

Addressing Stigma in Perinatal and Infant Mental Health

**Good practice guidelines for practitioners,
commissioners and providers**

January 2023

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1. Introduction

In April 2022 the Scottish Government Perinatal and Early Years Mental Health Team commissioned See Me¹ and the Mental Health Foundation (MHF)² to develop evidence-based good practice guidelines, to support the reduction of perinatal and infant mental health stigma as a core part of the Delivering Effective Servicesⁱ agenda, commitments within the Perinatal Mental Health Peer Support Action Planⁱⁱ and Action 6.5 in the Coronavirus (COVID-19) Mental Health Transition and Recovery Planⁱⁱⁱ.

MHF undertook a literature review between April and June 2022 to generate up-to-date evidence about perinatal and infant mental health stigma in Scotland, building on a previous review carried out by the Scottish Government in 2020^{iv}. The evidence review has been used to inform the development of a set of good practice guidelines for healthcare practitioners, commissioners, and providers of perinatal and infant mental health services, to reduce stigma.

The guidelines, which can be found in section 3 of this document, set out characteristics of good practice based on evidence of what works to address the stigma experienced by mothers³, their infants, partners, and families, and improve their mental health outcomes.

The guidelines are for:

- Leaders, managers, and practitioners planning, delivering and providing perinatal and infant mental health services and support.
- Leaders, managers, and practitioners across a range of professions, including midwives, health visitors, mental health nurses, GPs and social workers.
- Commissioners of services.

Understanding more about and taking action to address mental health stigma, at different points of a person's journey through perinatal and infant mental health services will: increase empowerment of women and their families, will encourage personalisation of service design and delivery and improve overall outcomes for expectant and new mothers and their families. All areas are encouraged to adopt the evidence-based guidelines presented in this document.

1.1. Note about language

Various terms are used in these guidelines in relation to poor mental health, acronyms and terms describing equality groups. We have tried to ensure the language used throughout these guidelines is inclusive and non-stigmatising.

¹ See Me is Scotland's national programme to end mental health stigma & discrimination <https://www.seemescotland.org/>.

² MHF is See Me's learning and evaluation partner, <https://www.mentalhealth.org.uk/scotland>.

³ The term 'mother' in this document refers to: pregnant women and people, birthing women and people, breast/chestfeeding women and people and postnatal women and people.



2. Understanding stigma in relation to perinatal and infant mental health

It is widely documented that perinatal mental illnesses are of particular concern due to their high prevalence; estimates suggest that up to 20% of mothers (Prevatt et al., 2018; Geller et al., 2018) and 10% of fathers (Cameron et al., 2016) experience poor mental health during the perinatal period.

Perinatal mental illnesses can have a significant detrimental impact on people's lives, exacerbating pre-existing long term mental illnesses, harmful substance use and risk of suicide (Knight et al., 2018). The evidence also points out the direct impact that perinatal mental illnesses can have on infant outcomes including early delivery, creating cognitive and developmental delays, increasing the risk of behavioural and attachment problems as the child grows and for some leading to personality disorders in adulthood^v. Despite widespread understanding of the potential for severe consequences for mothers, infants, partners and families, often these illnesses go unnoticed, untreated or mistreated. Many people affected by perinatal mental illnesses feel unable to speak up about their experiences, or access to treatment or support despite both being usually available. The evidence shows that stigma plays a significant role in this.

2.1. Understanding stigma in perinatal and infant mental health

It is clear from the evidence review carried out in 2020 for the Perinatal and Infant Mental Health Programme Board^{vi} that action to address stigma is variable across the country affecting both people's access to and experience of perinatal mental health services and impacting on the support given to mothers, their children and their families. Stigma continues to be a prevalent issue. It remains a significant barrier to the mother, their children, partners, and significant others in seeking and getting the help they need, when they need it.

'Stigma' can be defined as "the negative attitudes or beliefs based on a preconception, misunderstanding or fear of mental health and/or mental health problems". There are four components to stigma, defined by The Lancet Commission^{vii} as:

1. *Self-stigma (or internalised stigma)* - occurs when people with mental health illness are aware of the negative stereotypes of others, agree with them, and turn them against themselves.
2. *Stigma by association* - refers to the attribution of negative stereotypes and discrimination directed against family members (e.g., parents, spouses, or siblings) or to mental health staff.
3. *Public and interpersonal stigma* - refer to the forms of knowledge and stereotypes, negative attitudes (prejudice), and negative behaviour (discrimination) by members of society towards people with mental health illness.
4. *Structural (systemic or institutional) stigma* - refers to policies and practices that work to the disadvantage of the stigmatised group, whether intentionally or unintentionally.



