that affect perinatal outcomes, access and experience within the UK. Learning from the review findings, Apollo will now go on to work with patients to understand their experiences, perceptions and suggestions for ways to improve perinatal health access and outcomes across the South West. We hope that the findings will be informative for the SWAHSN perinatal health equity programme to achieve their aim of improving health equity and reducing inequalities across the region.

Method

A scoping review following the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) guidelines (Page et al., 2021) and Popay's Guidance on the conduct of narrative synthesis (Popay et al., 2006) was conducted. A grey literature search of the [Patient Experience Library](#) and Google Scholar was also conducted to ensure sufficient coverage.

Findings

Factors found to affect perinatal outcomes in the UK included:

- Ethnicity
- Being born outside of the UK
- Migrant status
- Being part of the travelling community
- Living in deprivation
- Rurality
- Education and employment status
- Mental health
- Domestic abuse
- Intellectual disability
- Maternal age
- Epilepsy
- Smoking
- Substance use

- BMI

Factors found to facilitate perinatal outcomes included:

- Working with affected communities (including fathers) to co-design and refine perinatal services
- Establishing support networks/ peer-support groups
- Providing continuity of care
- Developing empathetic and compassionate professionals.

Common barriers affecting perinatal access and experience included:

- Language barriers
- Ineffective communication
- Lack of service awareness and understanding
- Previous negative experiences
- Concerns of obesity-related stigma
- Intimate partner violence
- Social services involvement
- Insecure housing
- Pragmatic issues of childcare and transport
- concerns about confidentiality

While some barriers appear universal , other barriers appeared unique to certain groups. Unique barriers were observed for:

- Migrant and minority ethnic women
- Bereaved parents
- Travelling communities
- Communities accessing mental health services
- Individuals from the LGBTQIA+ community

Finally, factors found to facilitate perinatal access and experience included:

- Continuity of care
- Volunteer support
- Cultural competency and sensitivity
- Access to appropriate meals and medication that meet dietary requirements
- Availability of interpreters
- Building trusting relationships
- [airing women with healthcare professionals who speak the same language and/or are of the same ethnicity
- Using innovative picture cards/language apps
- Providing extended appointments
- Availability of subsidised transport
- Reminders
- Use of accessible language and inclusive literature.

Existing innovations:

A range of innovative programmes and applications were identified, including those that seek to address health inequalities in stillbirths and premature births; breastfeeding; education and support for fathers; peer support networks; parenthood during employment and epilepsy.

Recommendations and suggestions

Building on the review findings, recommendations from this research include:

- Supporting targeted and tailored perinatal interventions
- Adopting a whole system or life course approach
- Supporting innovations that target efforts to reduce harmful lifestyle choices
- Improving the accessibility, availability, quality and relevance of information provided
- Co-designing perinatal innovations and services
- Supporting innovations and services that address identified gaps, e.g., paternal support, breastfeeding and bereaved parents
- Co-designing and delivering training across a variety of topics known to affect perinatal outcomes, access and experience.

Introduction

Perinatal definition and focus

Defined as the period of pregnancy and the first 12 months after birth (Jankovic 2020), the perinatal period is often described as a time of significant vulnerability for women, babies and their families (Redshaw & Henderson, 2016). While perinatal care affects women and their families worldwide, given the SW AHSN's focus, this report focuses on perinatal outcomes, experiences and innovations in the UK.

Perinatal care in the UK

Within the UK, accounts of inequalities in perinatal outcomes, access and experiences are widely acknowledged (Allen & Sesti, 2018; McLeish, 2017). For example, using the National Maternity and Perinatal Audit (NMPA) dataset, the Ethnic and Socio-economic Inequalities report describes perinatal inequalities in Great Britain for over 1.37 million women and their babies (Webster & NMPA, 2021). Often referred to as '[the social determinants of health](#)', there is increasing recognition that most health inequalities arise as a result of the conditions in which people are born, grow, live, work and age (Allen & Sesti, 2018).

However, the NHS is working to improve equity of perinatal outcomes as demonstrated in their five priority areas, associated interventions outlined in the [equity and equality guidance for local maternity systems](#) and [four pledges to improve equity for mothers, babies and staff](#) outlined in Table 1 below. Such policy commitments are further enforced in the [NHS Long Term Plan's](#) ambitions to reduce health inequalities experienced by black and minority

ethnic individuals across England over the next ten years.

Women who find perinatal care hard to access

As reported by Hadebe et al. in 2021, women who have experienced difficulties in accessing perinatal care include women needing multiagency services; socially isolated women; women living in poverty/deprivation; who are homeless; refugees/asylum seekers; non-native language speakers; victims of abuse; sex workers; young women; women within travelling communities; women who are subject to safeguarding concerns; women with substance and/or abuse issues; women with physical/emotional and/or learning disabilities; women who have been victims of female genital mutilation and women who are HIV positive (Hadebe et al., 2021).

What this review adds

Despite the widely reported inequalities in service access and outcomes, limited research has explored the factors that affect perinatal outcomes, access and experiences across a diverse range of communities with a specific UK focus. This review, therefore, sought to address the following research question:

"What factors impact equity of access and patient outcomes for patients (and potential patients) of perinatal services in the UK?"

Table 1: Inequality priority areas and pledges proposed by the NHS in their Equity and Equality Guidance for Local Maternity Systems and Four Pledges to Improve Equity for mothers, babies and staff.

NHS Inequality Priority Areas	Description	Planned NHS approach/explanation
1	Restore NHS services inclusively	<p>At the national level, the decline in access among some groups during the first wave of the pandemic broadly recovered in later months. Some pre-existing disparities in access, experience and outcomes have widened during the pandemic.</p> <p>Systems are asked to ensure that:</p> <p>Providers offer face-to-face care to patients who cannot use remote services</p>
2	Mitigate against digital exclusion	<p>Complete data collection is carried out to identify who is accessing face-to-face, telephone or video consultations, broken down by relevant protected characteristics and health inclusion group</p> <p>They take account of their assessment of the impact of digital consultation channels on patient access.</p>
3	Ensure datasets are complete and timely	<p>Systems are asked to continue to improve the collection and recording of ethnicity data. NHS England and NHS Improvement will support the improvement of data collection, including through the development of the health inequalities improvement dashboard.</p>

4a	Understand your population and co-produce interventions	<p>Understand the local population – its health outcomes and community assets.</p> <p>Understand staff experience using Workforce Race Equality Scheme data</p> <p>Use this understanding to plan co-production activities to design interventions to improve equity for women and babies and race equality for staff.</p>
4b	Action on maternal mortality, morbidity and experience	<p>Local maternity systems (LMS) are asked to ensure equity in access, experience and health outcomes for women from Black, Asian and Mixed ethnic groups and those women living in the most deprived areas. They may consider other protected characteristics and inclusion groups.</p>
4c	Action on perinatal mortality and morbidity	<p>LMS are asked to address the leading causes of perinatal mortality and morbidity for babies from Black, Asian and Mixed ethnic groups and born to women living in the most deprived areas. LMS may consider other protected characteristics and inclusion groups</p> <p>LMS are asked to:</p>
4d	Support for maternity and neonatal staff	<p>Equip maternity and neonatal staff to provide culturally competent care</p> <p>Ensure maternity and neonatal staff experience race equality in the workplace.</p>

4e	Enablers	<p>LMS are asked to create the conditions to help achieve equity by:</p> <p>Considering the factors that will support high-quality clinical care</p> <p>Working with system partners and the vcse sector to address the social determinants of health.</p>
5	Strengthen leadership and accountability	<p>LMS set out their shared vision in a Local Maternity Transformation Plan in 2017 and should now supplement this with a co-produced equity and equality action plan.</p>

NHS Pledges	Description	Planned NHS approach/explanation
1	The NHS will take action to improve equity for mothers and babies and race equality for NHS staff	<p>The NHS will take action through a five-pronged approach:</p> <ol style="list-style-type: none"> 1. Understand your population and co-produce action plans 2. Take action on maternal mortality, morbidity and experience 3. Take action on perinatal mortality and morbidity 4. Support maternity and neonatal staff 5. Create the conditions to achieve equity.
2	Local maternity systems will set out plans to improve equity and equality	Local maternity systems will work in partnership with women and their families to draw up and publish: an equity and equality analysis by 30th November 2021 and Equity and Equality Action Plans by 28th February 2022.
3	Local maternity systems will receive support to improve equity and equality	LMS will receive £6.8m to co-produce and implement their Equity and Equality Action Plans and implement targeted and enhanced continuity of care. LMSs will receive support and guidance from regional maternity teams, clinical networks and integrated care systems (ICS).
4	The NHS will measure progress towards the equity aims	<p>The NHS will continue to track:</p> <ul style="list-style-type: none"> The mortality rates for babies from Black, Asian and mixed ethnic groups The mortality rates for babies born to mothers living in the most deprived areas Maternal mortality rates by ethnicity Maternal mortality rates for women living in the most deprived areas.

Methods

Methodology

A review following the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) guidelines and Popay's *Guidance on the conduct of narrative synthesis in systematic reviews* was conducted.

Search strategy:

Peer-reviewed literature

Five peer-reviewed databases (CINAHL, Medline (OVID), Embase, PsychINFO and SocINDEX) were searched on the 29th December 2021. Search terms (Table 2) were designed to maximise sensitivity and specificity using the PICO framework. Reference list searches were also conducted.

