Delivering the LTP Flexible Ambitions

Principles from the National Perinatal Mental Health Coproduction Group

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Introduction

The NHS Long Term Plan (LTP) renews the commitment to transformation in specialist PMH services, so that at least 66,000 women and birthing people will be able to access specialist perinatal mental health services every year by 2023/24.

In addition to ensuring that more women can access care, the LTP includes the following specific commitments:

- care provided by specialist PMH community services will be available from preconception to **24 months after birth** (extending from 12 months), in line with the cross-government ambition for women and children focusing on the first 1,001 critical days of a child's life.
- **expanding access to evidence-based psychological therapies** within specialist PMH services. Increased psychological provision should include a broad range of therapies including parent-infant, couple, co-parenting and family interventions to support a whole family approach.
- offering all **partners** of women accessing specialist PMH services and maternal mental health services (MMHS) assessment of their mental health and signposting to support as required.
- **developing and implementing Maternal Mental Health Services.** MMHS offer specialist assessments and evidence-based psychological interventions for women experiencing moderate-severe or complex mental health difficulties directly arising from, or related to, trauma or loss occurring in the maternity/perinatal/neonatal context. They also aim to implement a holistic, psychologically and trauma informed approach to care within and outside of the service, via staff training and supervision, for example.

This document aims to answer the following questions: ***what matters most to women with lived experience of perinatal mental illness? How can systems prioritise this, when implementing the LTP perinatal mental health ambitions?***

To answer these questions, the national perinatal mental health team worked with the national PMH coproduction group (NPMHCG). The NPMHCG is a group of women with lived experience of moderate, severe, or complex perinatal mental illness. All women are PMH peer leaders with unique experiences and insights into PMH care. All quotes included in this document are from NPMHCG members or (in the Partners Ambition section) their partners.

The Long Term Plan Ambitions

1. Extending care to twenty-four months after birth

> *"The end of maternity leave coinciding with end of mental health care was very anxiety-inducing, having specific support around these anxieties would have been beneficial. Psychological therapy after 12 months would have been ideal as I needed that time to fully process the traumatic experience.*
>
> *Two years of support (including peer support, nursery nurses and psychology) would provide a very good toolkit to take away, as well as being looped in with survivor communities and adequate signposting for continued care. Any contact with services was good, better to have a small bit of support rather than nothing".*

The time around a child turning one can be a difficult period for many women and families. Women frequently return to work at this time and are very often separated from their child for the first time. Infant separation anxiety often peaks at 12 months, which can trigger a relapse of mental health difficulties.

> *"I was under the care of the specialist PMH community service, my daughter turned one in December and my last appointment was the January. I was referred to a general community mental health team who said I wasn't 'bad enough' to be taken on. I was left with no support, fortunately I was able to pay for a private psychologist. Many women wouldn't be able to do this"*

When a woman is discharged, gentle transition is important to avoid inducing anxiety. Ongoing support, referral or signposting should be socialised with the patient as early as possible. Communication channels with health professionals involved in care beyond specialist PMH should be robust.

> *"I felt rushed to be discharged. I mentioned my intense anxiety over returning to work and my child going into nursery. I was told 'all mothers feel this way'. I was made to feel others needed the service more than me. Post discharge the only person I saw was a care coordinator who brought my prescription and simply asked 'how are you doing?'. I would always reply 'fine' despite only just getting through the basics of each day with very little left emotionally for my child. Specialist support in the second year of my child's life would have made such a difference to our relationship and my mental health."*

Key principles

Awareness: services should provide accessible information on the offer of specialist support up to 24 months and make clear timeframes for referral with relevant healthcare professionals within the perinatal pathway. Information should also include interventions available within the service, along with other wider sources of professional and voluntary support available in the area to health care professionals as well as patients and their families.

Timing: it is anticipated that the focus of the work in the 12-24 month period will be more psychologically based. There can be a long wait for psychological support in specialist PMH. In the interim period it's helpful to still receive other forms of support such as occupational therapy, nursery nurse support and/or peer support. These interventions can have a significant impact on preventing deterioration and feelings of isolation whilst waiting for psychological therapy.

Smooth transitions: services should facilitate smooth transitions and ensure there is no cliff edge for women when discharged at any point during care. This can be avoided by socialising the idea of discharge early and coproducing the plan for discharge. The full multidisciplinary team should be involved in developing the approach and timing of discharge. Services should ensure clear routes for returning to the service if needed, for example accepting self-referrals from patients previously treated at the service.

Collaboration: Building strong relationships with community mental health teams including specialist services such as eating disorders and parent-infant services, along with the rest of the pathway, will support softer transitions and develop clear exit routes to other services. Women should not have to tell their story multiple times. Services should work closely together to reduce the number of assessments required and where possible enable continuity of clinician across the service and pathway.