The evidence review carried out by MHF identified that stigma in relation to perinatal and infant mental health manifested in different ways such as shame, fear, judgement, dismissal, minimisation, lack of understanding, and lack of personalised, compassionate support.

2.2. Understanding the impact of perinatal and infant mental health stigma

Stigma in perinatal and infant mental health can have detrimental and long-lasting impact on people with lived experience of mental health problems; for example, leading to:

- Mothers feeling guilty and ashamed about their symptoms, concealing them and adopting alternative explanations for them.
- Reluctance to seek help for and be diagnosed with a perinatal mental health illness (for example, not wanting to emotionally burden families by sharing their symptoms; out of fear of losing custody of their child(ren), or family members discouraging disclosure or treatment because of the stigma this would bring to the whole family).
- Delay in asking for support when experiencing symptoms, presenting only when in distress or crisis, in doing so missing the opportunity for prevention and early intervention.
- Mothers, their partners, babies and families having symptoms normalised, minimised, dismissed, or not recognised by healthcare professionals.
- Partners experiencing shock, disbelief, trauma, stress, financial and work-related difficulties, relationship problems and sleep deprivation, also where mothers were admitted to the hospital/Mother and Baby Units (MBUs).

It is worth emphasising the significance of mental ill health during pregnancy and the perinatal and postpartum period; it is a stage when common mental health problems can manifest, with stigma and discrimination as exacerbating factors:

- Evidence tells us that stigma is experienced differently at different stages of care, including initial engagement, routine consultation, points of disclosure, assessing symptoms, diagnosis, signposting, and referral pathways to support and treatment, follow up and supported recovery.
- Intersectional stigma is pervasive and contributes to people experiencing multiple layers of stigma and discrimination as a direct result of their age, ethnicity, gender, sexuality, individual identity, and general health illness and disabilities.
- People within minoritised communities, across all protected characteristics, describe receiving poor or unequal treatment in both general and mental health services with their specific needs, preferences and circumstances not being considered.
- More specifically the evidence suggests higher levels of dual/multiple stigma when women and people and their families, who are struggling with their mental health, are from ethnic minority backgrounds.



- Stigma is exacerbated when mental health problems and factors relating to gender identity and sexuality combine. Many people expressed that they do not receive compassionate, personalised responses in perinatal care.

Much has been done through both the Perinatal Mental Health Network Scotland (PNMH Scotland)^{viii} and the national Managed Clinical Networks (MCNs)^{ix} to reduce stigma surrounding perinatal mental health and to encourage people to access help sooner.

It is important to share what is working well in different areas of the country to support learning and reduce variation of practice and experience. The evidence-based guidelines set out in this document provide a set of principles against which practice can be benchmarked and improved upon by commissioners, practitioners and services providing perinatal and infant mental health services.

ⁱ <https://www.pmhn.scot.nhs.uk/wp-content/uploads/2019/03/PMHN-Needs-Assessment-Report.pdf>.

ⁱⁱ <https://www.gov.scot/publications/peer-support-perinatal-mental-health-action-plan-2020-2023/>.

ⁱⁱⁱ <https://www.gov.scot/publications/mental-health-scotlands-transition-recovery/>.

^{iv} <https://www.gov.scot/publications/peer-support-perinatal-mental-health-review-evidence-provision-scotland-internship-project-report/>.

^v <https://spice-spotlight.scot/2021/11/23/an-update-on-perinatal-mental-health-in-scotland/>

^{vi} [Perinatal & Infant Mental Health Programme Board – Perinatal Mental Health Network Scotland](#).

^{vii} The Lancet Commission on ending stigma and discrimination in mental health, The Lancet (October, 2022).

^{viii} [Perinatal & Infant Mental Health Programme Board – Perinatal Mental Health Network Scotland](#).