Table 2: PICO search terms used

Population	Mother* OR Women OR Pregna* OR Birth OR matern*
Intervention	Perinatal or Peri-partum or Pre-natal OR Post-natal OR antenatal OR antepartum OR postpartum OR prenatal OR postnatal OR trimester OR puerperal OR puerperium OR post-birth
Comparison	N/A
Outcome	Inequalit* OR "health equity" OR disparit* OR inequit* OR "social determinant*"

Grey literature

Grey literature was also searched via Google Scholar and the [Patient Experience Library](#). Justification for the inclusion of grey literature includes its: acknowledged importance in the arsenal of search tools; vital adjunct to traditional database searches; ability to uncover innovative information often in an

earlier form following an acknowledged time lag between research and peer-reviewed publication and its ability to potentially minimise bias in a comprehensive search. Given the evolving nature of perinatal service design and delivery, particularly in light of Covid-19, the incorporation of grey literature can be well justified for the purposes of this review.

All review searches were conducted on the 29th December 2021.

Study selection

Studies were selected through a two-stage process. Firstly, two reviewers from the Apollo research team blindly assessed all returned abstracts for study inclusion using predefined inclusion and exclusion criteria outlined below and a collaboratively designed decision flowchart. When an inclusion decision could not be made from the abstract alone, the full article was retrieved. Potentially relevant articles identified through this screening process were then read in full and independently assessed for study inclusion by the Apollo research team. Any discrepancies that could not be resolved by discussion would have been resolved by being sent to a third reviewer until consensus was achieved, but this process was not required.

Inclusion criteria:

Articles of any study design conducted in the UK except for protocols, letters or theses published in the English language, between 2016 and 2021 that explored factors affecting perinatal service access, outcomes and/or experience were included. Justification for the date parameters used stems from the rapidly evolving nature of perinatal health service design and delivery and the desire to ensure only the most contemporary information was included.

Exclusion criteria:

Protocols, letters or theses not available in the English language, conducted outside the UK, or prior to 2016 that did not explore factors affecting perinatal service access, outcomes and/or experience were excluded. Due to limited resources, the authors could not ensure a sensitive interpretation of non-English articles. Non-English articles were therefore excluded, recognising this may have introduced a potential risk of publication bias.

Data extraction:

Two Apollo research team members independently undertook data extraction using a piloted data extraction form to facilitate data extraction consistency. Information extracted included: author name, publication date, study aim and location and any factors reported to affect perinatal outcomes, service access and/or experience.

Data analysis and synthesis:

Review findings were analysed using inductive thematic analysis as proposed by Braun and Clarke (Braun and Clarke, 2006). Identified themes were synthesised using a narrative approach defined as *“an approach to the systematic review and synthesis of findings from multiple studies that relies primarily on the use of words and text to summarise and explain findings of the synthesis”* according to Popay et al’s (1998) guidelines.

Results

As shown in Appendix 1, of the 133 unique peer-review abstracts identified, 40 articles were included. Forty-three articles identified through the grey-literature search were also included, resulting in a total of 83 articles being included. Review findings are presented in the following order: i) factors that affect perinatal outcomes in the UK ii) factors that facilitate perinatal outcomes iii) factors that inhibit perinatal access and experience and iv) factors that facilitate perinatal access and experience. Example perinatal innovations and programs are then briefly highlighted, followed by a list of recommendations for future innovation and service design.

Factors that affect perinatal outcomes in the UK

Factors found to affect perinatal outcomes in the UK included ethnicity; being born outside of the UK; migrant status; being part of the travelling community; living in deprivation; rurality; education and employment status; mental health; domestic abuse; intellectual disability; maternal age; epilepsy; smoking and substance use and BMI. Each factor and their related evidence are presented in turn below.

Ethnicity

Beginning with ethnicity, as recently reported in the media, *“pregnancy complications disproportionately affect black and minority-ethnic women...”* (The Guardian, 2021). For example, **ethnicity has been shown to influence: maternal mortality; still and preterm births; Apgar scores; c-section rates; hospital admission rates; maternal mental health; diabetes prevalence; late antenatal bookings; smoking and breastfeeding uptake**

(MBRRACE UK, 2021, MBRRACE UK, 2020). Each association is briefly described below.

Maternal mortality

The latest MBRRACE-UK Saving Lives, Improving Mothers’ Care report (2021) states that between 2017-2019, of the 2,173,810 women giving birth, 191 died during or up to six weeks after pregnancy; 495 women died during or up to one year after their pregnancy. While suggesting an overall decrease in maternal death rates, **women from Black ethnic groups are more than four times more likely to die during the perinatal period in comparison to women from White ethnic backgrounds** (MBRRACE UK, 2021, MBRRACE UK, 2020). The disparity in mortality rates between Black and White women was reportedly fivefold in 2015-2017, with a 2.5 fold difference also reported in 2009-2011 (Knight et al., 2020). The more recent MBRRACE-UK Saving Lives, Improving Mother’s Care report also suggests that **women from Asian ethnic backgrounds are also almost twice as likely to die in pregnancy compared to White women** (MBRRACE UK, 2021, MBRRACE UK, 2020). Similar findings have also been described by Knight et al., who conducted a national population-based cohort study concluding that women from Black and Asian communities have a higher mortality rate in comparison to White women (Knight et al., 2020). Women aged 35 and over and women from the most deprived quintile also had a higher mortality rate compared to White women, highlighting the complex and often interrelated nature of factors that affect perinatal outcomes as later described (Knight et al., 2020).

Stillbirth and preterm births

Mortality rates also remain exceptionally high for babies of Black and Black British ethnicity (MBRACCE UK, 2021). **Stillbirth rates among babies of Black and Black British ethnicity are more than twice those for babies of White ethnicity** (MBRACCE UK, 2021). **Neonatal mortality rates are 43% higher** (MBRACCE UK, 2021) **for Black and Black British ethnicity babies. Stillbirth and neonatal mortality rates for babies of Asian and Asian British ethnicity are also around 60% higher than for babies of White ethnicity** (MBRACCE UK, 2021). Recent research by the National Maternity and Perinatal Audit led by the Royal College of Obstetricians and Gynaecologists also reports that while overall stillbirth rates were low in 2020, rates were higher for babies born to women from South Asian and Black ethnic groups compared with White and Other ethnic groups and for women living in the most deprived areas (Webster & NMPA, 2021).

Furthermore, the NMPA analysed records of births between 1 April 2015 and 31 March 2017 in NHS hospitals in England, quantifying ethnic inequalities in stillbirth, preterm birth and foetal growth restriction (FGR). **Pregnancy complications were found to disproportionately affect Black and minority ethnic women – with 12% of stillbirths, 1% of preterm births and 17% of births with FGR attributed to ethnic inequality.** Importantly, adjusting for socioeconomic deprivation, maternal smoking and BMI had little impact on such outcomes, indicating that other factors related to discrimination based on ethnicity and culture may contribute to poor perinatal outcomes (London School of Hygiene and Tropical Medicine, 2021).

Apgar score

In addition to maternal mortality, still and preterm births, Apgar scores (a test usually conducted 1 minute and 5 minutes after birth to check a baby's condition) also appear to be affected by ethnicity. As reported by the Royal College of Obstetricians and Gynaecologists and others, **babies born to Black women are more likely to have an Apgar score of less than 7 at 5 minutes and be admitted to a neonatal unit when compared to babies born to women from White ethnic groups. Babies born to women from South Asian ethnic groups are less likely to have an Apgar score less than 7 at 5 minutes but are also more likely to be admitted to a neonatal unit when compared with babies born to women from White ethnic groups**, highlighting further disparities in perinatal outcomes (Webster & NMPA, 2021).

Congenital heart defects

Linked to the detection of signs and symptoms that may require extra medical care in Apgar scores, research suggests that the prevalence of congenital heart defects is *“significantly higher in Asian and Black ethnic groups compared with White ethnic groups (incidence rate ratios (IRR) (95% CIs): Asian 1.5 (1.4 to 1.7); Black 1.4 (1.3 to 1.6))”* with Knowles et al. concluding that *“significant ethnic variations exist in the incidence of congenital heart defects including for specific defects with high infant mortality”* (Knowles et al., 2016). The incidence of structural congenital heart defects requiring a cardiac intervention procedure during the perinatal period is 2.0 per 1000 infants in England and Wales. Compared with White ethnic groups, the incidence of all congenital heart defects in Asian and Black infants is around 50% higher and for severe and complex defects that have high infant mortality, the incidence in Asian and Black infants is reportedly double that of White infants, further unveiling disparities in

perinatal outcomes attributed to ethnicity (Knowles et al., 2016).

C-section rates and major postpartum haemorrhage

Other outcomes affected by ethnicity include caesarean or emergency caesarean birth rates, as reported by the NMPA in 2021. Caesarean birth rates are highest for women from Black ethnic groups, followed by women from South Asian groups when compared with women from white ethnic groups (Webster & NMPA, 2021).

Women and birthing people from Black ethnic groups also have higher rates of major postpartum haemorrhage (1500ml or more) when compared with women from white ethnic groups (Webster & NMPA, 2021).

