Report 5

Reducing Inequalities in Perinatal Mental Health Care

Recommendations on how to reduce inequalities in perinatal mental health care

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1. Introduction

From January 2019 until December 2021 a team of researchers from Born in Bradford and the Universities of York and Huddersfield have taken an in-depth look at the inequalities experienced by women with perinatal mental health (PMH) difficulties who live in West Yorkshire (see Box 1 for important definitions around this work). We have completed reviews of the research evidence, looked at the perinatal mental health pathways and available data in services across the region, interviewed women from ethnic minority and deprived backgrounds, interviewed practitioners from voluntary and community sector (VCS) organisations who work with 3 below.

We took our research findings, the identified barriers and potential solutions to two expert panels where we developed actionable recommendations to enable services to reduce the inequalities in the identification of PMH, and access to PMH support. Section 4 provides an overview of the recommendations that were developed in these expert panels.

2. Important definitions in this research

By inequality, we mean any unfair and avoidable differences in health caused by unequal conditions. Here we focus on disadvantages caused by socio-economic, ethnicity, language ability or pregnancy related issues. Our focus is on inequalities in PMH which we defined as mental health issues during pregnancy or in the first year after birth, including depression, anxiety and psychoses.

The population that this research focuses on is pregnant people and people who have given birth, referred to here as women and as mothers in describing the evidence that is presented here. We recognise however that some pregnant people are not women, and that some mothers have not themselves been pregnant or given birth. We also acknowledge that PMH issues can occur in partners of mothers (father, other co-parents and partners), however, we made the decision in consultation with the West Yorkshire perinatal mental health steering group to focus on mothers as the evidence shows us how much work is needed to make PMH care equal for mothers. Much work is also needed to enhance the support for all partners, and in Report 1, we describe the research evidence of inequalities in PMH for partners, and in our Report 2 we note that services need clearer guidance for the identification and support of partners during the perinatal period.

In this report we often talk about universal and specialist services. Universal healthcare means all healthcare that is offered to all women, including midwives, health visiting and GPs. Specialist services means all care that is designed to support women with greater needs including IAPT and specialist PMH services. VCS organisations deliver a combination of services designed for all women and for those in more need, so we would say within this report that VCS could sit within universal and/or specialist care.

To help us to pull together all of our research findings and recommendations, we used a 'sociotechnical framework' which allows us to describe the barriers and solutions to reduce inequality within the complex healthcare system. The framework includes four key components which all interact with each other: Processes, People, Technology and the System. More information on this framework can be seen in Appendix 1.

3. A summary of the research findings

A table detailing the main findings from this research programme can be found in Appendix 2 of this report. This table shows all of the barriers to inequitable identification and treatment access for women with PMH difficulties, and the potential solutions to these barriers that were identified in our research programme. The key findings from each report in this research programme are summarised here:

3.1 Report 1

Report 1 looked at the research evidence and found that there is **substantial inequality** in the disclosure and identification of PMH difficulties in **women with little or no English**, and to a slightly lesser extent, for **ethnic minority women** who do speak English. These are reflective of wider structural inequalities in society. At the juncture of PMH services, problems that need further examination include the use of translators and cultural misperceptions.

Due to a lack of research, it is unclear as to whether there is inequality along other axes of disadvantage such as economic status, relationship status or age. There is also poor understanding about treatment and management disparities in general, and about any inequality for women with disabilities and low literacy. Disparity by increased parity needs further investigation as does disparity in women who have complex social needs or who are disadvantaged in multiple spheres.

3.2 Report 2

We compared the guidance documents on PMH for healthcare professionals in maternity and health visiting services across West Yorkshire. We found multiple **inconsistencies in healthcare pathways** and **gaps in key considerations in the guidance**. There were inconsistencies in: the assessment tools recommended to identify PMH and their scoring; the provision of specialist PMH roles within universal services; in the definitions of levels of severity required for referral into specialist services; and varied specialist and VCS offers in different areas. The following key elements were missing from a number of guidelines: Guidance on supporting PMH conditions others than perinatal depression and psychosis; the use of translated versions of assessment tools; and responding to the mental health needs of fathers, other co-parents and partners.

The inconsistencies and missing elements in PMH guidance may produce inequalities in the identification and access to PMH support received by women living in different areas. These inconsistencies could also disadvantage some vulnerable groups more than others, thereby potentially widening inequalities across West Yorkshire.

3.3 Report 3

Report 3 examined data from: services across West Yorkshire, the national Maternity Services Data Set (MSDS), and the Born in Bradford research programme. The main finding in this report is that **routinely collected health data on inequalities and on PMH is not good enough** to tell us about prevalence or inequalities within the system. Information on key inequalities such as ethnicity, language ability or disability are not collected consistently enough to make them useful. Similarly, rather than recording the answers to identification questions, the national MSDS service records whether the questions were asked or not. This means that nationally and locally **we cannot**

determine the prevalence of PMH, **nor can we identify any inequalities** in PMH identification or treatment using routine data.