^{ix} Perinatal Mental Health Network Scotland – National Managed Clinical Network: [Managed Clinical Networks - Children and Young People's Services MKN \(scot.nhs.uk\)](#)



3. Guidelines to address stigma in perinatal and infant mental health

Guideline 1: Inclusive commissioning

The current challenges

Perinatal healthcare professionals often work in under-funded and under-resourced services in which time and staff shortages reinforce the prioritisation of physical healthcare (Perinatal Theme 3.3.1).

A lack of continuity of care was consistently highlighted as impacting on the ability of healthcare professionals to form and maintain relationships with parents that would facilitate disclosure and mothers' engagement in treatment (3.3.2).

Perceptions of fragmented services and lack of communication between services among healthcare professionals were sometimes considered to cause problems with interdisciplinary communication, hindering access to care for women (3.3.3).

Wider barriers to accessing perinatal healthcare were also identified within the literature, including lack of money, time, transport and childcare (3.3.5)

Good practice guidance 1

Commissioners should:

- Ensure sufficient resource and workforce capacity to focus on and respond to the specific mental health needs of all mothers (and their families).
- Provide continuity of care enabling women and families to form and maintain relationships with their healthcare professionals that encourage openness, disclosure of mental health problems and provide a response based on individual need.
- Promote interdisciplinary working that facilitates effective communication, co-ordination of mental health services and support tailored to individual needs.
- Identify and take steps to address barriers that prevent women and their families from disclosing and accessing services and support for their mental health.
- Resource and design services to ensure they provide equitable access for people from minority communities who experience mental ill health, taking account of individual needs and preferences.
- Build knowledge, skills, ability and confidence of health and social care professionals around perinatal mental illness, infant mental health and associated stigma - ensuring lived experience testimony is part of this.





Guideline 2: Leadership commitment to mental health inclusion

The current challenges

Perceptions of fragmented services and lack of communication between services among healthcare professionals were sometimes considered to cause problems with interdisciplinary communication, hindering access to care for women (Perinatal Theme 3.3.3).

Good practice guidance 2

Leaders and managers of services should:

- Engage people with lived experience of mental health problems in the procurement, design, delivery and evaluation of the services and support being provided.
- Create an open, inclusive and supportive organisational and clinical culture that challenges stigmatising attitudes and engenders positive behaviour change.
- Facilitate effective communication, co-ordination of mental health services and support tailored to individual needs, limiting the number of times a person using the service has to disclose.
- Model an inclusive ethos, where physical, social and cultural environments feel safe, promote trust and respect, protect fairness and equity for all people experiencing mental health problems.
- Encourage common language to talk openly about mental health problems and to challenge stigma and discrimination as it arises.
- Introduce lived experience-led policies that express commit to inclusion and action to address stigma.
- Ensure policies are being implemented consistently to encourage safe disclosure, promote recovery, prevent additional mental health problems, and provide personalised and accessible information, signposting and support.
- Prioritise workforce wellbeing, ensuring that colleagues can be open about their own mental health, access support and support each other.



Guideline 3: Inclusive service design and provision

The current challenges

Lack of sensitivity to the cultural and personal needs of women and families (Perinatal Theme 3.1.4). Healthcare services were often perceived as disempowering (1.3.5); women reported that their symptoms and experiences were sometimes dismissed or diminished by health services/ professionals (1.3.3).

Some women from minority ethnic backgrounds reported experiences of prejudice and discrimination in community healthcare service settings (1.4.4), and some that their needs and preferences were not always taken into account, for example requests for female practitioners and interpreters. These findings were repeated across groups of women with a wide range of protected characteristics.

Women and partners struggling with perinatal mental health issues often described feeling isolated from and misunderstood by family members and social networks (1.2.4), who may themselves lack the knowledge or understanding to provide support (2.1.1).

Insufficient information, opportunities and language to describe their experiences to others can result in women and partners not talking about or trying to hide symptoms of poor perinatal mental health (1.2.2).

Where women were experiencing mental health difficulties, partners and family members reported feelings of confusion, concern, helplessness, frustration, guilt and stigma (2.1.2), yet the response of services to partners and families was described as complex or ambivalent (2.1.5).

Partners and significant others often felt 'invisible', excluded and marginalised by healthcare professionals as mothers received care and treatment (2.1.4), and evidence reveals the impact of parenthood on partner's mental health (2.2).