2. Increasing access to psychological therapies

> *"I didn't have any psychological support initially when pregnant. I think it would have been really helpful in terms of the symptoms. If I had psych therapy to provide a context, I would have had more of an understanding of what I was feeling. It may have stopped or reduced the trauma I felt after birth."*

> "*I was referred to perinatal from the community MH team when I was pregnant, and got passed from one doctor to another. All I got asked was 'is my medication ok?' Meds, meds, meds. They would ask me if I was suicidal. Eight or nine times out of 10 I felt like crap but I didn't tell them because I felt my baby would be taken from me. But I needed to tell someone, I felt like crying.*"

Timely, appropriate psychological support can help to prevent existing or new mental illness deteriorating to a point where more intensive support is required.

> *"Under the perinatal team, I was waiting to see psychologist for 5 months and in the meantime, everyone was saying just wait. If there was something earlier then I might not have been so severe and had to go to an MBU."*

The timing and type of offer needs to be carefully considered and perinatally informed.

> *"I was offered psychological support in the neonatal intensive care unit (NICU) but at the time it felt like I just need to get through day by day. When I speak to some mums they share the view that you go into survival mode. This was not a time where I could accept therapy for myself. Practically speaking, a lot of mums are offered support but can't physically get there. There needs to be some kind of transport."*

> *"VIG [Video Interaction Guidance] was provided at the MBU, the person and the therapy really helped, they were instrumental in reminding me through all of the interactions that I was able to bond. It provided me with reassurance that despite what was going on with me, my baby was attached and doing well. Kindness and compassion in delivery made the difference. Further along in my journey when my child was one, I saw a community psychologist but, because it wasn't perinatally informed, it wasn't that helpful."*

It is important that professionals along the whole pathway are clear about the support available in PMH and MMHS services, including thresholds for care:

> *"I lost my first baby and had a traumatic birth with my second. I was never made aware of the psychological support services available to me at any point for either pregnancy. I was told 1-4 women experience miscarriage or loss and that it was common. The implication was that I should just 'get over it'.*
>
> *Later I was diagnosed with PTSD and provided with a support worker. The support worker would ask me if I was eating/sleeping and if I said 'yes' I wasn't offered anything else. I struggled with anxiety, however because I just about managed to cope, I was never deemed to be severe enough for support. Knowledge of what was available was limited. Both babies had tongue tie which was more of a focus. I feel like I did suffer mentally and maybe if I had that [psychological support] during pregnancy it would have been different."*

Continuity of care, so that the woman can repeatedly meet with the same person(s), helps to develop a safe, trusting relationship. This is especially important between MBUs and community PMH teams.

> *"I was seeing a lot of professionals, don't get me wrong, but they were just seeing me for what I'd gone to them for, not seeing the whole picture"*

The setting for treatment should also be appropriate, and sensitive to the triggers and associations some women may have with a hospital setting.

> *"I experienced acute postpartum anxiety and despite finding the hospital where I gave birth triggering, my meetings with my psychiatrist took place at the hospital's maternity ward where I was expected to sit in the waiting room surrounded by pregnant women. I was so triggered that I was heaving throughout the session and could barely speak to the therapist."*

Telephone, though not ideal, could increase services' ability initially to reach women who would prefer not to be seen on video. Practitioners can then work with individuals to explain the clinical need for face to face or video contact.

Key principles

Compassion: all services should offer psychological treatment with a personalised, sensitive, and compassionate approach.

Awareness: services should provide accessible information to patients and families on psychological support and interventions available within the service, along with other sources of professional and voluntary support available in the area. Services should also ensure clinicians and referrers are aware of the mental health support available to women in the perinatal period.

Continuity: services should support smooth transitions and continuity of care in the delivery of psychological therapies across the service and perinatal pathway, linking closely with wider psychological therapy providers. Women should not have to tell their story multiple times. Services should work closely together to reduce the number of assessments required and where possible enable continuity of clinician across the service and pathway.

Family: to ensure families receive evidence-based and NICE-recommended psychological interventions in PMH and MMH services, services should increase psychological provision through a broad range of therapies including parent-infant, couple, co-parenting and family interventions, to support a whole family approach.

Specialist: referrals and recommendations for psychological therapy should be made by the appropriate healthcare professional. Perinatal psychological therapists are best placed to determine a need for psychological support from specialist community PMH teams for women in the perinatal period. Teams should work with healthcare professionals along the pathway, such as health visitors and maternity staff, to raise awareness of the nature of PMH and the availability of services.

Flexibility: services should use blended approaches that combine in-person and digital delivery, where clinically appropriate, and provide a range of videoconference platform options in addition to face to face appointments.