Hospital readmission rates

Further evidence of poorer perinatal outcomes for Black and minority ethnic women is also shown in hospital readmission rates. Following the analysis of deliveries in January 2018-December 2020, **research shows a consistent trend of Black women having the highest rates of hospital readmissions during the six-week postpartum period, while White women consistently had the lowest readmission rates.** Further analysis suggests that **Black women had a significantly higher rate of readmission in the postpartum period over the course of 2020 than all other women, with a 30% difference between readmission rates for Black and White women (93 readmissions per 1,000 deliveries vs 68 readmissions per 1,000 deliveries)** (Care Quality Commission, 2021).

Intensive care admission rates

Similar results have also been suggested by Jardine et al., (2021) who report that **Black women are more than twice as likely as women from other ethnic groups to be admitted to intensive care during pregnancy** (odds ratio [OR] 2.21, 95% CI 1.82–2.68), with such associations only partially explained by demographic, lifestyle, pregnancy and birth factors (adjusted OR 1.69, 95% CI 1.37–2.09). Jardine et al. conclude that **black women have an increased risk of intensive care admission that cannot be explained by demographic, health, lifestyle or pregnancy and birth factors. Therefore,** interventions should focus on the early identification and management of severe illness in Black women in order to reduce inequalities in intensive care admission (Jardine et al., 2021).

Mental health

Furthermore, as reported by Womersley et al., in 2021, *“women from Black and ethnic minority backgrounds and lower socioeconomic groups are at greater risk of physical and psychiatric complications of pregnancy compared to white British women”*. Research by Redshaw and Henderson suggests Asian and Black women are substantially and significantly less likely to report being offered mental health treatment, 20 and 18 %, respectively, compared to 41 % of White women (Redshaw & Henderson, 2016). As later described (factors that affect perinatal access and experience), many reasons for reported disparities in mental health outcomes and experience have been put forward, including language barriers; unfamiliarity with the United Kingdom mental health system; racism; stigma; cultural misunderstandings; lack of awareness and beliefs about mental health; previous experiences of mental health services and a disparity between what women want and experience (Watson et al., 2019).

Late antenatal booking

Other areas of disparity reported in existing literature include antenatal bookings, with **women from minority ethnic groups more likely to book late**, with 62% of Black women booking after 10 weeks of pregnancy compared to 46% of the overall population (Public Health England, 2020). Research by McDonald et al., 2020, provides similar conclusions that women from Black or minority ethnic communities, born in Somalia or of the Jewish religion are more likely to book antenatal care after the recommended 10 weeks' gestation (McDonald et al., 2020).

Diabetes

Women from South Asian and Black ethnic groups and those from the most deprived areas also typically experience higher rates of hypertension and diabetes when compared with women from White ethnic groups and those in the least deprived areas (Webster & NMPA, 2021)

Smoking

Smoking has also been reported as considerably higher among White ethnic groups and those in the most deprived quintile (Webster & NMPA, 2021). Smoking during pregnancy has been shown to increase the risk of having a baby who is born early, with low birth weight, stillborn and increase the risk of sudden infant death syndrome (Webster & NMPA, 2021)

Breastfeeding

Similarly, rates of receiving breast milk at the first feed are significantly lower for babies born to White women and those living in the most deprived areas (Webster & NMPA, 2021). Although widely believed to positively impact the lives of both mother and baby, in the UK,

while 81% of women initiate breastfeeding, only 1% of women breastfeed exclusively for 6 months, as recommended by the World Health Organisation (Musgrave et al., 2021). The UK ranks lowest in the world for breastfeeding at 12 months of age (Musgrave et al., 2021). As later described, one intervention that seeks to improve these statistics is the Baby Buddy App which has been designed and implemented by the UK charity Best Beginning to reduce health inequalities experienced in breastfeeding (Musgrave et al., 2021). Maternal age (another factor found to influence perinatal outcomes) has also been shown to affect breastfeeding uptake, with younger women less likely to breastfeed at 6-8 weeks postpartum (Musgrave et al., 2021).

Being born outside of the UK

In addition to ethnicity, being born outside of the UK also appears to influence perinatal outcomes (Nellums et al., 2021). In 2018, **more than one in four births in the UK were to women born outside of the UK**. (Womersley, 2021 and Public Health England, 2020) However, Womersley et al. state that **women born outside of the UK are often over-represented in maternal and perinatal mortality figures**, highlighting the association between place of origin and perinatal outcomes (Womersley, 2021).

For example, evidence provided in the British Medical Association's report suggests non-UK-born women have a higher maternal mortality rate of 8.8 in comparison to UK born women (7.87 mortality rate). This figure rises when analysing the specific country of origin. For Jamaicans, for example, the relative risk (RR) compared with UK-born women (RR=1) is 6.36 and for Nigerians or Pakistanis, the relative risk is 2.25 and 2.24, respectively. Furthermore, a quarter of women who died during maternity in 2012–2014 were born outside the UK and

46% of these women were not UK citizens (Allen & Sesti, 2018).

Migrant status

Often linked to ethnicity and place of origin, the migrant status of an individual and their family also appears to severely influence perinatal outcomes (Filby et al., 2020). While Public Health England recently stated, *“recently arrived migrants, women with limited English proficiency (LEP), asylum-seekers or refugees, undocumented migrants and trafficked women are known to be at high risk of adverse outcomes, and multiple vulnerabilities can intersect and increase risk. However, migrant status on its own does not always confer higher risk... When comparisons are made within a single ethnicity, outcomes for infants of foreign-born mothers are sometimes better than those of UK-born mothers of the same ethnicity”* (Public Health England, 2020). Others acknowledge a *“clear relationship between migration and disadvantage”* with *“clear inequalities in health between migrant women and host populations”* (Allen & Sesti, 2018).

Nellums et al. report that migrants and refugees are at increased risk of poor obstetric outcomes compared to non-migrants and have been shown to seek antenatal care later and access fewer maternity services. Within the UK, migrant women comprise 23% of maternal deaths and are significantly less likely to receive the recommended level of antenatal care (Nellums et al., 2021). Suggested reasons for this disparity include the lack of a nutritious diet. Recent research suggests that food available at migrant centres is often not palatable or acceptable for pregnant and lactating women. For example, *“they give too much of rice, pasta and French fries which are actually not good... we should have some way of cooking ourselves.”* Similarly, *“the food in the centre that I’m breastfeeding my baby on...*

it’s just fish and chips, ugh... what was coming out from our breasts was like water” (Filby et al., 2020). Other suggested reasons include a lack of facilities for hygienic formula preparation and storing breast milk (Filby et al., 2020) as well as other identified factors such as policies of deterrence, fear, lack of trust and cultural/system level-barriers as later described.

Migrant women are not entitled to free NHS maternity services, including antenatal, perinatal or postnatal care and are charged 150% of the NHS rate (Nellums et al., 2021). As reported by Nellums et al., 2021, the cost of routine antenatal and postnatal care and an uncomplicated delivery starts at £6,500. Whilst such care is deemed ‘urgent and immediately necessary’ and cannot be withheld if payment cannot be made upfront, women are still chargeable.

Gypsy, Travellers and Roma

Gipsies, Travellers and Roma are also reportedly less likely to access perinatal healthcare services and experience significantly poor health outcomes compared to the general population (Jackson et al., 2017). As reported by Jackson et al., despite an often greater health need, there is low uptake of health services by the travelling community.

Deprivation

Deprivation also appears to significantly affect perinatal outcomes (Best et al., 2019, Heazell et al., 2020, Hadeve et al., 2021, Redshaw & Henderson, 2017; Harpur et al., 2021). For example, as reported in the Maternity Audit, **babies born to women living in the most deprived areas are more likely to be born early, be small for gestational age, have a low Apgar score, need admission to a neonatal unit or be still born** (Webster et al., 2021).

Stillbirths

As suggested by Best et al. (2019) and Harpur et al. (2021), infant mortality and stillbirth rates appear consistently higher in the most deprived areas (London School of Hygiene and Tropical Medicine, 2021). For example, Harpur et al. report that **every unit change in the deprivation quintile is associated with a 16% increase in the incidence rate of infant mortality** (Harpur et al., 2021). Data on 5,694 stillbirths and 2,368 neonatal deaths obtained from the Mothers and Babies: Reducing Risk through Audits and Confidential Enquiries across the UK (MBRRACE-UK) also identified that **women from the most deprived areas were 1.68 (95% CI 1.56 to 1.81) times more likely to experience a stillbirth and 1.67 (95% CI 1.48 to 1.87) times more likely to experience a neonatal death than those from the least deprived areas**. Described another way, **women living in the most deprived areas are 68% and 67% more likely to have a stillbirth or have a baby who died in the neonatal period compared with women living in the least deprived areas of the UK** (Best et al., 2019, MBRRACE 2, 2021). This equates to an excess of 690 stillbirths and 231 neonatal deaths per year associated with deprivation.

Researchers from the NMPA also estimate that 24% of stillbirths, 19% of live preterm births and 31% of live births with FGR would not have occurred if all women had the same risk of adverse pregnancy outcomes as women in the least deprived group. However, adjusting for ethnicity, maternal smoking and BMI substantially reduced these inequalities (12%, 12% and 16%, respectively) – suggesting that a considerable part of the socioeconomic inequalities in pregnancy outcomes can be explained by these maternal characteristics (London School of Hygiene and Tropical Medicine, 2021).

