





Report 1

Reducing Inequalities in Perinatal Mental Health Care

Inequalities in identification and management of perinatal mental health problems: A review of academic and local reports

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This report has been prepared for the Perinatal Mental Health steering group. The purpose is to inform the group about the evidence base of inequality in identification of perinatal mental ill health, and access to perinatal mental health services. This is the beginning of a detailed package of work to identify how to enhance perinatal mental health services in West Yorkshire.

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Executive summary

Mental health problems in the perinatal period are debilitating and costly. Parents living in disadvantaged circumstances have worse mental health, and may receive less health care. Partners are not routinely included in perinatal mental health care efforts. This report investigates the academic and local evidence on perinatal mental health inequality in health services for women and partners, and examines the collection of data to support monitoring and evaluation.

There is evidence of substantial inequality in the disclosure and identification of mental health problems 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 perinatal mental health services, identified problems that need further examination include the use of translators and cultural misperceptions. The effects of interventions such as cultural competency training are poorly understood but a more diverse work force should be seen as an opportunity. It is unclear whether there is inequality along other axes of disadvantage such as economic status, relationship status or age. Due to a lack of research, there is 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.

The feasibility and acceptability of identifying perinatal mental health problems in partners is not yet established and there may be different considerations for different settings (e.g. universal maternity or health visiting services, primary care, mental health services, voluntary and community organisations). There may be barriers around partner ambivalence, such as questioning the legitimacy of their experiences or needs. Tailoring services to address partner's needs may be helpful and warrants further exploration but any efforts to systematically address partners' mental health concerns must be inclusive of diverse family forms. Group inequalities within partners (e.g. by ethnicity, gender) have not been studied at all.

Problems and variation in capturing accurate mental health data are caused by a large range of interconnected factors from organisational policy, through to processes of care and suboptimal electronic health record (EHR) systems. Social determinants must also be captured, or be linked on individual records in order to monitor inequalities and attention paid to standardising the same information on each record across social groups. There is merit in approaching this from systems and socio-technical viewpoints.

1. Background

In this report we predominantly refer to women when referring to mothers, a birthing parent or gestational parent, and to partners when referring to a non-birthing parent or co-parent, who may not necessarily be in a current relationship with the woman. These and other terms are explained in the Glossary (Appendix 1).

1.1 Inequalities in mental health

Mental health (MH) problems including anxiety and depression (common mental disorders, CMD)

affect around one in four of the general adult population a year (1). In general, mental disorders are more likely to occur in people who are demographically, socially or economically disadvantaged, through processes such as stress and discrimination, and lack of access to resources (2-6). This is health inequality¹, the unfair and avoidable differences in health caused by unequal social conditions (7). The social determinants of health (SDH) are the social conditions by which health varies, for example by ethnicity, religion, age, gender, occupation, income etc. People who are disadvantaged are those whose health is systematically worse due to being in some category of these conditions (e.g. ethnic minority, women with little or no English, older age). People with CMD who are disadvantaged may be less likely to have their disorder recognised in the healthcare system, and be offered, and uptake an offer of treatment (8-10). Reasons are related to the unequal social and economic conditions, and difficulties in navigating the health service (known as candidacy, see Glossary in Appendix 1) which perpetuates the intertwining of poor health with disadvantage (11). The NHS upholds the Equality Act 2010, granting the rights of people with protected characteristics from unfair treatment and discrimination (12).

1.2 Women

It is estimated that around one in four women experience a mental health problem during pregnancy, and postnatal depression is diagnosed in around one in eight and postnatal anxiety in around one in ten women (13-15). Post-traumatic stress disorder affects 3-4% of women in the perinatal period (16); it also increases vulnerability to tokophobia (severe fear of childbirth) in a subsequent pregnancy, although tokophobia can affect any women, regardless of previous birth experience (17). Globally, incidence of puerperal psychosis is 0.9 to 2.6 per 1000 women (18). These perinatal mental health (PMH) problems can cause significant distress and loss of functioning and can interfere with biological processes, parenting and relationships. For some, this disruption can track through to the children causing lifelong impacts (19, 20). In the UK, the cost per case to society for perinatal depression was estimated in 2014 at £74,000 with 70% of these costs relating to the child, and £35,000 for anxiety (40% relating to the child) (21). Puerperal psychosis costs relating to the women are around double that of depression (21).