Location: services should provide psychological treatment and care within locations that are accessible and child-friendly, so women can be seen with their infant (and other children) if they choose. Ideally there should be a choice of location and the offer of home visits where appropriate. Hospital settings should be avoided as treatment locations, because of the triggers and associations some women may have with the setting.

3. Delivering the partners ambition

> *"When my wife was on the ward, I felt I did not have the time, energy or headspace to have extra meetings about how I was feeling or coping. I just wanted to look after my family. I valued the support of ward staff and the wider community who were ready to listen as-and-when, or who were on the end of a phone, should I need them.*
>
> *Much later, when everything seemed more 'back to normal', I started to process everything that had happened. All the experiences of the family crisis caught up with me. I needed to seek help, and knowing where to find it was important."*

Offers of support should be made routinely, regularly, and at a time when the partner has space to consider their own needs. It's important to recognise that partners can also suffer birth trauma; but may not have the space to process this until much later.

Signposting to peer support and other sources of support in the community may help partners overcome some of the isolation of dealing with the stigma of a perinatal mental health disorder, and the practical difficulties of maintaining a social life in a situation of role overload.

> *"Outside of medical provision, I found amazing support in my local faith community which offered practical help and listening ears."*

Peer support can vary in format, including a professionally facilitated group, access to a 1:1 peer support worker, or enabling informal chats amongst partners. It may be provided directly by a specialist perinatal mental health service, maternal mental health service or by a third sector organisation.

> "*To speak to another who has been where you are now removes the isolation, it takes the unknown into a place that allows you to feel understood, supported and you no longer feel alone. Without peer support, everything is facts and figures and confusing language, but to put a face to the story makes it real and relatable.*"

It is important to understand the potential barriers to partners of women in specialist community PMH services or maternal mental health services seeking or accepting support for their own mental health. Many of these apply to all partners, some are particularly relevant to men and fathers, whilst other barriers may be faced by LGBTQ+ partners:

- Dads and partners may be functioning in 'crisis' mode to deal with the immediate presenting situation and not recognise the toll this is taking on their own mental health.
- Men can lack knowledge or language to be able to describe feelings and identify when help is needed.
- Partners may feel selfish discussing their needs when the birthing parent is having such a difficult time. In some cases, a dad may feel shame, perceiving their own mental health issue as 'not being able to cope' during such a life-changing period.
- Partners may not feel comfortable speaking to a person involved in their partner's care.
- Partners may be reluctant to use their own limited time for a meeting about themselves rather than spending that time with their partner and baby.
- Some partners may fear that if considered not to be coping, their child/children could be removed.
- Exclusion of partners at pre- and post-natal appointments and during the birth can make them feel undervalued and that their needs are not important.
- Same-sex partners may find that support is not tailored to them, leaving them feeling excluded, particularly in group settings.
- Partners can also be side-lined at home by family and friends with the focus being on mum, reducing opportunities for partners to discuss how they are feeling.

Key principles

Awareness: services should develop information on PMH and the impact of becoming a new parent which can be sent home and shared digitally. Literature should help partners to understand what their loved one is going through as well as what *they* may experience. Information should be developed to normalise feelings and to help partners know where to seek support or an assessment.

Timing: the offer of support to the partner should be ongoing throughout mum's treatment. This increases the chances of finding an appropriate time for a partner to talk about their feelings honestly. Many partners only identify their own mental health need once mum is doing well.

Flexibility: It should not be assumed that there will be an opportunity to speak to a partner when they attend appointments with mum. Making support available outside of these times may help increase uptake.

Independence: partners should be given space, separate to discussions on mum's care, to discuss their own needs. This may be supported by a discussion with a peer support worker who is not involved in their partner's care.

Peer Support: peer support can help partners in numerous ways within the principles above. Most importantly, *partner* peer supporters can help partners to share their experiences with others who understand, have their feelings normalised and validated, and gain reassurance that the current situation will pass.

4. Maternal Mental Health Services

Maternal Mental Health Services provide specialist assessments and evidence-based psychological interventions to women who experience moderate to severe or complex mental health difficulties arising from trauma or loss in the maternity, neonatal or perinatal context and falling through the gaps of existing service provision. This is likely to include women suffering PTSD associated with birth trauma or perinatal loss (including loss through removal of a baby) or tokophobia.

MMHS differ from specialist community PMH services. In every area, both services should work closely together to clarify pathways, referral criteria and ways of working that make sense in the particular local context. There should be close working with other existing services to determine where the exact boundaries lie.

MMHS also aim to implement a holistic, psychologically and trauma informed approach to care both within and outside of the service, via staff training and supervision, for example.