Using Born in Bradford data we found that 14% of women living in ethnically diverse and deprived inner-city areas of the city reported moderate-severe symptoms of depression, however, less than one in three of these women were identified as having poor PMH in their maternity, health visiting or GP healthcare record. Data from the specialist PMH services in West Yorkshire showed that, in two of the three services, **White women were more likely to be referred and to receive treatment than ethnic minority women**. In the third service, the alternative was true, with more ethnic minority women being referred and receiving treatment than White women. Born in Bradford data suggested that **White British women living in deprived areas are the most likely to report PMH symptoms**, the most likely to receive specialist PMH support and have a PMH related prescription. However, the poor data nationwide means that we do not know whether White British women living in deprivation are more likely to have PMH difficulties or if it is the case that this group of women are more able to disclose their concerns and to have them identified by HCPs.

3.4 Report 4

Report 4 provided insights on PMH inequalities using surveys with HCPs and interviews with workers in VCS organisations and women with an ethnic minority or deprived background. Barriers and facilitators were mapped to the socio-technical framework(see Appendix 1) to understand the role of processes, people, technology and the system as follows:

Processes: barriers include the availability/provision of interpreters, modality of contact, digital exclusion, access to transport and childcare which were found to impact on women from ethnic minority and/or deprived backgrounds, and particularly on those who were seeking asylum.

People; women: many barriers came from personal perceptions and a lack of knowledge in the women themselves with concerns including: stigma of PMH; a lack of awareness of PMH difficulties and available support; fear of consequences of disclosure; a lack of empowerment and distrust of practitioners/services.

People; healthcare practitioners (HCPs): A number of barriers/facilitators to enabling HCPs to identify and support PMH difficulties came from their level of knowledge and confidence around: asking about, and discussing, PMH; how to navigate referral pathways and available services; cultural competency (specifically in the context of PMH). Other barriers/facilitators included: having the time to cover all of a woman's needs in an appointment; building relationships and trust; the ethnicity and cultural background of practitioners; and, attitudes and at times discriminatory approaches.

People; others: The influence of others (i.e., partners, other family, peers, interpreters) could facilitate or inhibit women's PMH support, both in relation to being physically present (or absent) at an appointment, but also the anticipated reaction of others (for example, in relation to mental health being taboo). It was noted that the influence of others was relevant for appointments that took place remotely; for example with some women living in multi-generational households being unable to have private telephone conversation with mental health services.

Technology: technological barriers were indicated regarding instances of poor information sharing with women and between services. For example, women were not always kept informed about the outcome of their referrals.

System: the system-level barriers and facilitators include the extent to which PMH is viewed as a core business, partnership working between services, representation in workforce, high turnover of staff, high caseloads and fixed short appointment times, staff capacity for training, narrow rules on engagement and culturally insensitive services.

Many of the barriers/facilitators described in Report 4 had an impact on all women. However, many were exacerbated in women from ethnic minority backgrounds, recent migrants, those who don't speak English well and those living with trauma. All stakeholders expressed that several of these influences have been further compounded by the covid-19 pandemic.

4. What we set out to achieve in the expert panels

We invited healthcare professionals and commissioners with expertise of supporting women with PMH from across West Yorkshire to come together to look through our findings and develop a set of recommendations to make sure that PMH care is accessible to all women, regardless of their language, social circumstance or culture. We held two expert panels, on the 25th November 2021 and 3rd December 2021. The panels took place online via Microsoft Teams and 19 participants took part from midwifery, health visiting, specialist PMH services, other mental health services (e.g. IAPT), VCS organisations and clinical commissioning groups. Notes were made by facilitators during discussions and using recordings of the sessions (which were then deleted). Following the meeting we reviewed the notes and pulled together the recommendations made by these expert panels into the four categories from the framework. Appendix 2 shows these recommendations as they link to each barrier identified in the research. Section 6 below synthesises this learning into ten key recommendations to reduce inequalities in PMH.

5. A note about the current context

The research findings in this programme of work were undertaken between 2019 and 2021. We are aware that this is a constantly moving context, and we are aware of a lot of work ongoing within West Yorkshire which may not all have been captured here in this report. We are also aware of a lot of examples of good care that is reducing inequalities, and many of these examples were shared within the expert panels. Where we have been able to, we have collated these examples to share here to demonstrate how each recommendation is feasible in practice, and in many cases, are already happening in some, but not all areas. If you are aware of any relevant case studies, please do share them with us so that we can build our list of helpful case studies.

We are also aware of the recent national report on inequalities in Perinatal healthcare more widely[1]. Our findings here echo those in the national report, and the majority of our findings and recommendations resonating with the whole of perinatal healthcare. There are a few recommendations that relate specifically to perinatal mental health including stigma and cultural competency, and these have been *italicised* here for emphasis.

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[1] https://www.npeu.ox.ac.uk/mbrrace-uk/reports

6. Ten Recommendations to Reduce Inequalities in Perinatal Mental Health Support

There is unfair and unequal access to PMH support, with the most vulnerable women being the least likely to have their difficulties identified and to access treatment.

The changes required to make PMH support equitable for all women are substantial but critical. We have identified whether the change is needed in universal and/or specialist services. We recommend that services become 'evidence-generating', assessing the impact of any changes made, using a combination of data, stakeholder perspectives and user voices.