Good practice guidance 3

Leaders, managers and practitioners should design, plan and deliver services that:

- Are co-produced with experts by experience, including parents, families and people with intersectional identities with experience of mental health problems.
- Offer longer-term, consistent and tailored support, based on a social model of care.
- Ensure that people with lived experience are treated with fairness and compassion.
- Take a multidisciplinary approach to identifying and addressing the specific barriers, created by stigma, within the family or the treatment pathway.
- Services and support for mental health are inclusive and accessible to all regardless of any protected characteristics.
- Embed a whole family approach to supporting perinatal mental health needs encouraging openness, compassion and early action when people are struggling with their mental health.



Guideline 4: Supporting policy into practice

The current challenges

Evidence highlighted the value in offering solutions-oriented and appropriate referral pathways to ensure that women and their families feel in control of their care journey and be hopeful for positive outcomes, rather than taking part in a 'tick box' exercise (Perinatal theme 1.3.4).

The need for professional training with a focus on awareness, culturally sensitive language and treatment options and reframing support for mental illness that is person centred and promotes recovery (1.3.5 and 1.4.2).

Healthcare professionals were at times reluctant to identify perinatal mental health illness because of limited referral options. (3.3)

Limited referral options were also highlighted within the infant mental health literature (Infant theme1); infants often do not enter the mental health care system through traditional routes (Infant theme 3), often coming through community services instead. Highlighting the need for good communication & flexible but clear referral paths between services working with families.

The importance of culturally sensitive language and treatment options for promoting engagement and empowerment was highlighted throughout the review

Women felt that healthcare services and professionals normalised, minimised, diminished or did not recognise their symptoms, with screening being a 'tick box' exercise without the likelihood of accessing realistic support and referral options (Perinatal theme 1.3.4).

A woman's desire to be a 'good' mother and have close relationships with their children were key motivating factors for recovery from perinatal mental illness (1.1.2 and 1.1.7).

Good practice guidance 4

Managers and practitioners should ensure local policies and procedures are designed and implemented effectively so that:

- Knowledge and awareness of perinatal and infant mental health stigma is increased amongst parents, families and professionals.
- Language and terminology is accessible and inclusive, consulting with service users affected directly on decisions about which terms to use, wherever possible.
- Services provide a positive, compassionate and recovery focused experience for mothers, partners, infants and families. Services provide stigma-free, person-centred, solution-focused treatment, care and support.
- Services provide effective referral pathways, both locally and nationally.
- Perinatal and infant mental health and social care professionals are knowledgeable, confident and well equipped to deliver stigma-free high-quality care, support and treatment that meets the needs of service users.
- Services have access to compassionate and culturally sensitive screening and diagnostic tools and use these routinely.
- Perinatal and infant mental health care is preventative and takes a multi-disciplinary joined-up approach.



Guideline 5: Peer support

The current challenges

Evidence revealed that women and their partners often feel isolated through stigma related to perinatal and infant mental illnesses, but that peer support can offer connection, learning and support. Continued efforts should be made to understand the benefits of peer networks and peer-based approaches to recovery and effectively signpost to referral pathways that advocate these methods where appropriate.

Recent evidence tells us that while some women found their social networks to be discouraging in relation to disclosure and help seeking, others found them encouraging and helpful (Perinatal theme 1.2.1). Several results in the 2022 search discussed the positive perceptions or effects of support from peers with similar mental health illness and experiences (1.2.5). For example, low levels of knowledge about mental health illness among women has been addressed in some instances through reading and discussion with peers (1.3.2).

Good practice guidance 5

Evidence suggests peer support can increase awareness of mental health problems, reduce mental health stigma and encourage help seeking.

Peer support (both individual and in groups) can provide a compassionate and safe space, free of judgement, where people are respected irrespective of their experiences of mental ill health.

Peer support workers and volunteers provide valuable real life insights, individualised support, guidance and encouragement based on their own learning and experiences.

Peer support can reduce isolation and loneliness through connecting with and speaking to others who have had similar experiences.

Service providers should:

- Invest in approaches that extend peer support for all women and family members who wish to access it.
- Increase the numbers and diversity of people providing quality peer support to women and people and their families.
- Trial new models of peer support that takes account of the specific circumstances and needs of women and people and families.
- Ensure the wellbeing and safeguarding of peer supporters, embedding a sustainable peer support system for the long term.