Congenital abnormalities

Reflecting previous discussions around congenital heart defects, socioeconomic deprivation was also significantly associated with neonatal death in babies born with a congenital anomaly (RR=2.45, 95%CI 2.00 to 3.02, $p<0.001$), preterm at 24–27 weeks (not Small for Gestational Age) (RR=1.94, 95%CI 1.50 to 2.51; $p<0.001$) and small for gestational age (SGA) at term (RR=2.03, 95%CI 1.17 to 3.52; $p=0.01$). Congenital anomalies accounted for most of the deprivation gaps for neonatal deaths (59%) (Best et al., 2019). Similar associations with congenital heart defects and deprivation have also been reported by Knowles et al., 2016 who concluded that children affected by CHD were more likely to be living in deprived areas.

Six-weeks check-up provision and uptake

Deprivation also appears to influence six-week check-up attendance and provision. Research conducted by Li et al., (2022) suggests that **a late or no six-weeks check-up is more common amongst women registered in more deprived areas**, younger women and women of preterm babies (Li et al., 2022). As indicated by Li et al., the provision or uptake of six-week check-ups does not appear equitable with younger women and those living in more deprived areas less likely to receive such a check (Li et al., 2022).

Late antenatal bookings

In addition to six-week check-ups, evidence suggests late antenatal bookings (after 10 weeks' gestation) are more likely for women living in more deprived areas (McDonald et al., 2020, Barber et al., 2017). Women who lived in the most deprived quintile waited on average 10 days longer from referral to booking than those living in the least deprived quintile (McDonald et al., 2020). As described by McDonald et al., antenatal booking

appointments offer a holistic assessment of a woman's physical, emotional and social health, timing is, therefore, crucial (McDonald et al., 2020). Early antenatal bookings enable minimising risks through early health promotions and health and social care referrals (McDonald et al., 2020). Late or missing antenatal appointments are, therefore, often associated with poorer perinatal outcomes (McDonald et al., 2020).

Mental health

Low socioeconomic status has also been linked to poor mental health due to stress and anxieties caused by low income or relying on government benefits for financial stability (Morrell, 2021).

Rurality

Perhaps particularly relevant to the SW AHSN, rurality is another factor that appears to affect perinatal outcomes. Social opportunities and prevention services are often limited in rural locations which can lead women to feel geographically isolated and lonely, feelings that can often contribute to women becoming unwell in the early stages of motherhood (Jackson et al., 2020). For example, a new mum living with pre-existing anxiety and depression in a rural town described, *"I don't really have a support network, it's my husband and that's it"* (Jackson et al., 2020). Similarly, while recalling their experiences of mental health in a rural area during the perinatal period, one participant acknowledged that their mental health deteriorated over a month when her health visitor had not visited her because she was 'over stretched' due to the large geographical area she had to cover (Jackson et al., 2020).

While some women reported paying for private treatment to help address some of the service gaps, e.g., counselling or

hypnotherapy, not all women could afford such services (Jackson et al., 2020). Other acknowledged difficulties living in a rural area include access to transport due to limited availability and high costs (Jackson et al., 2020). Some women explained that family members provided transport to facilitate treatment access. However, when this was unavailable, many women described missing treatment appointments with detrimental impacts on their health and wellbeing (Jackson et al., 2020). The geographical isolation and limited services experienced by pregnant women, mothers and babies was perceived to restrict beneficial socialising opportunities that benefited perinatal health and outcomes (Jackson et al., 2020).

Educational and employment status

Evidence also suggests that lower occupational/employment status, especially manual occupations and unemployment, are associated with increased risk of multiple adverse pregnancy outcomes including stillbirth, neonatal mortality, perinatal mortality, preterm birth and low birth weight (Thomson et al., 2021; Wilding et al., 2019; Heazell et al., 2020). For example, research conducted by Thomson et al. suggests that **babies born to mothers with unemployed partners at the antenatal booking appointment are 68% more likely to be born small for gestational age in comparison to babies born to mothers with employed partners** (Thomson et al., 2021). Similarly, evidence provided by Wilding et al., 2019 suggests **babies born to mothers educated up to secondary school level, who were unemployed or with unemployed partners are at greater risk of being small for gestational age** (Wilding et al., 2019).

Mental Health

Maternal mental health

As later discussed, the most recent MBRRACE-UK Savings Lives, Improving Mothers' Care report (2021) states that **maternal suicide remains the leading cause of direct deaths within the first year after pregnancy** (MBRRACE UK, 2021). Furthermore, as suggested by Womersley et al., it is a common misconception that the window for concern about perinatal mental health disorders closes after the first 6 weeks post-birth, *"approximately one third of women who experience perinatal mood and anxiety disorders continue to have symptoms beyond a year after delivery with depressed mothers showing significantly elevated levels of anxiety 3.5 years after childbirth compared with non-depressed mothers"* (Womersley et al., 2021). Timely, relevant and accessible interventions are, therefore, key in supporting perinatal mental health.

In addition to detrimental outcomes associated with perinatal mental health, including an increased risk of placental abruption, postpartum haemorrhage, infant and maternal mortality (Royal College of Psychiatrists, 2021) there is also a significant financial burn associated with maternal mental health and related perinatal outcomes. For example, ***"for every one-year cohort of births in England, the long-term costs from lack of timely access to good quality perinatal mental health care is estimated to be £1.2 billion to the NHS and social services and £8.1 billion to society"*** (NHS England, NHS Improvement, National Collaborating Centre for Mental Health, 2018). Approximately £6 billion of this £8.1 billion relates to the impact on the child rather than the mother.

Paternal mental health

However, one area often overlooked in factors affecting perinatal outcomes is paternal

mental health (Darwin et al., 2017). As recently stated by the Royal College of Psychiatrists – *"the importance of addressing fathers' mental health problems in the perinatal period is increasingly recognised with potential benefits for fathers, mothers and infants... fathers have similar rates of perinatal depression and anxiety to mothers... perinatal mental illness in fathers may be linked to adverse child developmental outcomes and child maltreatment particularly in the context of additional familial risk factors such as substance use, inter-parental conflict and socioeconomic disadvantage"* (Royal College of Psychiatrists, 2021). Paternal perinatal anxiety and depression can have a profound impact on fathers' wellbeing, functioning and relationships. Emerging evidence also suggests that their children may face an increased risk of adverse outcomes (Darwin et al., 2017). While paternal perinatal mental health costs are largely unknown, it is likely to be considerable given the UK's costs of maternal perinatal mental health are estimated at £8.1 billion, as previously described.

Interestingly, men largely describe their 'stress' as opposed to 'mental health' with reference to exhaustion, poor concentration and irritability. Despite feeling excluded by maternity services, fathers questioned their entitlement to support, noting that services are pressured and 'should' be focused on mothers. Men also emphasised the need to support their partner and protect their partnership as central to the successful navigation of fatherhood. Despite the presence of some informal support networks, fathers noted a paucity of tailored and targeted support for fathers, with a clear desire among fathers to have more information about pregnancy and parenting. For example, *"I wouldn't have a clue how to go about [accessing groups for fathers] with [partner] she can go online and find 28*

different chat rooms... I don't know if those things even exist for fathers and I wouldn't know where to look". Hearing about other fathers' experiences appears particularly valuable. Readers are encouraged to read Darwin et al. for an in-depth analysis of father experiences and suggestions.

Domestic abuse

Other factors affecting perinatal mental health include domestic abuse (often highly prevalent among women with severe mental health), an important risk factor for perinatal depression, anxiety and PTSD, as acknowledged by the Royal College of Psychiatrists. Domestic violence is often reported to start or escalate in pregnancy and is strongly associated with maternal suicide, homicide and adverse perinatal outcomes (Royal College of Psychiatrists, 2021). Heazell et al. also report an increased risk of late stillbirth for women who declined to answer the question about domestic abuse, demonstrating a further impact of domestic abuse on perinatal outcomes (Heazell et al., 2020).

Intersectionality of mental health, ethnicity and migrant status

Perhaps unsurprisingly, existing evidence also suggests intersectionality between mental health, ethnicity and migrant status (Womersley, 2021, Public Health England 2020, Moore et al., 2019). For example, research conducted by Moore et al. suggests that compared with non-migrants, migrants had statistically significantly increased odds of psychological distress and decreased odds of treatment (Moore et al., 2019). Another area of concern includes identified flaws in psychiatric diagnostic tools with widely used screening tests such as the Edinburgh Postnatal Depression Scale favoured in the NHS often unable to detect somatic symptoms

that women from non-Western cultures typically present (Womersley, 2021).

Intellectual disabilities

Women with intellectual disabilities also appear to have increased rates of adverse perinatal outcomes as well as increased rates of perinatal mental health (Royal College of Psychiatrists, 2021). Concerns about being embarrassed to seek help if they did not understand written information has been cited as a barrier to accessing perinatal service amongst women with intellectual disabilities or learning difficulties (Barber et al., 2017).

Maternal age

There also remains a disparity in perinatal outcomes depending on maternal age, with both younger and older women affected (Harron et al., 2020). For example, evidence suggests that **women aged 20 and under are at a 33% increased risk of stillbirth and a 75% increased risk of neonatal death compared to mothers aged 30-34.** (MBRRACE, 2021) Conversely, **mothers aged 40 and above are at a 41% increased risk of stillbirth and a 37% increased risk of neonatal death compared with mothers aged 30-34.** (MBRRACE UK, 2021). Furthermore, as previously described, not receiving or attending a six-weeks check-up is often more common among younger women, with the proportion of women receiving their six-weeks check-up on time highest among women aged 30 and over (Li et al., 2022).