The ten recommendations are:

1. **Perinatal Mental Health needs to be viewed as 'core business'**
2. **Enhanced partnership working between statutory and VCS organisations**
3. **A campaign to improve community understanding and awareness**
4. **Development of, and commitment to, routine staff skills training**
5. **A skilled and equipped interpreter workforce for PMH**
6. **Additional support for vulnerable women**
7. **An equitable service offer across areas**
8. **Consistency in guidance, services and referral pathways**
9. **Changes in data capture and sharing**
10. **A review of Information Provision**

6.1 Perinatal Mental Health needs to be viewed as 'core business'

Universal and Specialist Services:

✓ PMH carries considerable economic cost to society, the majority of which concerns impacts for children. Policymakers, decision makers and commissioners need to be aware of the stark inequalities in PMH care, and that, investment in reducing those inequalities by identifying and preventing / intervening early for all women could result in a significant economic impact and potentially sizeable savings for the NHS, local authority and workforce.

✓ There needs to be a commitment to additional funding and staff capacity to address these inequalities.

✓ There needs to be a shift in service provision to focus on supporting the most vulnerable women: services should be re-designed to work for women who have the greatest inequality of access to support, rather than being designed for the majority as they currently are. This important shift will help all women to feel emotional safety in their care, encourage disclosure of their PMH difficulties and empower them to access the support that they need (see recommendations 4.5-8).

✓ Within all universal services, PMH should be a standing agenda item in team meetings to keep it at the forefront of HCPs minds.

✓ Within all universal services, there needs to be appropriate time within appointments to discuss PMH, viewing this as of equal importance with undertaking physical health checks.

6.2 Enhanced partnership working between statutory and VCS organisations

Universal and Specialist Services:

✓ The value of bi-directional learning between statutory and VCS organisations needs to be recognised and enhanced.

✓ VCS organisations have knowledge and skills in training, awareness raising, engagement of marginalised groups, strong relationships with communities, and with women themselves to give them a voice in service design and planning.

✓ Statutory services can support VCS organisations with key healthcare knowledge and skills.

✓ Partnership working can be nurtured through activities such as shared training and working together in reviewing referral criteria.

✓ Partnership working can develop shared understanding and shared language.

6.3 A campaign to improve community understanding and awareness of PMH

Universal and Specialist Services:

✓ Communication campaign to change perceptions about PMH, to understand it and help women from all backgrounds feel safe to disclose and to access mental health support.

✓ The campaign needs to raise awareness and reach to the whole community – through faith leaders, elders, places of worship, community groups, trusted organisations, preconception work with young people in secondary schools (see Case Study 1).

✓ Use positive case studies – for families, and communities to hear from others the same as them about their experiences of PMH in the family (e.g. partners, elders, faith leaders etc).

✓ Consider the potential for a campaign to also improve understanding about the potential for any parent to be affected by perinatal mental health difficulties

6.4 Development of, and commitment to, routine staff skills training and ongoing support

Universal and Specialist Services (excluding PMH specialist services):

✓ Commissioners and service managers need to commit to training for all staff by:
- ➢ Giving capacity to all staff to attend annual training
- ➢ Making training mandatory and a part of CPD

✓ A comprehensive training package for all HCPs, VCS and interpreters involved in the care of women during the perinatal period needs to be developed. Key training components required are:
- ➢ Trauma informed care
- ➢ Building trusted relationships
- ➢ Inequality awareness in PMH
- ➢ Cultural awareness specifically relating to PMH
- ➢ Applying 'cultural humility' e.g. asking a woman to explain important cultural context
- ➢ How to ask questions if a partner/other family member is present
- ➢ Family-focused approaches to PMH, including that any parent may be vulnerable to PMH difficulties and that older children in the family may also be affected
- ➢ Reflective practice and self-awareness of personal expectations / bias
- ➢ Availability of local PMH services and the referral pathways

✓ PMH should be a regular part of supervision meetings to support any concerns of HCPs.

6.5 A Skilled and equipped interpreter workforce for PMH

Universal and Specialist Services:

✓ Interpreters working in perinatal services should receive training on PMH, use of translated assessment tools, services on offer, reflexive practice on personal / cultural / religious expectations.

✓ Practitioners should have access to the validated translated versions of identification and assessment tools to give to interpreters to use.

✓ Interpreters should have access to other key information already translated and culturally validated (e.g. words around perinatal mental health and services).

✓ Interpreters need access to appropriate supervision, e.g. they may be involved in relaying traumatic accounts.

✓ Interpreters and their supervision should always be costed in as a standard part of a VCS service.

✓ Wherever possible the womans' preferences should be considered about their choice of interpreter (e.g gender / to see someone same or different culture as them).

✓ As a longer-term goal, aim to increase the diversity of the workforce - bilingual HCPs will improve support for women with little or no English, reduce the costs of interpreting services as well as address cultural competency needs.

6.6 Additional support for vulnerable women

Universal Services:

✓ Components of continuity of carer models including longer appointment times, reduced case loads and opportunity to build trust have both been demonstrated to enhance trust, and disclosure of PMH concerns in vulnerable women (See Case Study 2).