Supporting Maternity services to 'plant the seed' and raise awareness of mental health among women and their families, will help to improve access to services, and enable earlier intervention. Using simple language to do this is important, as not everyone will be familiar with the word 'perinatal', for example.

Sensitivity and compassion is extremely important in MMHS:

> "*My experience of my little girl passing away was traumatic enough, insensitive comments were said from people and professionals. Those comments never leave you they add to your trauma and memories forever.*
>
> *Once my daughter was born there was very little support for parents like us, I had our bereavement midwife but that was it. I've only recently got help which is nearly four*

> *years on. I had some counselling sessions but the PTSD and my mental health after my second daughter rapidly went worse. I would now say please acknowledge parents experience but also please offer some form of support even if it's only small*"

It is important to validate and affirm a woman's experience and acknowledge their loss.

> *"acknowledge the experience. I think a lot of the time they don't know what to say so don't say anything."*

MMHS are expected to advocate for a focus on mental health and trauma-informed care within services involved in women's care in the perinatal period, including maternity services. The objectives are to prevent and mitigate mental health disorders directly arising from maternity/perinatal/neonatal experiences, and to improve the rate of identification of such mental health issues antenatally and postnatally.

Simple signposting to services, resources and information could help to improve access to support. There are many helpful resources available to women experiencing PMH issues, for example the book *Good Mums Have Scary Thoughts* (Karen Kleiman and Molly McIntyre). Both MMHS and community PMH services have a role to play to ensure that maternity staff are aware of such resources.

As with all PMH services, MMHS should aim be inclusive, and take into account different cultural needs and family structures including LGBTQ+ parents, single parent families, and extended multi-generational families.

MMHS may want to employ dedicated peer support workers in their team, or to build partnerships with third sector providers.

Peer support can be extremely beneficial, particularly while waiting for a therapy to start. Access to peer support can offer a space for women to discuss their experiences without fear of judgement.

> *"I was in a world of my own... I was just seeing professionals, I couldn't connect with any one with my experience. I felt ashamed. I would have gained from a peer support worker. If I had support I would have known there were people like me."*

The most appropriate setting for MMHS should be determined locally. Maternity services may be able to see women more quickly, and this location supports wider awareness among the workforce, however this setting may be triggering to women who have experienced traumatic births, or loss. Community PMH services may offer a more neutral setting, particularly for those who have experienced trauma or loss. A combination of different settings may be the most appropriate option to ensure that the needs of all women are appropriately met.

MMHS are currently testing timeframes in which to support women following trauma or loss occurring in the maternity/perinatal/neonatal context. Services should consider the appropriate time boundaries for offering support as there is no clear end point for recovery.

Families may require extended support, as issues can be ongoing and multifaceted. For example, a traumatic birth experience may have long-term implications for physical and

developmental health as well as mental health. Support from other services may be required as well as support for any subsequent pregnancies.

Key principles

Proactive: maternity services have the earliest opportunity to identify and refer women at risk. MMHS should encourage midwives to initiate open conversations about mental well-being with all women, to normalise PMH issues and reduce stigma.

Shared awareness: midwives and other health care professionals in contact with women during the perinatal period should be confident to recognise and refer women with potential mental health problems. MMHS can play a key role in educating, raising awareness and spreading knowledge, both to professionals and women and families.

Peer support: opportunities to meet peers who are going or have been through similar experiences can be a vital source of support, particularly in the interim while waiting for treatment to start. Peer supporters can make recommendations, signpost, and share knowledge and tools, from a position of understanding. MMHS may want to employ dedicated peer support workers in their team, or to build partnerships with third sector providers.

Sensitivity: MMHS may be used by women who have experienced conception difficulties, birth trauma and bereavement. As far as is possible, the location and setting for services should be sensitive to this. For example, a woman who does not have a baby may prefer not to be in an environment intended for mothers and babies. The language and support provided should also be sensitive to a woman's experience and acknowledge what they have been through.

Person-centred: services should strive to offer personal, holistic and tailored support that is inclusive and reflective of different cultures, backgrounds and family structures. When deciding eligibility criteria, MMHS should consider that mental health difficulties relating to trauma and loss may arise long after the birth and require care over an extended period.

Recap of the four ambitions and the principles for delivery:

Principles for extending care to twenty-four months after birth

- Awareness
- Timing
- Smooth transitions
- Collaboration

Principles for increasing access to psychological therapies

- Compassion
- Awareness
- Continuity
- Family
- Specialist
- Flexibility
- Location

Principles for delivering the partners ambition

- Awareness
- Timing
- Flexibility
- Independence
- Peer Support

Principles for Maternal Mental Health Services

- Proactive
- Shared awareness
- Peer support
- Sensitivity
- Person-centred