In this report we explore inequalities in PMH problems for women.

1.3 Partners

Approximately 5-10% of fathers experience perinatal depression and approximately 5-15% experience perinatal anxiety (22, 23); fathers may themselves also experience childbirth-related post-traumatic stress symptoms (23). Vulnerability to depression and anxiety appears higher amongst partners of women (i.e. gestational parents) who are themselves experiencing PMH problems, with evidence from small studies estimating prevalence between 25-50% (24). Rates amongst other co-parents and partners are unknown however there is some initial indication of distinct challenges facing these groups in the perinatal period, including those relating to assisted conception, stigma, marginalisation, visibility and recognition as parents (25-27).

Mental health problems in any parent carries implications for their relationships with their partner and with their baby; the parent's own outcomes and their child's development (28). In addition,

¹ in this report we use inequality, inequity, and disparity interchangeably, to the same meaning

having a supportive partner can promote a women's wellbeing and assist in recovery from mental illness (29, 30) as well as being beneficial for the child's outcomes (24). However, whereas mental health is routinely assessed in women (i.e. birthing parents), partners' mental health in the perinatal period remains largely unexplored by services. The NHS Long Term Plan commits to evidence-based assessment of partners of those accessing specialist PMH services and (future) maternal mental health services (formerly known as maternity outreach clinics); no equivalent commitment has yet been introduced for universal services (e.g. maternity and health visiting). Discussions with services have identified examples in individual voluntary and community organisations and in parent-infant relationship services where mental health assessment is offered to partners; in addition, practitioners in some universal services have also reported signposting partners (e.g. to GPs, IAPT) where concerns are indicated (e.g. through discussion with either parent).

In this report, we focus on disclosure and identification of partners' mental health problems in the perinatal period, including inequalities by social conditions within partners.

1.4 Data

Accurate and complete capture of clinical data relating to PMH is needed for a range of purposes: clinical management; sharing of clinical caseloads within an organisation, sharing or referring care to another organisation; audit; summary reporting to agencies; and enabling research.

Data collected in a manner optimised for one purpose may not fulfil another. For example, notes stored as free text in an electronic health record (EHR) may be useful for conveying complex information to another clinician but are inaccessible to analysts and researchers. Such fragmentation of the record can result in problematic decontextualisation. If some or all of the free-text information on, for example, symptoms, diagnosis or treatment are not also coded in a structured manner accessible for analysis then a variety of assumptions might be made. For example, that this patient does not have the condition of interest, or perhaps is being managed in a sub-optimal manner. Depending on the method used to mine records for reporting purposes (the case ascertainment strategy), such mismatches may also impact on the accuracy of audit and reporting of summary data to agencies. Mismatches can be known, in which case they are limitations, or they can remain undetected. Undetected mismatches can result in biased or wrong estimates of, and subsequent inferences about, volume and care quality.

Problems related to the capture of clinical data can be broadly categorised as;

- Completeness are all the expected data recorded?
- Accuracy does the data reflect the clinical picture?
- Accessibility are all the data available for review in the EHR?
- Consistency are data entered or presented in a similar manner
 - o throughout the record, across different data items
 - across patients
 - o over time
 - o across clinicians
 - across organisations?

To enable an understanding of inequalities, clinical data must also contain robust information about membership of vulnerable social groups – social determinants data. The format of clinical data must not vary by social groups in order to accurately account for need. Social determinants data with the most value is that which relates to the individual (e.g. gender, age, ethnicity, language spoken, poverty). Area-based information such as the Index of Multiple Deprivation can tell us something about the circumstances in which people in that area live, but do not tell us about the circumstances in which that individual lives. Area-based data is useful in some contexts, such as examining equity of referrals.