✓ Women who need an interpreter (or have other communication needs) need longer appointment times to cover all that is required within an appointment.

✓ As a minimum, allow HCPs to manage their own diaries to enable flexibility in appointment length and times so that they can offer personalised care.

Specialist Services:

✓ Implement a Clinical Engagement, Access & Inclusion Coordinator, or equivalent role (See Case Study 3).

✓ Implement a support role (e.g. peer supporter or community connector) to help vulnerable women navigate the system, be confident to access new services, remove practical barriers (e.g. transport, digital exclusion), build trust, and ask about their preferences (e.g. time of appointments, location, preference to see someone same/different culture as them, with/without family).

6.7 An equitable service offer across areas

Universal and Specialist Services:

✓ Commissioners and specialist service leads need to commit to a framework of shared service offers across an area, with flexibility based on local needs. Services can be aligned by identifying:
  ➤ Gaps in current service offer for populations
  ➤ Overlap of current services
  ➤ Service equity for women who live on service/organisational boundaries

✓ Key offers need to include a specialist PMH lead in every maternity, health visiting and VCS service; this links to having PMH as part of core business

6.8 Consistency in guidance and referral pathways

Universal Services:

✔ A single PMH guideline for maternity and health visiting services based upon evidence and national guidance

✔ Use of a single point of access in each organisation, enabling consistent access and appropriate referrals, without HCPs needing to know all service offers and eligibility.

Specialist Services:

✔ Consider a service directory for PMH referrals in each area which includes details about the services aims and eligibility.

✔ Ensure referral pathways and eligibility criteria are consistent and clear across areas

✔ Consider having services branded under the same organisational / service umbrella so that women see the services that they are referred to as a part of their core/usual care.

✔ Make it a consistent practice to allow the child to be with the mother in PMH specialist services; where there are older children / therapeutic reasons not to have child present, offer a crèche for clinic appointments, or appointment times to coincide with existing childcare support for home visits / online appointments.

6.9 A meaningful change in data capture and sharing

Universal and Specialist Services:

✔ Data systems need to change to ensure that inequality characteristics and outcomes of identification questions, assessments and referrals are recorded, accessible and reportable at all stages of the PMH pathway. To do this there should be:
  ➢ Use of mandatory codes to record outcomes of identification questions / assessments / referrals at all universal perinatal appointments
  ➢ Use of mandatory codes to record all protected characteristics (potential inequalities) on all clients in all services (making sure that they are identified appropriately e.g. ethnicity is defined as per Census categories and includes notes on migration status and English language ability)
  ➢ Add outcomes of identification, assessments and referrals to service Key Performance Indicators (KPIs) to improve data capture (See Case Study 4)
  ➢ Add inequalities data to KPIs to improve data capture
  ➢ Include prevalence and inequality characteristic data in routine local reporting of PMH
  ➢ Complete regular audits of data capture
  ➢ NHS England to be encouraged to review and change the MSDS reporting to enable identification of prevalence and inequalities in PMH

✓ There should be data sharing agreements and processes to allow the flow of key data about women who are being supported by different organisations to improve communication and care. This can be done by:

➢ Working with women and HCPs to consider the feasibility of a health-wellbeing passport for women with vulnerabilities (See Case Study 5)

➢ Implement flags on systems for indicators of PMH difficulties and referrals, that are shareable / accessible with other organisations working with the same women

➢ HCPs to check if/when referrals have been accepted (or not) and to feedback to women about this, regardless of the outcome

✓ Commitment to a longer-term goal of a shared data record based on a woman, not on an organisation.

6.10 Review of information provision:

Specialist services:

✓ Co-produce letters / information with your local communities to ensure that they use a range of terms, including culturally validated language to describe PMH (Case Study 6).

✓ Review the processes for women who do not attend /disengage from a service, e.g. consistently use multiple modes of communication to contact them (e.g. after a letter, use a phone call) to help to address their barriers to attendance; it may also be helpful for services to capture this activity to capture the amount of activity involved.

✓ Use multiple modes of information in multiple languages e.g. videos, podcasts, online with translation tools.

✓ Use positive case studies – for women to hear from others who they can identify with (e.g. who they share characteristics with) about their experiences, as noted for the awareness campaign.

✓ Make sure the use of imagery is representative and inclusive of the diverse population, including diversity in relation to all protected characteristics.

✓ Show PMH services as a safe place: Design easily accessible information about services and what they do (and don't do); review the names of the services to ensure they are culturally appropriate.

7. Case Studies

Case Study 1 - Community Engagement Work with the Sikh and Muslim Communities in Leeds

The Leeds Perinatal Community Team has employed a Clinical Engagement, Access and Inclusion Coordinator (see Case Study 3) to engage and listen to the voices of local communities, working in partnership with local places of worships and faith leaders to help build community trust, dispel cultural myths, raise awareness and improve access & PMH outcomes for diverse communities.

From our data we chose to focus on two communities to start off with, which are the Sikh Community and the Muslim Community. We have built strong connections with the Sikh Alliance Yorkshire and currently working in partnership with them attending dedicated health and wellbeing events at the local Sikh Gurdwara's and holding PMH stalls to engage local people on a grassroots level. We have also identified 11 Mosques across Leeds who are wanting to work in collaboration with us.