Guideline 6: Workforce development and capacity

The current challenges

The evidence revealed considerable perceived variation amongst professionals in their level of knowledge of and confidence in dealing with perinatal mental health illness, awareness and understanding of stigma, treatment, referral pathways, roles of different healthcare professionals and interpersonal skills (Perinatal theme 3.1.1). A lack of knowledge in the area of infant mental health was also reported.

There were mixed attitudes among professionals about perinatal mental illness and, while some healthcare professionals held positive attitudes, stigma and negative judgement was still widespread and mental health issues regarded as taboo in some cases, for example with younger women, women who are experiencing language barriers and women with learning disabilities (3.2.1).

Literature reviews revealed criticism of current standards of screening and calls for more efficient yet sensitive approaches to the identification of mental health issues in infants and mothers (3.2.4).

Labelling or diagnosis by health professionals was shown to create power imbalances and leave people feeling permanently 'tarnished' in some instances (1.1.3).

Literature on infant mental health reveals that issues indicating or impacting infant mental health are not being identified efficiently (Infant Theme 3).

Good practice guidance 6

Service providers should invest in workforce development and capacity building to ensure that all practitioners:

- Have a good understanding of their role in preventing perinatal and infant mental health stigma and do all they can to reduce it in their practice.
- Have knowledge, skills and confidence to approach screening and diagnosis of a mental health issue in an inclusive, and compassionate manner.
- Work alongside women and their families to design post diagnostic solutions and pathways around the particular needs and preferences of the women and their families in their care. Proving advocacy support where necessary.
- Ensure people who experience perinatal and infant mental health problems have a good understanding of symptoms, the impact these may have, where to find medical, social and community based help and sources of support.
- Perinatal and infant mental health care, support, treatment and referral pathways are clearly mapped to enable women and people and their families to be informed and empowered to make decisions around their care.





Guideline 7: Addressing stigma at different levels

The current challenges

The impact of stigma on parents, families and infants can be profound. Stigma inhibits help seeking for both perinatal (Perinatal themes 1.1.2; 2.2.2) and infant mental health problems (Infant Theme 5).

Early life experiences pave the way for later mental health (Infant Theme 2); consequences of delays to treatment and recovery during these early stages can therefore be significant.

Stigma is experienced differently at different stages of care, including disclosure, assessing symptoms, diagnosis and treatment. Women experience perinatal mental health stigma in different ways including self-stigma, public stigma, associated stigma and structural stigma. To add to this, intersectional stigma is still pervasive, for example for young parents, ethnicity, gender, sexuality, individual identity, and general health disparities experienced by particular ethnic groups (Perinatal theme 1.4.4).

Good practice guidance 7

Perinatal mental health service providers should be able to recognise and address specific variations of stigma. This can be achieved by:

- Designing and delivering targeted anti-stigma campaigns, education and training that have been co-produced with people with experience of mental ill health and take into account context and culture.
- Developing services and supports that allow people to express feelings of self-stigma, understand that mental-ill health is not a sign of weakness, promote help-seeking behaviour, and help challenge self-stigma where it occurs.
- Acknowledging and addressing structural stigma within systems and services to prevent from discrimination.
- Reviewing perinatal and infant mental healthcare journeys through the lens of stigma.
- Supporting people's social support networks to identify types of stigma and address them, using evidence-based strategies and a whole-family approach.
- Delivering perinatal and infant mental health services that show a good understanding of intersectional stigma and can demonstrate how they are developing clear strategies to address and reduce it.
- Taking a whole population and targeted approach to raising knowledge and awareness of different types of stigma and who experience them.



4. Next Steps

The guidelines set out in this document will be reviewed and updated periodically as the knowledge base develops.

See Me and MHF will work with existing networks service providers and with people with lived experience of mental health problems to gather and disseminate widely a series of case studies, benchmarking current practice in perinatal and infant mental health against the guidelines, and setting out 'what works' in creating inclusive and stigma free perinatal mental health services, where mothers, their partners, child (ren) and families can ask for help, and get the support they need when they need it. Please direct any enquiries or expressions of interest in participating in good practice case studies to info@seemescotland.org.

5. Acknowledgements

See Me and MHF would like to thank Aigli Raouna of the University of Edinburgh, who carried out the foundational review about issues relating to perinatal mental health stigma in 2020 during a research internship with the Scottish Government.