In this report we consider the capture, accuracy, accessibility and consistency of mental health data for all purposes, with a focus on PMH where possible, and on the capture of social determinants data.

1.5 Aims

- 1. Understand inequalities in the disclosure and identification of PMH problems in women within universal services, and access / take up of PMH services, including appropriate referrals, and provide explanatory reasons for these.
- 2. Understand challenges related to the disclosure and identification of PMH problems in partners.
- 3. Understand challenges related to the capture of PMH and social determinants data by health professionals in universal services.
- 4. Examine existing local reports on PMH pathways for women and partners and compare to findings under Aims 1-3 to look for common and unique challenges and opportunities.

2. Methods

We reviewed the academic literature, and local reports provided by West Yorkshire PMH Steering group, to identify evidence of inequalities and data problems. The review included reports published up until 2020; a review of published (and papers in preparation) research literature on women's PMH from 2011 to 2018; and a review of published research literature on partners PMH up until 2020. The academic literature we compiled included several systematic reviews conducted by the authors (two published (31, 33) one unpublished (32) and one published by others (34), preliminary findings from a mixed methods study we carried out in Bradford during 2019 (35, in preparation) and other research known to us. For maximum relevancy, we focus only on the UK context for women and for data, and mostly in universal services. For partners, where there is much less academic literature, we also examined literature from outside the UK.

We considered women, partners and data at key steps in the identification and management of PMH. We used PROGRESS-Plus (see Glossary, Social determinants of health) to broadly organise the social determinants of health for women and partners (36). For readability we report findings under the following headings; language, ethnicity, and socio-economic circumstances (including education and occupation). Under the —Plus categories we included personal characteristics that might be related to perinatal inequalities; age, parity, relationship status, literacy and (own) disability. We looked at inequalities of the partner in relation to the women, and also for social characteristics within partners.

A list of the papers and local reports that we reviewed can be found in the References section. It is important to note that some of the local reports we had access to did not look at inequalities or did not include participants from ethnic minorities or other disadvantaged groups as defined above.

3. Findings

Note: We use social determinants of health categories as an organising framework to report on disadvantaged circumstances, but most of these categories are interdependent and synergistic. Intersectionality - circumstance generated by belonging to multiple groups - will be poorly represented in the findings that follow. This is typically due to the large sample sizes needed to investigate multiple group membership. Therefore, when we present findings for a certain group (e.g. women with little or no English), it must be remembered that any inequality may vary for other categories of disadvantage (e.g., lower SES and multiparous) -- or indeed, advantage.

3.1 Women's disclosure and identification

Nationally, 'most' women are asked about their mental health (37) but not all of those excluded will be in a disadvantaged group. It is the difference between the advantaged and disadvantaged groups that are classified as inequalities; the difference between the advantaged group and the service standard, and the average and the service standard, are not the focus on this review.

3.2 Women with little or no English

There is a reasonably coherent body of evidence to suggest that perinatal women with little or no English are less likely to have a MH problem identified than English-speaking women. Much of this evidence comes from the perspective of the health care provider, consequently less is known about disclosure aspects. The scale of the disparity may be in the order of only one woman with little or no English identified by GPs for every two White British women identified (38).

Two interlinked factors, the use of translators and cultural perceptions, are implicated with nearly half of midwives and health visitors stating that these are barriers to identification (39, 40).

Using interpreters lengthens antenatal booking appointments, which may inhibit raising mental health conversations (41). The physical presence of an interpreter can affect rapport which can reduce the likelihood of the health care provider from starting a MH conversation (35). Informal translators such as family members can unhelpfully direct or dominate conversations (35, 42). Disclosure may be impacted if the woman knows the interpreter, which can happen in a small community (35). Midwives and health visitors are uncertain about translation accuracy and whether translators make cultural interpretations that are not conducive to the identification of MH problems (35, 42, 43).