Young maternal age is also associated with lower birth weight and higher rates of preterm birth, with risks of adverse perinatal outcomes reportedly highest among teenage women in all countries, including the UK reviewed by Harron et al., 2020. Harron et al. report that

teenage mothers had between 1.2% (95% confidence interval [CI] 0.7, 1.7, Sweden) and 2.0% (95% CI 1.4, 2.5, NSW) more preterm births, and between 9.8 (95% CI 7.2, 12.4, England) and 19.7 (95% CI 8.7, 30.6, Scotland) more deaths per 10 000 infants, compared with mothers aged 30-34 (Harron et al., 2020). *“Mothers ages 15-19 were between 1.26 and 1.39 times more likely to have a preterm birth compared with mothers aged 30-34... risk of mortality increased by between 2.21 and 4.38 times for teenage mothers compared with mothers aged 30-34 demonstrating an inverse relationship between maternal age and adverse infant outcomes”* (Harron et al., 2020). Harron et al. conclude that *“infants born to teenage mothers had universally worse outcomes than those born to older mothers... Current mechanisms to support teenage mothers have not eliminated maternal age-related disparities in infant outcomes; further strategies to mitigate excess risk in all countries are needed”* (Harron et al., 2020).

Epilepsy

Neurological causes, including epilepsy and stroke, are the second most common indirect cause of maternal death and the third commonest cause of death overall (MBRRACE, 2020). Concerningly, **there has been a statistically significant increase in maternal mortality due to Sudden Unexpected Death in Epilepsy (SUDEP)** (MBRRACE UK, 2020). One of the major findings identified by MBRRACE when reviewing perinatal care received by women with epilepsy was the low proportion whose medications were optimised either before or during pregnancy. Clear and rapid access pathways to neurology and/or epilepsy teams with expertise in caring for women before and during pregnancy need to be established. The MBRRACE report states that it is *“recognised that disparity in maternal mortality simply because of a woman’s ethnicity is unacceptable. The conversation*

now also has to encompass the recognition that it is equally unacceptable for women with pre-existing medical conditions such as epilepsy to receive a lower standard of care simply because they are pregnant” (MBRRACE UK, 2020). **It is estimated the risk of death in women with epilepsy is 10 times higher than in women without epilepsy** (Morley et al., 2018), with the highest risk of death in the third trimester following birth, miscarriage or termination of pregnancy (Morley et al., 2018).

Smoking and substance use

Lifestyle choices such as smoking and substance use have also been shown to increase the risk of having a stillbirth, a baby born early or with a low birth rate (Webster & NMPA, 2021, NIHR, 2017, Wilding et al., 2019).

BMI and diabetes

Finally, other maternal factors associated with poorer perinatal outcomes include weight or body mass index (NIHR, 2017, Barber et al., 2017, Wilding et al., 2019, Atkinson et al., 2016), with BMI acting as a significant predictor of maternal and perinatal health outcomes including an increased risk of maternal and perinatal mortality, gestational diabetes, pre-eclampsia, pre- and post-term birth, stillbirth and congenital anomalies when mothers have a BMI in the overweight or obese ranges compared with women who have a BMI in the recommended range (Barber et al., 2017). There are also increased risks for mothers with an underweight BMI, including preterm birth and miscarriage (Barber et al., 2017).

Barber et al. conclude that *“the likelihood of a woman experiencing an intrapartum intervention or adverse maternal outcome, or her baby experiencing very serious complications following birth, increases as BMI increases... babies born to women with a BMI of 30 kg/m² or above are less likely to receive*

skin-to-skin contact within 1 hour of birth or breast milk for their first feed than babies born to women with a lower BMI... **Women with an overweight or obese BMI also access antenatal care later than women with a recommended BMI** (aOR 1.11, 95%CI 1.09–1.12; aOR 1.04, 95%CI 1.02–1.06 respectively), and underweight women accessed care earlier (aOR 0.77, 95%CI 0.74–0.81). **Women with obesity were 42% more likely to access care in the third trimester compared with women with a recommended BMI.** All results remained significant following adjustment for socio-demographic variables” (Barber et al., 2017). Accessing care late in pregnancy means opportunities for routine screening such as the foetal anomaly scan at 20 weeks’ gestation are missed. Late antenatal bookings and its related impacts on perinatal outcomes remain a recurring theme throughout the literature reviewed, particularly for women with diagnosed and undiagnosed HIV (Peters et al., 2018).

Factors that facilitate perinatal outcomes

While identifying factors that affect perinatal outcomes is helpful, it is also important to acknowledge factors that facilitate beneficial outcomes, as outlined in Table 3.

As later highlighted, continuity of care appears particularly important in facilitating supportive and trusting relationships (Mills et al., 2016). Continuity of care has consistently been linked with positive perinatal experiences and perceptions, including for women who have previously experienced a stillbirth or neonatal death (Mills et al., 2016). When not available,

women often express dissatisfaction with traditional models of care where they encounter different midwives at each visit. For example:

“I found the hospital antenatal appointments extremely hard because I had to see about 4 different professionals each visit (other clerk, assistant to take BP, phlebotomist? to take blood, registrar and sometimes sonographer). Each time I had to run the gamut of meeting these people and them potentially saying something insensitive because they didn't know my background. It also meant that I got less psychological support than if these checks had been done by a community midwife who I had a relationship with. It was production line medicine rather than person centred care” (Mills et al., 2016).

As reported by Mills et al., often described as the “Rolls Royce” of care, “women felt strongly that continuity, being cared for by known and empathetic midwives at all their antenatal appointments was important.” (Mills et al., 2016) As described by one bereaved woman:

“Our Midwife in our subsequent pregnancy was the same midwife who delivered our stillborn daughter. She was simply amazing. Nothing was too much trouble. It was like having a personal midwife. She even came out to me one evening (around 10 pm) when I was concerned at lack of movement to reassure me. We will never forget her kindness and dedication” (Mills et al., 2016).

Table 3: Factors that facilitate perinatal outcomes

Facilitating factor	Supporting evidence
Working with affected communities (including fathers) to co-design and refine perinatal services	“Services should work in collaboration with fathers/co-parents and other family members to help them to support mothers in their recovery and to support fathers and co-parents to develop his/her relationship with their baby. They should assess the mental health needs of the father/co-parent and offer support or signposting where indicated” (Royal College of Psychiatrists, 2021).
Establishing support networks/groups	“Women described that support from friends, family, neighbours, the spiritual community and work colleagues helped them to cope. Women particularly valued and sought out support from others with the same experiences of poor perinatal mental health in person or through an online, virtual connection... women also identified that they wanted the opportunity to meet other mothers in similar situations either in group settings or in community-based peer-support schemes” (Watson et al., 2019).
Continuity of care, e.g. caseload midwifery (continuity of midwifery care from booking to the postnatal period)	“Men emphasised the need to support their partner and protect their partnership as central to the successfully navigation of fatherhood; they used existing support networks where available but noted the paucity of tailored support for fathers” (Darwin et al., 2017). “There was a significant reduction in preterm birth rate in women allocated to caseload midwifery when compared with those who received traditional midwifery care. Caesarean section births were significantly reduced in women allocated to caseload midwifery care, when compared with traditional midwifery care (24.3% vs 38.0%; risk ratio: 0.64; p=0.01; 95% CI 0.47 to 0.90; number needed to treat: 7.4) including emergency caesarean deliveries (15.2% vs 22.5%; risk ratio: 0.59; p=0.03; 95% CI 0.38 to 0.94; number needed to treat: 10) without increase in neonatal unit admission or stillbirth... This study shows that caseload midwifery implemented in a deprived inner city community improves outcomes by significantly reducing preterm births and birth by CS, without increasing NNU admission or stillbirth. The data also suggest that caseload midwifery had the greatest impact in the highest risk populations (mothers in higher IMD quintiles and from BAME backgrounds)” (Hadebe et al., 2021).

Empathetic, compassionate professionals

“Women valued building a relationship with empathetic and compassionate professionals during their pregnancy. Trust and mutual respect provided reassurance that everything possible was being done to improve the outcome of this pregnancy” (Mills et al., 2016).

Factors that inhibit perinatal service access and experience in the UK

Common barriers to accessing perinatal services include language/communication barriers (Peters et al., 2018); ineffective communication (Redshaw & Henderson, 2017); lack of awareness and understanding of existing services (Rayment et al., 2019); previous negative experiences (Barber et al., 2017); concerns of obesity-related stigma (Barber et al., 2017); intimate partner violence (Peters et al., 2018); social services involvement (Peters et al., 2018); insecure housing (Peters et al., 2018) pragmatic issues of childcare and transport (Moore et al., 2019) and concerns about confidentiality.

While some barriers appear universal across different groups, other barriers appear unique, particularly for migrant and minority ethnic women; bereaved parents; travelling communities; communities accessing mental health services and individuals from the LGBTQIA+ community.