Although we have just recently started our community engagement work the feedback from members of the Sikh and Muslim community has been very positive. Having a presence in places of worship with professionals who represent the community is very impactful and they are considered to be good role models who can relay information in native languages, help open honest conversations, build trust and relate to cultural issues that impact on the community. Common themes such as lack of awareness of the support available for PMH services, how to access such support, lack of awareness of PMH affecting men have been identified. Although, some members of the communities are aware of depression and anxiety, very few have ever heard of postpartum psychosis.

Providing culturally sensitive support is important to help educate, build trust, break down barriers and allow people to make informed choices to access support for their health and well-being. Over the next 12 months we will be working very closely with our places of worship and members of our local communities on tackling health inequalities and improving maternal mental health outcomes.

Case Study 2- Continuity of Carer in Vulnerable Women

As a part of the Better Start Bradford project, a continuity of carer (CoC) midwifery team was commissioned to provide care for women in deprived inner-city areas, the majority of whom were from an ethnic minority and 1 in 3 of whom needed English language support at their midwife appointments.

The evaluation of this programme showed that:
- Women were significantly more satisfied with their care from the CoC team than women receiving usual care.
- CoC promoted trust to disclose personal issues including anxiety and depression
- CoC increased women's confidence in, and reassurance with, their birth choices
- Some women reported that the important element of the model was not having the same midwife, but having extended appointment times and additional care and attention
- High levels of job satisfaction reported by midwives in the CoC team contrasted with high levels of stress and burnout reported by standard care midwives.

Further detail available here:
https://bmcpregnancychildbirth.biomedcentral.com/articles/10.1186/s12884-021-03671-2

Case Study 3 - A Clinical Engagement, Access and Inclusion Coordinator

The Leeds and York Partnership NHS Foundation Trust established the Clinical Services Engagement and Inclusion Team to address health inequalities within different service areas in the Trust. As a part of this team, the Leeds Perinatal Community Team employ a Clinical Engagement, Access, and Inclusion Coordinator. The role involves the Inclusion Coordinator raising the awareness of PMH illnesses within diverse communities, improving their access, and supporting the frontline and leadership team to provide a culturally responsive service to meet the needs of our local communities. Examples of work completed by the coordinator include media coverage on local radio stations, building relationships with religious leaders through Gurdwaras and mosques and establishing a Diverse Mums' Group, which provides tailored support to meet the cultural needs of PMH service users.

More information can be found here:
https://www.leedsandyorkpft.nhs.uk/news/articles/world-mental-health-day-2021-mental-health-unequal-world/

Case Study 4 – Changing the data captured on PMH identification questions

NICE guidelines recommend that the Whooley questions are completed to assess maternal mental health and a full mood assessment completed if the woman answers positively. In the health data system in Bradford (as is the case nationally) we discovered that the code for the Whooley questions is present if the questions were asked, but it doesn't record the response to the questions. This is very challenging for understanding prevalence and inequalities in PMH because we can only assume the outcome of the assessment by subsequent actions, e.g. if no other action was taken we assume a negative response to Whooley, but this might not be the case.

We worked with the commissioners of the Health Visiting service to amend the Key Performance Indicators to require reporting on the prevalence of potential poor PMH through the response to the Whooley questions. We also supported the systems provider at Bradford District Foundation NHS Care Trust to amend the Whooley data fields to enable the actual response to the questions to be captured. In Bradford we are now beginning to access information on identification of PMH rates, and potential inequalities in these. For more information please visit: www.borninbradford.nhs.uk

Case Study 5 - The Wellbeing Passport

The Wellbeing Passport is used in Yorkshire and was developed by the Lancashire Youth in Mind as a tool for young people and their supporters to help them to share information about their mental health and emotional wellbeing. The Wellbeing Passport and card supports a young person to share information and details about their mental health challenges in different situations. This means that if they feel unable to talk about it out loud, or if they forget vital pieces of information, they can show their passport instead.

It is something that can be used in many situations and settings, where it is important for young people to feel confident to tell their story. The Wellbeing Passport is a small booklet with different pages that hold different pieces of information about the young person. The card is smaller and can hold one or 2 pieces of important information, that can be shown to someone in an emergency. A young person can fill in their own Wellbeing Passport and card with guidance from their supporters if they need it. There is also a downloadable guidance document which provides examples of the kinds of information that can be added in each section. (https://wellbeingpassport.org.uk)

Case Study 6 – Providing Information in Accessible Ways

In South West Yorkshire Foundation Trust, the PMH service have created a number of innovative ways of sharing information with women from ethnic minority backgrounds. They have created a leaflet about PMH illness that has been translated into Gujarati, Urdu and Arabic. Midwives give this information out at the booking appointments with the other maternity information.

The team have also published a Perinatal Awareness article in a local South Asian community magazine which is translated into Urdu and Gujarati to raise awareness of PMH across the community and different generations.