Midwives may be less likely to use case-finding questions (such as those recommended in clinical practice) where a woman has limited English due to the perception that different cultural understandings of mental health problems would get in the way (43). These perceptions, which may often be mis-perceptions, may be due to a lack of training (42). Health care providers have concerns that the wording of identification questions and assessment tools may not be directly translatable to other languages, which may inhibit their use (35). It is possible that in some situations case-finding

questions may be culturally inappropriate and it is important to note that this may also apply to women who speak English (44).

Factors that might affect disclosure include the woman not considering that PMH symptoms indicate an illness, and not having the words in their first language to describe the feelings as a disorder (34). Cultural expectations around not seeking help outside the home has been also implicated (34). Similarly, fulfilling internal or external expectations of happiness, or strength, in the perinatal period have been noted by ethnic minority women (34, 35), however, it is unclear the extent to which this is essentialising, as such beliefs are not limited to ethnic minority women (44).

Locally, it is noted that none of the Trusts provide PMH leaflets in languages other than English (45).

3.3 Ethnic minority women who speak English

There is a small but reasonably coherent body of evidence to suggest that perinatal ethnic minority women who speak English are less likely to have their MH problems identified than White women.

The scale of the disparity could be in the order of 61 ethnic minority women who speak English identified for every 100 White women identified antenatally (GPs) (38), and 92 women recalling being asked about their MH antenatally (78 postnatally) for every 100 White women recalling being asked (46) in (31). There is some variation between ethnic groups, which might be due to small samples, but there is a similar pattern of ethnic minority women being less likely to be identified. This disparity is consistent with the wider literature in the general population where 82% of White GPs correctly diagnosed anxiety in vignettes of White patients but only 39% correctly diagnosed it in vignetted Asian patients (47).

There are few explanations for this disparity. In one study where health care providers cited a lack of familiarity with Caribbean culture, it was conversely the *lack* of language problems that might lead to oversight identification in this group – with HCPs focusing their attention on women with whom they have communication challenges (48).

Uncertainty around real or perceived cultural differences, including the appropriateness of case finding questions, cultural inhibition around help-seeking, and lack of words in a first language to describe the symptoms as a disorder, noted in the section relating to women with little or no English, are also likely to apply here.

3.4 Lower individual and area-based SES

It is not consistent or clear whether aspects of social disadvantage other than ethnic minority status are associated with identification and disclosure disparities (38, 46). Identification studies in primary care (not perinatal specific) have also found few disparities (49).

3.5 Younger or older than average childbearing age

There is a mixed picture for the relationship between age and the identification of MH problems. Antenatally one study found that case-finding and detection was reduced for younger women (43), another finding this relationship in White British women only (38) and a third study found it reduced among older women compared with women of average child-bearing age (46). Postnatally, women

under 25 were at risk of under-identification (46). There is obvious intersectionality with parity.

3.6 Multiparous

Multiparous women are slightly less likely to be asked about past mental health problems (research included midwives and health visitors), with 97 to 98 multiparous women asked for every 100 primiparous women (46) in (31). In another study (GPs), there was little observed disparity antenatally (38). Postnatally, an increased number of children in the household could limit the time available within the visit, which may impact on the identification of MH problems by health visitors (35).

3.7 Not in a relationship

Antenatally, there seems to be little association between relationship status and women being asked about current or past/family history of mental health problems or being identified with a MH problem (38, 46). Postnatally, single women were less likely to be asked about their mental health compared with partnered women (46).

Relationship status can influence the disclosure of mental health problems by women and identification by health professionals. The presence of a partner at the booking appointment might inhibit how much women disclose and midwives report that they would be less likely to use case finding questions if a partner attended (42, 43). There is overlap with the need for translators for women with little or no English for women who attend appointments alone.

3.8 Disability

One study reported that midwives might hesitate to use case-finding questions if the woman had learning difficulties (43).