Migrant and minority ethnic women

Barriers identified as particularly relevant to migrant and minority ethnic women include:

- Lack of understanding of the purpose and structure of perinatal care (Jankovic et al., 2020; Rayment-Jones et al., 2019; Moore et al., 2019), e.g. *“what is your understanding of the midwife's role? To check my baby's heartbeat that's about it”* (Filby et al., 2020)
- Lack of signposting to services - *“I actually, I would like legal help, or help that is, with my claim but I don't know how to get it or where to go to get some help”* (Filby et al., 2020)
- Inadequate interpretation services (Rayment-Jones et al., 2019,

McDonald et al., 2020; Chitongo et al., 2021), e.g. *“we did have the Language Line but you never know how this information that we were transferring to the women, how it was communicated because when you speak to the person on the Language Line, they translate in their language, of which you wouldn't be knowing whether, what they're now speaking is actually what you've conveyed for them to explain to the women”* (Chitongo et al., 2021)

- Lack of cultural sensitivity (Rayment-Jones et al., 2019, Filby et al., 2020; Firduos et al., 2020)
- Immigration status (Peters et al., 2018, Nellums et al., 2021), including legal entitlement to care (Moore et al., 2019) and concerns about being charged for maternity care meaning informed decisions can often not be made (Nellums et al., 2021). As reported by Nellums et al., 2021, there are significant inconsistencies in how migrant patients are identified, notified and informed about health service charges (Nellums et al., 2021)
- Restrictive and unclear migrant and asylum policies (Nellums et al., 2021), e.g. *“we have a high proportion of women here who are charged for their care and I do think that impacts women's engagement, especially with ante-natal care because they get frightened, they get bills which can affect their immigration status”* (Chitongo et al., 2021)
- Language barriers (Jankovic et al., 2020; Moore et al., 2019, McDonald et al., 2020, Nellums et al., 2021),

including the accessibility of information (Moore et al., 2019) and availability of information in own language (Filby et al., 2020)

- Differences in cultural beliefs, values and practice (Jankovic et al., 2020, Moore et al., 2019) such as not disclosing pregnancy to protect the child from ill-wishers
- Not receiving perceived culturally appropriate/sensitive support (e.g. no available female doctors) (Jankovic et al., 2020, Public Health England, 2020)
- Poor health literacy (Moore et al., 2019, Chitongo et al., 2021)
- Cross-cultural applicability of screening instruments (Moore et al., 2019)
- Perceived discrimination (Filby et al., 2020)/ health provider assumptions and attitudes based on race, class, ability and/or age (Rayment-Jones 2019, Jankovic et al., 2020, Redshaw & Henderson, 2017; Chitongo et al., 2021; Firdous et al., 2020, Public Health England, 2020)
- Insufficient healthcare professionals.

However, it is important to acknowledge that, as reported by Moore et al., many of the reported barriers above *“place the onus on women, characterising them as hard to reach, rather than underserved”* (Moore et al., 2019)

Bereaved parents

Other population groups with specific barriers included bereaved parents where ineffective communication; poor interpersonal skills; not feeling listened to; lack of continuity of care and insensitive follow ups were identified as significant barriers to perinatal care and experience, with many women believing improved communication may have changed their perinatal experience (Mills et al., 2016). For example, *“the greatest sadness of all is that*

this could have simply been avoided if the midwives had listened to me and spotted the obvious signs that were there to see such as the infection in my water and my slow rupture of membranes” (Redshaw & Henderson, 2017) Similarly, *“the main upset was having to explain every time to different midwives my situation because it was someone different each time and they hadn't read the notes so would ask the same questions, “I bet you're excited” answer “no, not excited just petrified of losing my baby.....” P 311”* (Mills et al., 2016)

Travelling communities

Language, literacy levels, discrimination, limited access to the internet and cultural concerns also appear particularly influential for travelling communities accessing perinatal health services (Jackson et al., 2017), particularly with regards to immunisations and vaccinations. For example, *“I took my son twice [for vaccinations] I didn't know what they were actually saying, I didn't know what it was for; I didn't understand. If I go somewhere I do manage to make myself understood, that time I didn't”* (Jackson et al., 2017). Many participants described being unable to read immunisation leaflets or letters/texts about appointments as well as struggling to make sense of conversations held with healthcare professionals (Jackson et al., 2017). Other barriers identified as unique to the travelling community included difficulties registering with a GP practice without a fixed address and a nomadic lifestyle that often meant letters were sent to outdated addresses.

Mental health services

Other barriers that appear unique to accessing perinatal mental health include stigma, guilt and shame, particularly concerns that parents might be seen as a 'bad' or 'weak' or risk having their children removed and cultural

explanations/transferability of mental illness definitions and checklists.

Extensive research conducted by Watson et al. (2019) identified several other factors that also appear to affect access to and experience of perinatal mental health services. Barriers encountered often centred around:

1. **Awareness and beliefs about mental ill-health** - with many women not considering symptoms to be an illness, attributing symptoms to practical problems such as a lack of rest, isolation or support, or not having the language to describe the collective symptoms as a disorder, e.g. *"don't know what to call it, in Pakistan where used to live, they don't have depression there. There is no word in Urdu for depression."*
2. **Cultural influence** - Black Caribbean and South Asian women explain that depression is culturally unacceptable because of its impact on women fulfilling their role in society, with Bangladeshi women seeing depression as a sign of weakness. For example, *"I do think that Black people get depression, but I don't think we're allowed to have depression"* Watson et al., reports that many articles reviewed described how it was culturally unacceptable for women to talk about feelings or emotional issues outside the family unit or home and if such feelings were revealed, it would result in stigma.
3. **Awareness of support and fear** – many women are often not aware of the available support for women with perinatal mental health problems. Other women reportedly avoid accessing perinatal mental health services due to a fear of being labelled with a diagnosis, not wanting to take

medication or wanting to avoid services that were not facilitated by providers of the same ethnic background. For example, *"I wouldn't wanna particularly unburden myself to some white woman if I'm honest about it... it's about having someone you can chat to who understands what you're doing, where you're going, where you're coming from and all that kind of stuff"*. However, as recognised by Watson et al., 2019, many of the fears and concerns raised by women from minority ethnic backgrounds are also experienced by White British women, including a fear of being considered an unsuitable parent due to their mental health problems. However, stigma appears to disproportionately affect people from ethnic minority backgrounds who may experience what Watson et al. describe as double stigma of experiencing prejudice or discrimination within the healthcare service setting and internal stigma within their own cultural communities.

4. **Cultural and practical barriers** – throughout their review, Watson et al., 2019 also describes how women may be required to overcome cultural expectations that they will not discuss personal issues outside the family home as described above. Other cultural barriers included lack of culturally appropriate services, e.g. being seen by male providers, particularly if husbands were not attending with them. *"In Pakistan we only saw lady professionals, but here you don't have a choice, you have to see the men as well otherwise you don't get to see a doctor. My husband is always at work so he can't come with me, I feel very uncomfortable."*

5. **Language difficulties** can also make it difficult for women to explain their symptoms and ask for support, particularly if the information is not provided in their first language and interpreters are not available.
6. **Detrimental attitudes** from health care providers can also prevent women from accessing perinatal mental health services. Women from ethnic minority groups reported that some healthcare providers were too busy, did not ask about perinatal mental health problems or dismissed women's concerns.

LGBTQIA+

birthing people from LGBTQIA+ communities may also face additional barriers to accessing perinatal services associated with their sexual and gender identity (Morrell, 2021). Reports of transphobia, homophobia, prejudice and discrimination amongst LGBTQIA+ communities are unfortunately not uncommon (Morrell, 2021) with perinatal experiences of partners in the LGBTQIA+ community under-researched. Recent research suggests non-birth mothers have specific needs and stressors warranting tailored perinatal mental health support. Furthermore, where the gender of the pregnant person/partner does not conform to expectations, the quality of care received can be negatively affected (YHNN Network, 2021). Authors have indicated a need for health care providers to communicate responses for different feeding choice other than chest feeding and that providers should neither assume a desire to chest feed or push for it. Readers may be interested in watching the following [YouTube video](#).

Factors that facilitate perinatal service access and experience

Finally, mirroring some of the factors found to facilitate perinatal outcomes, factors found to facilitate perinatal service access and experience, including continuity of care, are outlined in Table 4.

Table 4: Factors found to facilitate perinatal access and experience.