A peer support worker within the team has also set up a South Asian Peer Support group. Women report feeling more at ease to attend the group as they feel that the other women understand the challenges and issues they face as they are from the same cultural background. Women feel able to talk about very personal issues about their illness, for example, the effect on their relationships and other social issues which they say they would have felt unable to do in any other setting.

Appendices

Appendix 1: The Socio-Technical Framework

To help us to pull together all of our research findings and recommendations, we used a sociotechnical framework. This framework allowed us to view the complexity of inter-related components of the healthcare system as well as the interactions between practitioners, patients and healthcare processes. The framework consists of 4 components which all interact with each other:

1. **Processes** which describe practical elements such as socio-economic issues, communication etc.
2. **People** which we split into three key groups: a) **Women** – which includes the complexities involved in being aware of and willing to disclose their PMH concerns; b) **Healthcare practitioners** – which includes the complexities of their own knowledge, skills, clinical judgement and own cultural identities; c) **Significant others** – which includes the womens' wider family knowledge, understanding and influence, peer support / interpreters and their cultural influences.
3. **Technology** which describes information sharing and collection processes and the design of healthcare data systems
4. **System** which describes the local and national organisational context and service infrastructure including things like commissioning and service design.
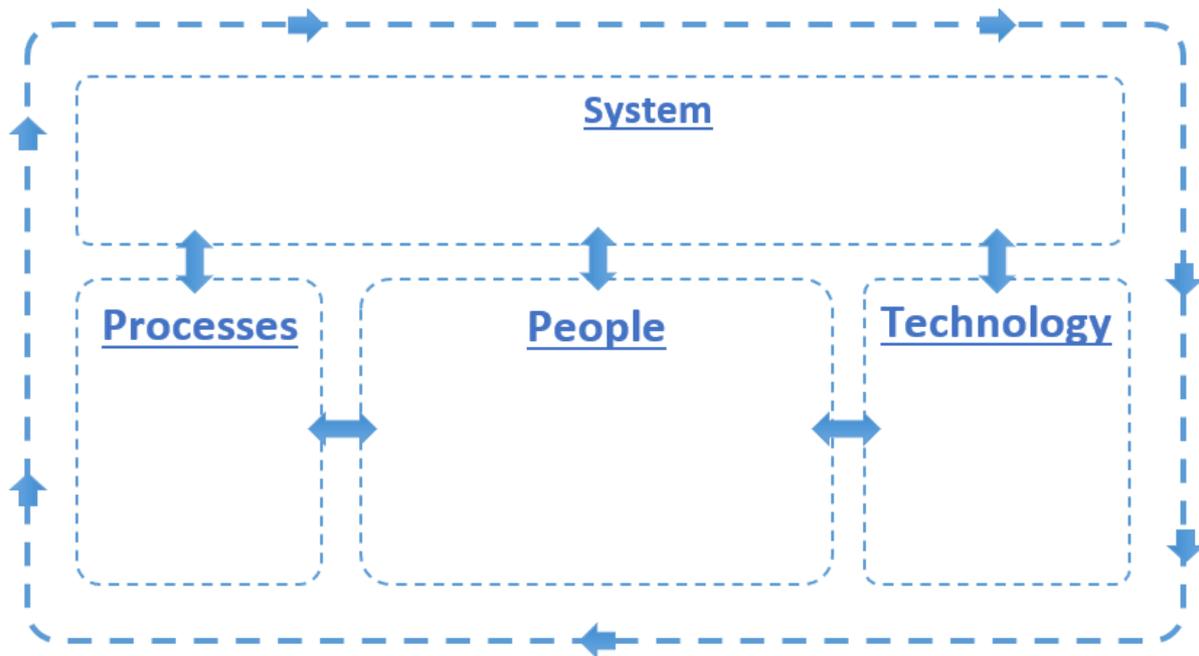
Appendix 2: The barriers and key recommendations from this programme of work, using the socio-technical framework.

2.1 Remove the practical barriers to women being able to receive appropriate support

Framework Component: Process
Remove the practical barriers to women being able to receive appropriate support

Inequality	Barrier	Recommendations
Women with little or no English Women with other communication difficulties Women who are illiterate (in any language) Migrant women Ethnic minority women	Use of interpreters: ● Takes more time ● Have no training ● Availability in services varies ● HCPs don't always know what is being translated Appointment letters are sent in English Information about services is in English Services have a '3 strike' rule / narrow rules of engagement	Longer appointment times for women who need an interpreter Interpreters in midwifery/health visiting should receive training on PMH, use of assessment tools, services on offer. Have validated translated versions of assessment tools available for use Have other key information translated and culturally validated (e.g. words around perinatal mental health and services) Interpreters should always be costed in as a standard part of a VCS organisation service Offer information in multiple modes and in multiple languages e.g. videos, podcasts, online with translation. Translated wording must be culturally appropriate and validated (e.g. words around perinatal mental health and services) Make sure use of imagery is representative and inclusive of the diverse population If women DNA, call them, ask what the barriers are and help to address them [see section 1. 2 (People: Women)].
Women living in poverty Women living in rural areas Women who are socially isolated	Costs of / access to travel Childcare Digital poverty / exclusion	Offer support in advance of an appointment to help identify and overcome practical barriers i.e. to arrange travel and childcare Consider home visits where feasible Make it a consistent practice to allow the child to be with the mother; where there are older children / therapeutic reasons not to have child present, offer a crèche. Recognise that resolving digital poverty has been explored and is very hard to resolve. Contact local VCSO who may be able to support with this as part of their role.