Annex: List of themes identified in accompanying literature review

Perinatal Theme 1. Women's perspectives	Perinatal Theme 2 Partners' and families' perspectives	Perinatal Theme 3. Healthcare professional perspectives
<p>1.1 Mismatch between (self) expectations and experiences of motherhood</p> <p>1.1.1. Distress at a time when happiness is 'expected'.</p> <p>1.1.2. 'Coping' entwined with 'good' mothering</p> <p>1.1.3. Perinatal mental health diagnostic labels</p> <p>1.1.4. Public stigma of a perinatal mental health diagnosis</p> <p>1.1.5. 'Double stigma' of mental illness and motherhood'</p> <p>1.1.6. Custody fears</p> <p>1.1.7. NEW: Motivators in seeking treatment and recovery</p>	<p>2.1. Underneath the 'unsupportive layer': lack of knowledge and information</p> <p>2.1.1. Impact of lack of knowledge on family support</p> <p>2.1.2. Partner and family emotional responses</p> <p>2.1.3. Emotional responses to hospital admission</p> <p>2.1.4. The invisible parent</p> <p>2.1.5. Involvement of partners and families by healthcare services</p> <p>2.2. Struggling to identify and meet their own needs</p> <p>2.2.1. Missing the signs</p>	<p>3.1. Mixed levels of knowledge and confidence</p> <p>3.1.1. Knowledge and confidence around perinatal mental healthcare</p> <p>3.1.2. Interpersonal skills</p> <p>3.1.3. Knowledge of perinatal mental illness</p> <p>3.1.4. Cultural differences</p>
<p>1.2. Personal network: when the personal becomes impersonal</p> <p>1.2.1. Personal networks: mixed experiences</p> <p>1.2.2. Varying manifestations of stigma</p> <p>1.2.3. Stigma by association</p> <p>1.2.4. Sociocultural and generational impacts</p> <p>1.2.5. NEW: Peer support</p>	<p>2.2.2. Perception of mental illness in fathers</p> <p>2.2.3. When partners seek help</p> <p>2.2.4. A predominantly mother-baby oriented environment</p> <p>2.2.5. Reluctance to take focus off the mother</p> <p>2.2.6. NEW: Impacts on sexual minority partners</p>	<p>3.2. Self-Reflection: attitudes and stereotypes</p> <p>3.2.1. Mixed attitudes</p> <p>3.2.2. Perinatal mental health issues still a taboo subject</p> <p>3.2.3. Reluctance to use diagnostic labels</p> <p>3.2.4. Screening tools</p>
<p>1.3. The healthcare experience: a case of missed opportunities</p> <p>1.3.1. Healthcare experiences: A mixed picture</p> <p>1.3.2. Healthcare professionals' key role in education</p> <p>1.3.3. Dismissal of symptoms</p> <p>1.3.4. Screening: a 'tick box' exercise</p> <p>1.3.5. Neglecting to discuss treatment options</p> <p>1.3.6. Lack of connection</p> <p>1.3.7. NEW: Reluctance to take medication</p>		<p>3.3. Practical and infrastructural barriers</p> <p>3.3.1. Staff and resource shortages</p> <p>3.3.2. Lack of continuity of care</p> <p>3.3.3. Fragmented services</p> <p>3.3.4. Limited options for referral and treatment</p> <p>3.3.5. NEW: Practical barriers to accessing services</p>
<p>1.4. Socio-cultural considerations: values and language barriers</p> <p>1.4.1. Overcoming cultural expectations</p> <p>1.4.2. Cultural preferences</p> <p>1.4.3. Translation and interpretation services</p> <p>1.4.4. Intersectionality of stigma</p> <p>1.4.5. NEW: Identities</p>		

4.3. Infant mental health stigma themes	4.4 Interventions
Theme 1: Service provision & knowledge	Theme 1: Evaluation of single interventions
Theme 2: Critical periods	Theme 2: Reviews of groups of interventions
Theme 3: Issues impacting infant mental health	
Theme 4: Challenges identifying mental health issues	
Theme 5: Stigma inhibits help seeking	
Theme 6: Interventions	
Theme 7: Importance of family relationships	
Theme 8: Impact of the COVID pandemic	
Theme 9: Maternal and infant mental health	

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