Facilitator	Supporting evidence
Continuity of care	<p>“I had the same three midwives care for me over a two day period. This was really good as I knew them when the shifts changed and they understood the situation without me having to tell them. All were excellent in their care for me. The two midwives we had were amazing. They looked after us and made a hard situation bearable. They were a credit to their profession and instilled a great belief in the nursing system. I can’t thank them enough and will always be grateful” (Redshaw & Henderston, 2017).</p>
Volunteer support	<p>“Third sector organisations offering volunteer support for pregnant women and new mothers can be valuable partners in reaching very disadvantaged women who may find it difficult to engage with services. Volunteers can build up a relationship of trust with vulnerable mothers over time, but need to be well supported to do this safely and effectively” (McLeish et al., 2017).</p> <p>“The volunteers enabled these mothers to feel noticed: “[The mother in prison] said, ‘Thank you for coming to see me’. It was really important that she was remembered” (McLeish et al., 2017).</p>
Cultural competency and sensitivity	<p>“Women from minority ethnic groups in three studies spoke about the importance of the cultural competency of HCPs to promote and encourage help seeking” (Jankovic et al., 2020).</p> <p>“What women want - women identified a number of ways that perinatal mental health service provision for women from ethnic minority backgrounds could be improved. They suggested that health professionals would benefit from cultural competency training [41], and that culturally specific support should be provided” (Watson et al., 2019).</p>

Access to appropriate meals and medication that meet dietary requirements	“Appropriate meals that meet dietary requirements regarding the women’s needs of having Halal... also lacked detailed information regarding medication and whether it was free from animal based products” (Firdous et al., 2020).
Interpreter services	<p>“All women reported that interpreters were always available at their IA centre and hospital appointments. Satisfaction was expressed at the quality of the Language Line service. There was no clear preference between telephone or in- person interpreters” (Filby et al., 2020).</p> <p>“For women with experience of trauma, abuse and discrimination or those who lack a sense of control, the ability to build a relationship with a health care professional was key to regaining trust in the system and control over what happens to them and their baby” (Rayment-Jones et al., 2019).</p>
Building trusting relationships	<p>“Trustful relationships with health professionals were important and continuity of care valued. The importance of relationships with health professionals, with GPs and Health Visitors particularly, emerged strongly across all six communities. Many Travellers, predominantly women, described positive relationships based on trust and respect that often developed by attending the same GP practice and seeing the same health professionals over a prolonged period of time” (Jackson et al., 2017).</p>
Pairing women with healthcare professionals who speak the same language (although not recommended as this places extra pressure including workload and responsibility/accountability on healthcare professionals)	<p>“When I speak to my patients [sic] in their own language, they feel more comfortable, secure and confident” (P 19) Some participants who spoke the same language as some of the women receiving care in the unit reported that the provision of language concordant care can improve women’s experience, increase their comfort, enable them to feel listened to and enhance their satisfaction with the care they receive. “it is such an added benefit when I care for women that speak the same language as myself. I have full confidence that they there is full informed consent and that they are in control of their labour” (P 17) (Chitongo et al., 2021).</p>
Same ethnicity	“Where support was facilitated by someone from the same ethnic background, women felt that the sessions were culturally specific and sensitive” (Watson et al., 2019).

Using innovating picture cards/language apps	“In order to overcome communication barriers, participants also described other approaches used in practice, including friendly body language, adjusted speaking styles, innovating creative picture cards, and using language apps on digital devices” (Chitonogo et al., 2021).
Extended appointments	Particularly for underserved communities (Filby et al., 2020).
Bookable subsidised transport	“Traveller participants, particularly women, across all six communities, reported a range of methods by which they are prompted to attend for immunisations for their children or themselves. Most commonly they referred to letters from their GP practice
Recall and reminders	or from school to inform them that a vaccination is due. Some spoke about receiving texts and telephone calls as a reminder to attend or to rebook a missed appointment. These recall and reminder systems appeared to be seen as effective for the majority of people including those who travel (when texts are useful). Those with literacy and language barriers employed a variety of strategies to navigate these systems, including using Google Translate to understand the letter and asking staff at the GP practice to read out the letter” (Jackson et al., 2017).
Use of accessible language	“She’s good, I like her [the Health Visitor]. You’re worried about things and you say to her like “I don’t know what, what I should do”. She, she’ll tell you, but she’ll tell you in our words that we understand... whereas if you go to a doctor... you’ll sit there and you’re thinking “I don’t know what you’re saying but I’ll pretend I know otherwise I’ll look stupid”, you know what I mean?” (Jackson et al., 2017).
Inclusive literature	“All midwifery educators and hospital Trusts should be providing staff education about how to work in an inclusive manner, and asserting that the use of correct gender pronouns is a necessity. It is also important that any reading material or online literature recommended to service users is inclusive and portrays both heteronormative and non-heteronormative different family structures” (Morrell, 2021).

Example innovations, innovation programmes and innovation funds

This penultimate section explores existing innovation programmes/innovation funds and innovations both within and outside the South West that directly respond to some of the barriers and enablers identified above.

Innovation programmes/innovation funds

Department of Health and social care fund

Following a new £7.6 million health and wellbeing innovation fund to help give babies the best start in life, 19 projects have been funded by the Department of Health and Social Care to promote nutrition, learning, language development and mental health during the perinatal period. Designed to reduce health inequalities as outlined above, some of the funded projects and innovations include a scheme in Leicester that will provide a joined-up care pathway for all families with a focus on BAME communities, giving children the best start in life complementing existing statutory provision. The service will expand the reach of breastfeeding antenatal support, with a focus on younger women and those who do not speak English. Other funded innovations and projects specific to the South West include:

- Trelya, Cornwall - The current service 'Skylar' is a community-centred, whole-family provision that takes a '360-degree holistic approach' considering and working within all areas of each child's life. The project will expand to include a specialist provision for

children and families from pregnancy to 2.5 years

And

- Splitz Support Service, Wiltshire, South West England - The project aims to improve community knowledge, access to and engagement with pre-conception, perinatal, domestic abuse and other specialist services for targeted communities. The service employs BAME community development workers aimed at increasing the number of BAME being referred and supported to domestic abuse and family interventions and improving services to meet the health and social care needs of individuals and groups. It delivers dedicated community-based individual and group programmes targeted at vulnerable young women (principally care leavers) at risk from abusive relationships, unwanted pregnancies and self-harm/suicide.

For more information about these projects and the innovation fund, please click [here](#).

IMPROVE HIT Programme - Perinatal Mental health

The [IMPROVE HIT](#) programme (improving perinatal mental health, health integration team) based in Bristol consists of a team of mental health practitioners, women and children's health practitioners, commissioners and academics working together to improve the identification of services and support for parents with mental health issues during the perinatal period. The four areas IMPROVE HIT focuses on include:

- Improving the care pathways for mothers screened for depression and anxiety
- Collecting information to identify those with past or current severe mental illness
- Helping parents make informed decisions about medication during pregnancy and breastfeeding
- Addressing the role of fathers and ensuring perinatal care pathways refer to men

The overall aim of IMPROVE HIT is to improve the identification and subsequent care of parents with poor mental health before and following the birth of their child.

Better start Bradford

Between 2015 and 2025, [Better Start Bradford](#) will provide over 20 projects for pregnant women and families designed to improve emotional and social development, communication, language development, nutrition and reduce obesity.

Action for Children – Parent Champion Programme

Centres in Torbay and Plymouth run a successful [Parent Champion Programme](#) where volunteers with lived experience offer parents and carers advice and support for their

mental health. The programme has been very successful and received highly positive feedback.

Peer support

The [Family Action Perinatal Support Services](#) are early intervention, low-intensity services for those with low to moderate level diagnosed mental health issues or at risk of developing perinatal mental illness. The services are led by a professional project co-ordinator with early years, health or social care background and provided by a team of volunteer befrienders who have experience of parenthood and sometimes have received help from the service themselves.

PATH – perinatal mental illness

[PATH](#) is an Interreg 2Seas project designed to enable women, families and healthcare professionals to prevent, diagnose and successfully manage mild/moderate perinatal mental illnesses via radical systemic change, developing an inclusive, holistic health structure and co-creation with patients. Main outputs from the PATH project include a new multi-media international support hub, including gaming/avatars, to help families develop parental awareness and recognise, prevent and overcome perinatal mental illness (PMI); scientifically evaluated modular prepared parenting & PMI training (building on existing best practice) to increase knowledge and upskill healthcare professionals/employers/parents; a multi-media campaign to raise awareness of and destigmatise PMI and community support groups for new families, increasing self-resilience via the wider community and social networks. South West partners for this project include Plymouth and District Mind.

Innovations

LGBTQIA+ - Mummies Tribe

The LGBT Mummies Tribe was founded by Laura-Rose and Stacey after encountering numerous barriers when starting their own family. Purpose: to educate; share and celebrate by achieving parity for LGBT+ people, both in terms of ease of access and also the quality of care through lobbying for equality, visibility and policy change for LGBT+ women and people; providing information, guidance and knowledge on the different pathways to parenthood through the LGBT Mummies Tribe website, social channels and support groups and creating a kind and caring safe haven and community for like-minded women and people who are looking to start a family. For more information about the LGBT Mummies Tribe, please click [here](#).

Stillbirths and premature births - Tommy's App

The [Tommy's App](#) is a clinical decision tool developed for women and maternity staff designed to prevent stillbirths and premature births. It uses AI to process the data routinely gathered during antenatal appointments to assess individual risk of potential complications. Tommy's App is due to be nationally rolled out in [2024](#).

MUTU System – exercise

The [MUTU system](#) is a health tech application for women offering evidence-based exercises using real-time videos and expert-led support for perinatal health.

Baby Buddy App – education and support, including breastfeeding for mothers, fathers, co-parents and caregivers

[Baby Buddy](#) is a free multi-award winning app that provides support for families from conception to baby's fifth birthday. Designed to increase parental confidence and capacity, Baby Buddy is also designed to support the physical and mental wellbeing of both parents and infants, introducing personalised information for fathers and co-parents alongside mothers. Having reached more than 3 million families across the UK, trained and supported over a thousand professionals, the Baby Buddy App has been successfully integrated into more than 27 localities of maternity care pathways across the UK.