3.9 Women's mental health management – referral and treatment

This includes offer of support, referral or treatment, and uptake of these offers.

3.10 Ethnic minority women

There is very little research on differences by language spoken; this may be due to small sample sizes in studies (50). Similarly, studies often have insufficient numbers of women from many ethnic minority groups to analyse.

There is a reasonable coherent body of evidence to indicate that ethnic minority women experience treatment disparities. Analysis of GP data from the Born in Bradford study indicates that, adjusted for indication, ethnic minority women may have less access to treatment both antenatally and postnatally, and were less likely to be dually treated with pharmacology and non-pharmacological modalities in the postnatal year than White British women (13% ethnic minority versus 30% White British for dual modality treatment) (50). In general populations, decreased prescribing for depression (adjusted for need) in Black and Asian people has also been noted (8, 9).

Another study of perinatal women found that 77 Black and 78 Asian women reported they were offered treatment antenatally for CMD for every 100 White women (37% of women overall were

offered treatment), with similar disparities in receipt of treatment postnatally (80 Asian for every 100 White; sample sizes too small in other groups to ascertain) (46) in (31). The average recall of receipt of treatment was 45% antenatally and 50% postnatally.

The under-representation of ethnic minority health care professionals leads to increased cultural and religious misunderstandings, which are not present when support is facilitated by someone of the same ethnic background (34). Culturally insensitive services, for example being seen by a male healthcare provider for some women, can lead to feelings of discomfort. Feeling part of, or wanting to attend, a support group can be compromised if discussions are dominated from someone of a different ethnicity, and as noted in the disclosure section, fear of breaches of confidentiality in communities can be a concern (34).

Locally, a benchmarking report found Asian women to be over-represented on inpatient units compared to community caseloads (5% vs 1%) (51).

3.11 Lower individual and area-based SES

In one quantitative study based on women's recall, there were few disparities in the offer and receipt of treatment antenatally or postnatally except that less education was associated with *increased* levels of antenatal treatment offer and postnatal treatment receipt (46).

Locally, a respondent experiencing homelessness, and escaping domestic violence, noted that she was not offered mental health support by any health professionals (52).

3.12 Personal characteristics; parity, age, relationship status, literacy and disability

There were few observed differences in management by age, parity and relationship status for the one study that examined these determinants, except that women aged 16-19 and those 40+ were less likely to be offered treatment antenatally compared to women aged 30-34, as were multiparous women versus primiparous (46). Low levels of literacy in areas of high deprivation could interfere with women being empowered to engage in shared decision making about treatment with GPs (53).

Locally, one respondent noted that her condition worsened with each child, but support lessened with each child (52). Another said that there was good questioning and emotional support with the first child, but not for the second. She noted that the second birth was more straightforward, which she thought impacted on the support offered. A third, who had problems after the birth of her first child, noted that for her second, health care providers had been supportive (52).

3.13 Partners' disclosure and identification

The majority of this section of the report relates to acceptability of assessing partners' mental health in the perinatal period, as this was the focus of a recent review carried out using systematic methods (33). Acceptability was assessed in relation to specific measures (e.g. the Edinburgh Postnatal Depression Scale; EPDS) or examining the proposal of partners' mental health assessment more broadly (e.g. parent and health professional views on mental health being assessed within services). Acceptability included anticipated (prospective) and experienced (retrospective) cognitive and emotional responses of those (potentially) receiving or delivering assessment. Relevant behavioural aspects (e.g. completion of assessment) were also reported as potential indicators of acceptability

but recognising that these may be influenced by other factors. Key findings from the review that are relevant to practice considerations are summarised here, together with additional information regarding equity.

Twenty studies were identified that reported on acceptability; all were from high-income Westernised countries (UK:7, Italy:2, Sweden:5, Australia:4, USA:1, international experts:1). Parent perspectives were reported in eight studies and health professionals' perspectives were reported in nine studies. Participants' perspectives were not reported in three of the studies that examined feasibility and implementation. Although the majority of studies reported some PROGRESS-Plus characteristics in describing study samples (i.e. parity, age, relationship status, ethnicity, language/migration, education, employment/occupation, other socioeconomic aspects, e.g. income, private health insurance), reporting was highly variable; furthermore, few discussed inequalities or inequity.