2.2 Enhance the emotional safety of women in services, in their home and in their community

Framework Component: People - Mother		
Enhance the emotional safety of women in services, in their home and community		
Inequality	**Barrier**	**Recommendations**
Relates to all women, but heightened in: Low education Teenage mothers Poverty LGBT+ families Migrants Refugee & Asylum seekers Ethnic Minorities Women with communication issues	Unaware of symptoms Shame Stigma Personal expectations (self / others) Religious/cultural expectations	Communication campaign to change perceptions about PMH, to understand it and make it safe to disclose for the whole community [see Process] Preconception work with young people in secondary schools to learn about PMH so they can recognise and understand Use culturally validated language to describe PMH, (e.g. being aware of how words such as 'mental' may translate), and consider using a wider range of terms Use positive case studies – for women to hear from others the same as them about their experiences
	Fear of consequences Wariness of new services Women unaware of and unable to navigate the system Women not informed about their care Long waiting lists risk disengagement	Use of peer – peer supporters to promote services Easily accessible information about services that exist; easily accessible information about the services and what they do (and don't do). Show them as a safe place. Review names of services to ensure they don't exacerbate stigma / fear Help ease women into a new service, use peers or community connector to learn more about it beforehand, address practical barriers [See section 1.1 (Process)], to support them to get there, and to keep them informed about where their referral is / what to expect next. Enable data sharing between services to enable better communication HCPs to check referrals are accepted and to feedback to women about this
	Lack of trust / relationship with HCP caused by: Previous negative experiences of services, Having to retell story Bureaucracy in appointments (e.g. form filling) Short apt times	Create a good balance between conversation and form filling. Spread it out over appointments where possible. Consider acceptability of a 'health-wellbeing' passport that contains key information Use of peer / MSW / connector role to complete a pre-visit to complete forms; Continuity of care and longer appointment times for vulnerable women to build trust, help to navigate the system Training of HCPs [See section 1.3 (People: HCPs)] Move away from online / phone services to face to face where possible; prioritise in certain circumstances.
	Women are not empowered - unable to share concerns; express preferences to remove barriers	Ask women about their preferences – time of appointments, location, preference for someone same/different culture/ethnicity [see section 1.3 (People: HCPs)], to be seen with/without family [see section 1.4 (People: significant others)] Ask women what they want, how can the service help them Consider using peer / connector worker to do this before clinical appointment

2.3 Promote the emotional safety of women as a shared goal; Make PMH core business for all

Framework Component: People – Healthcare Practitioners (HCPs)

Promote the emotional safety of women as a shared goal; Make PMH core business for all

Inequality	Barrier	Recommendations
Relates to all women, but heightened in: Ethnic minority women Women who don't speak English/ other communication issues Migrant women Women who have experienced trauma / ACES Low education Teenage mothers Poverty Migrants Refugee & Asylum seekers Learning disabilities LGBT	Current training of staff is not sufficient or appropriate: some HCPs in universal services lack confidence / knowledge to: ● have PMH conversations ● Use assessment tools	A Training package needs to be developed for all HCP staff (including peer supporters, VCSO and interpreters) who provide support during the perinatal period. It should include partnerships with VCSO and women themselves to deliver training. Training components required are: ● Cultural awareness relating to PMH (aware that this varies hugely across communities and cultural humility might be better first step) ● Inequality awareness in PMH ● Trauma informed care ● Building trusted relationships ● Use of cultural humility – don't be afraid to ask about what you don't know about ● Self awareness of own personal expectations / developing reflective practice ● PMH referral pathway and selection of appropriate services
	HCPs are unaware of services available and the referral pathways are inconsistent	Consider a service directory for PMH referrals in each area which includes details about the service aims and eligibility. Use a Single Point of Access for PMH referrals across all services to ensure that the most appropriate referral is made Consistent services and referral pathways across the region [see section 1.6 (Systems)]
	Staff are over-worked and at risk of burn out: HCPs may lack emotional strength and capacity to identify and understand concerns of all women in caseloads	Regular supervision with discussions around PMH concerns in women seen Regular conversations in team meetings about PMH to keep it at the forefront of HCPs minds, and also to support any queries / concerns of HCPs. Reduced caseloads and increased apt times for midwives supporting women with: PMH concerns; those who need an interpreter; other complex cases.