Dad Matters – paternal support

[Dad Matters](#) is a Home-Start project which helps prepare dads for the arrival of a new baby, build successful relationships with their families and look after their own mental health and wellbeing. This project aims to work through targeted interventions for Dads in Salford, who can be prone to develop poor mental health or may find themselves supporting a partner with perinatal mental health illness and supporting their needs.

MUSH – peer support networks

[Mush](#) is a free app that supports mums to meet with other women nearby to develop peer support and friendships. The app is on the pathway at a number of hospitals to better support women in their transition to motherhood.

Peppy health – life transitions during employment

Designed to support people through life's transitions, including becoming parents or

fertility journeys, [Peppy](#) connects employees with experienced practitioners to ensure they feel supported and informed about health care experiences and services. They offer specialist video call appointments and targeted mental wellbeing programmes as well as an extensive library of resources.

Recognize – employment

Similar to Peppy health, [recognize](#) provides perinatal health and wellbeing services, helping workplaces to understand and support colleagues who are also new parents.

PERIPrem (Perinatal Excellence to Reduce Injury in Premature Birth)

Launched in April 2020, [PERIPrem](#) is a perinatal care bundle designed to improve the outcomes for premature babies across the West and South West AHSN regions. Described as the first of its kind, the bundle supports maternity and neonatal units in implementing innovative elements of care that may contribute to a reduction in brain injury and death.

EpSMon – epilepsy

The SUDEP self-risk assessment and communication tool ([EpSMON](#)) is a multi-award winning structured, evidence-based risk assessment and communication tool that provides prompts to check for any changes in a person's epilepsy. Midwives can encourage women with epilepsy to download this free app on their phones at prenatal bookings. EpSMon was created by a team of partners based at Plymouth University; SUDEP Action; Cornwall Foundation NHS Trust and Royal Cornwall Hospital.

Recommendations:

From the findings of the review, we provide the following recommendations:

Support targeted and tailored interventions

Innovations and service design should be targeted and tailored to different community groups. For example, targeting breastfeeding information and support in specific areas/communities where breastfeeding rates are low (younger women, White ethnic groups).

Adopt a ‘whole system’ and life course approach

Innovations designed to improve perinatal outcomes, experience and access should also incorporate a ‘whole systems’ or life-course approach that address wider determinants of health as opposed to focusing on a single barrier or concern (Thomson et al., 2021). As argued by Prady et al., focusing on a single risk factor when designing research, innovations or services may mean the complexity of health inequalities are overlooked and deficits within the existing system are disregarded (Prady et al., 2016).

Target efforts to reduce harmful lifestyle choices and behaviours

Lifestyle choices such as smoking, maternal obesity, diabetes and substance use may also benefit from targeted efforts. Targeting efforts to reduce such behaviours and lifestyle choices such as smoking cessation services, weight loss

services, improving periconceptional folic acid intake, folic acid food fortification and interventions to reduce obesity in women of childbearing age in an engaging and meaningful way could be beneficial (Best et al., 2019).

Improve accessibility, availability, quality and relevance of information provided

This includes providing information in a variety of languages and formats across a range of settings, e.g. posters, notices, leaflets, photographs, online video and audio clips. Ensuring effective cross-cultural understanding is also warranted, as is ensuring any reading material or online literature is inclusive and portrays both heteronormative and non-heteronormative different family structures.

Co-design perinatal innovations and services

As stated in the equity and equality guidance referred to in the introduction of this review, perinatal innovations and services should be co-produced with the individuals who use these services, their families, carers and local communities. It is vital that service-user insights shape perinatal innovation and service design to ensure they are acceptable, appropriate and valued. Identifying ways to facilitate continuity of care in existing pathways was also identified as essential.

Support innovations that address existing gaps, e.g. paternal support

As suggested by Darwin et al., resources are needed that are tailored to men, framed around fatherhood and resilience rather than mental health or mental illness that align with men's self-care and their role as supporter and protector (Darwin et al., 2017). Darwin et al. *"propose developing and evaluating information resources in different modalities i.e. printed, online that are made more accessible by being framed around fatherhood and including reference to stress and behaviours"* (Darwin et al., 2017). Service delivery that focuses on the psychological wellbeing of the couple and family rather than the individual may also be beneficial.

Bereaved parent support

Other suggested interventions include interventions that enhance appropriate and sensitive care pathways for bereaved parents (Mills et al., 2016). As acknowledged by Mills et al., current interventions designed to alert professionals to previous stillbirth or neonatal deaths, such as prominent special sticks are not consistently recognised or acknowledged in practice suggesting possible room for improvement (Mills et al., 2016).

Training

Recommendations frequently described in existing literature also included the co-design and delivery of training at both an undergraduate and postgraduate level focusing on cultural/competency sensitivity, religious beliefs including birth customs, entitlements to care for migrant women, bias and discrimination, epilepsy, bereavement, trauma-informed care, weight management services, sexual and gender identities including

correct gender pronoun use, volunteer support and perinatal mental health.

Priority areas for diabetes

Readers are directed to the study by Ayman et al., 2021, titled "Top 10 research priorities in diabetes and pregnancy according to women, support networks and healthcare professionals" for the information regarding (i) diabetes technology, ii) best test for diabetes during pregnancy, iii) diet and lifestyle interventions for diabetes management during pregnancy, iv) emotional and wellbeing needs of women with diabetes pre- to post-pregnancy, v) safe full-term birth, postnatal care and support needs of women, vi) diagnosis and management late in pregnancy, vii) prevention of other types of diabetes in women with gestational diabetes, viii) women's labour birth experiences and choices and improving planning pregnancy (Ayman et al., 2021).

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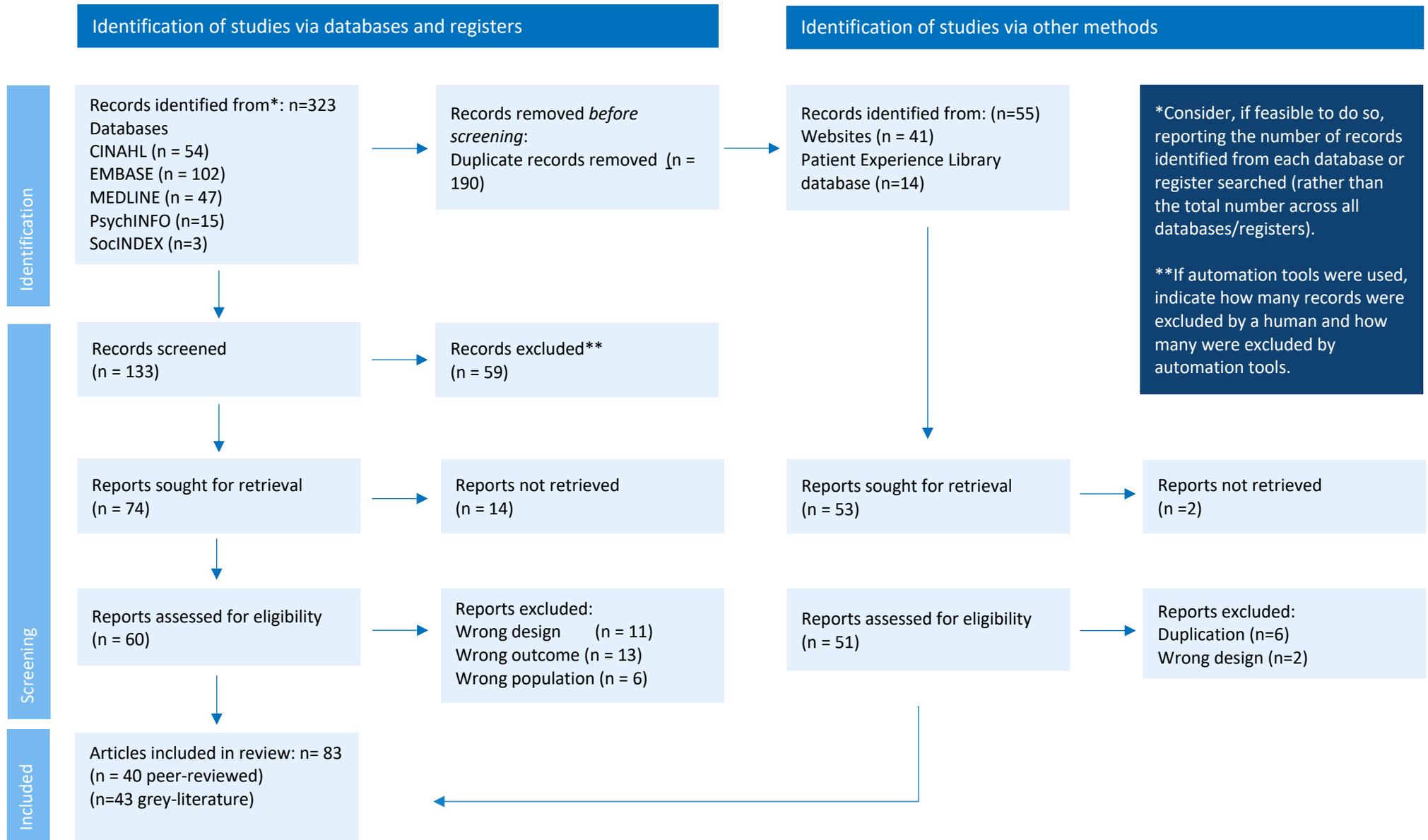
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Appendix 1: PRISMA diagram of included articles.



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