3.14 Inequality for the partner

Nineteen of the 20 studies identified that fathers (n=18) or non-birthing parents (n=1) faced distinct barriers that were not necessarily common with women (birthing parents); however none framed this as an issue of equity.

3.15 Inequalities around social determinants of health including protected characteristics for partners

Four of the 20 studies mentioned inequalities related to ethnicity, language and culture (54-57). Two were conducted outside practice settings. In a UK study with 21 first-time fathers of diverse ethnic backgrounds, some voiced the potential for it to be culturally and socially unacceptable to discuss difficulties of fatherhood (54). A UK study found that health visitors had concerns that asking fathers about their mental health may cause offence due to fathers' individual culture, religion or personal beliefs (56). The other two studies were conducted within practice settings and are discussed below.

3.16 Findings from studies that examined identification in practice settings

Seven of the 20 acceptability studies reported on acceptability of identification when conducted by professionals in practice settings. All were conducted in postnatal settings: child health (i.e. health visiting or well child visits; n=4, UK, Italy, Sweden), neonatal or paediatric intensive care units (NICUs/PICUs; n= 2, UK and USA), and early parenting services that provide support relating to early parenting difficulties (n=1, Australia). None examined targeted assessment of partners on the basis of the woman's (birthing parent's) mental health, which is part of the commitment for the NHS Long Term Plan. Some used self-reported measures of symptoms of depression, anxiety or trauma (55, 57-60). One used a broader psychosocial interview that included depression identification questions (61) and another - the study to report from UK universal settings - used questions about broader experiences relating to fatherhood (62), without explicitly focusing on mental health.

3.17 Inequality for the partner

Two Italian studies (55, 58) examined feasibility of identification at universal well child visits with paediatricians. One introduced the study at the first visit, seeking consent to complete at the EPDS at

the second visit, and found that participation in the assessment was lower for fathers than (birth) women attending the clinic (38% vs. 73%) (58). Uptake of onward support was low in both groups and lower for fathers than women (0/24 fathers vs. 11/126 women). Comparisons were not provided for any other characteristics. The other study (55) involved the EPDS being completed as standard practice in the first visit. Fewer fathers than women attended the appointment (499 vs. 1,122) but amongst those that attended, participation in the EPDS assessment was similar for fathers and (birth) women (99.6% for both).

A small pilot study by a UK health visitor (62) used a questionnaire about fatherhood and the birth experience to encourage discussion of "feelings and emotions" without using specific mental health questions. All fathers that were approached took part and completed the questionnaire however it is noted that these were fathers on the author's own caseload; no details were reported regarding equity. In the remaining study conducted within a universal postnatal setting (61), child health nurses in Sweden conducted parental interviews with non-birthing parents; these interviews included identification using the Whooley questions and assessment using the EPDS. At the time of data collection, nurses had only experienced interviews with fathers and no details were reported regarding equity. Nurses described fathers' reactions as largely positive; they also noted that some fathers first accepted the

invitation but later cancelled the interview, either directly to the nurse or through the woman. Numbers were not reported.

In a study of professionals' views and experiences on assessing fathers' mental health (including depression and anxiety) in early parenting services in Australia, distinct barriers were presented concerning fathers (e.g. relationship with the service) (57).

Two studies reported on the feasibility and implementation of assessing parents' mental health in intensive care unit settings: a highly specialised high-resource neonatal unit in the USA (59) and a paediatric unit in the UK (60). The UK study reported that assessment for vulnerability to post-traumatic stress disorder was acceptable to parents (60). The US study (59) described high assessment compliance rates and noted that fathers were receptive to assessment during the woman's hospitalisation; participation in assessment was lower for fathers than (birth) women (79.6% fathers vs. 96.5% women).