2.4 The influences of significant others: View PMH as holistic care, involving the whole family

	Framework Component: People – Significant Others
	PMH must be viewed as holistic care, involving the whole family

Cause	Barrier	Recommendations
	Unaware of symptoms Shame Stigma Personal expectations (self / others) Religious/cultural expectations	Communication campaign to change perceptions about PMH, to understand it and make it safe to disclose [see section 1.1 (Process); section 1.2 (People:Women)] Awareness and reach to the whole community – through faith leaders, elders, places of worship, community groups, trusted organisations For women experiencing PMH difficulties, where women give permission, HCPs need to have discussion with whole family to enable understanding of issues and how they can help to support a woman and baby. Use culturally validated language to describe PMH, (e.g. being aware of how words such as 'mental' may translate), and consider using a wider range of terms [see section 1.1 (Process); section 1.2 (People:Women)] Use positive case studies – for families, and communities to hear from others the same as them about their experiences of PMH in the family (e.g. partners, elders, faith leaders etc.)
	Women unable to discuss concerns when family present NOTE: sometimes family / peers are a positive aspect – might identify issues before woman does, might encourage disclosure / help seeking.	HCPs need training to know how to ask questions if a partner/other family member is present, including consideration of potential for presence to act as a barrier or facilitator to disclosure and uptake of support. Need to consult different communities and hear from women about how to ask / find out if a woman wants her family present or not.

2.5 Technology

Framework Component: Technology		
Inequality	**Barrier**	**Recommendations**
Collection of some kinds of information is prioritised over others, which brings about inequality because some characteristics can't be monitored and therefore not addressed	Data about a woman is not shared across organisations involved in care HCPs lack information on a womans' circumstances and background Data protection / IG concerns stop sharing of information between services	Long-term goal – a shared information record for a woman, not for an organisation. Add flags to the system that can be shared with other organisations Consider feasibility of a health-wellbeing passport for women [see section 1,2 (People: Women)]
	Prevalence rates of PMH are unknown	Data systems need to change to ensure that outcomes of screeners, assessments and referrals are recorded, accessible and reportable at all stages of the PMH pathway. The national MSDS data needs to be highlighted as unhelpful for understanding of PMH. NHS England to be encouraged to review and change this reporting.
	Screening tool and assessment outcomes are not recorded consistently in healthcare records	Training of HCPs in the use of tools [see section 1.3 (People: HCPs)] Use of validated translated tools by interpreters [see section 1.1 (Processes: Interpreters)] Use of mandatory codes to record outcomes of screening / assessments / referrals Add outcomes to KPIs to improve data capture Complete regular audits of data capture
	Inequality measures are not always recorded in healthcare records so can't be monitored and addressed	Use of mandatory codes to record inequalities on all women Add inequalities data to KPIs to improve data capture Complete regular audits of data capture Include inequalities data in routine local reporting of poor mental health (break down by ethnic group etc.)

2.6 Changes in the system to make PMH core business

	Framework Component: System **PMH as core business; Partnership working across all PMH services in an area.**	
	Barrier	**Recommendations**
	Budget funding and resources in PMH are not sufficient and are a restraint on delivering on any recommendations	Make PMH core business: A comms strategy needs to be developed that will make policy, decision makers and commissioners aware of the inequalities in PMH support, make them aware of the economic impact of this inequality, and the potential savings for NHS and workforce capacity that changes will bring. Dissemination of the research findings and these co-produced recommendations can form part of this strategy
	Services vary between postcode boundaries	Commissioners and specialist services need to commit to a framework of service delivery, with flexibility based on locality needs. This would involve them working together to align their services by identifying: Gaps in current service offer for population Overlap of current services Service equity for women who live on service/organisation boundaries
	Referral pathways are inconsistent and not seamless to women	Commissioners and specialist services should commit to commonality across the same services that are delivered in different areas. Use of a single point of access in all organisations – enables consistent access without HCPs needing to know all service offers and eligibility. Services should be branded under the same umbrella so that women see the services they are referred to as a part of their core/std care. Ensure referral pathways and eligibility criteria are clear
	People don't fit in the services or referral boxes we have made	Re-design services to work for the 20% with greatest inequality of access, take a personalised approach and think about whom the service should prioritise. This would probably benefit the 80% as well.
	Service guidelines are inconsistent	Expand upon the LMS guidance to create a single PMH guideline for maternity and health visiting which addresses inconsistencies in guidelines
	HCP workforce is not representative of the population it cares for	Implement model used in Leeds of a Clinical Engagement, Access & Inclusion Coordinator Partnership working with VCSO so can use peer support as a solution Training for interpreters working with women in the perinatal period [see section 1.1 (Process:Interpreters)]
	Training for HCPs is not sufficient	Find resources to develop and deliver training. Give capacity to all staff to attend annual training Make training mandatory and a part of CPD Use women's voices in the training, to share how they would like to be asked etc. Partner with VCSOs who have in-depth knowledge and experience of engaging with diverse groups.

	HCPs do not have the time / capacity to identify and support vulnerable women	Consider continuity of carer approach for vulnerable women Reduce case loads and increase apt times where a woman has identified PMH, requires an interpreter and/or has other vulnerabilities. As a minimum allow flexibility in appointments for HCPs to offer personalised care – enabling the woman to identify what is most important to her
	A lack of partnership working	Recognise and enable partnership working between organisations and VCSOs where bi-directional learning could add huge value: e.g. VCSOs have knowledge and skills in training, awareness raising, engagement of marginalised groups, strong relationships with communities. Enable data sharing agreements to allow flow of key data between organisations that are supporting the same woman. Consider sharing data systems in the future across organisations to enable this data sharing to be simple and effective.