Outside of acceptability, there was some, but not much, mention of partners in locally available reports. Where the woman has a mental health problem, Leeds Specialist Mother and Baby Mental Health Service (SMABS) also supports her partner and has ambition to include a mental health assessment of partners by 2023 (63). Maternity services in four (BRI, Airedale, Leeds, CHFT) of the six local Trusts reporting implement assessment for partners (45). The extent and nature of that provision needs further exploration; e.g. history or current mood, independent or only when woman has a MH problem, only opportunistically assessed if attends appointment, etc.

3.18 Inequalities around social determinants of health including protected characteristics for partners

In a study of professionals' view and experiences on assessing fathers' mental health in early parenting services in Australia, (57), authors noted the absence of discussion of assessment with

"minority groups of fathers such as Aboriginal fathers or those from culturally and linguistically diverse communities" (p.505). The other study reported on the feasibility of assessing fathers' mental health using the EPDS at well child visits in Italy (55), finding different completion times according to language.

Locally, a respondent in the Healthwatch Leeds survey into Maternity Mental Health Services noted that underlying homophobia may present a barrier to lesbian women accessing support (64). Although this was not explicitly linked to assessment, this has relevance for the development of services.

3.19 Data

Clinical data

We first report on findings from a parallel mixed-methods study we carried out in Bradford in 2018-2019 involving service mapping, data analysis and qualitative interviews to identify and understand when, where, how and why healthcare professionals record PMH information (35). Data were analysed under a socio-technical framework to organise positive data capture and active failure data capture events along with the conditions and environment (latent preconditions) that were necessary for them to occur.

In Table 1 we summarise findings from 14 interviews conducted with health professionals: five with health visitors, five with midwives and four with GPs. 'Data' here relates to any PMH information, such as the application of identification and/or assessment questions, recording of a problem and its severity, or management including referrals. Problems were identified with processes of care, technology and latent preconditions.

Note that for any data capture to take place, a clinical attempt has to be made (e.g. an attempt to identify a PMH problem). When factors affecting clinical attempts were considered, problems related to a heading 'People' emerged (e.g. presumptions that other universal services were making the clinical attempts, lack of training) and 'Processes' expanded (e.g. continuity of care problems, pressures in home visits). Where related to inequality, these factors are discussed in the 'Women' section above.

We carried out a scoping review of the literature that assessed variation in the data contained in a UK EHR, or processes describing this variation, that affect electronic mental health care data (32). The review was not specific to PMH, and we found no studies on PMH, or in specialist PMH services.

Table 1. Factors that affect capture of PMH data

| Processes of care | |
|--|--|
| Identification –how/when | Variation by and within services around when assessment is carried out and whattools are used (if any) resulting in the information being recorded in different places in the EHR |
| Information sharing | Limited feedback on referrals and outcomes means local EHR often incomplete |
| Technology | |
| | Different templates, free-text boxes and paper notes to record PMH information |
| Different recording | Potentially not recorded at all if problem anticipated to be short term |
| practices causing variation | Sensitive data might be recorded in a restricted access comments box |
| within services | Some data not entered to prevent viewing by other family members (e.g. woman's situation recorded on child's record) |
| Use of free-text recording | Very widespread practice |
| Multiple and deficient template options | Multiple places available in EHR to record the same data Some identification and assessment tools do not have a template; forms are done on paper, scanned and uploaded in without coding |
| | To facilitate data capture |
| Use of paper recording | Usually, but not always, transferred to EHR – takes up time in the visit |
| | Referrals done on paper, or made verbally |
| Different electronic systems across services | Services use different EHR to which other clinicians had varying (if any) access |
| Compositivity | Key barrier to data entry while in patient homes |
| Connectivity | Data entry impacts on interactions in patients homes |
| Latent preconditions (fa | ctors distal to the event that permit or prevent a data capture event) |
| Communication withinand between services | Uncertainty about how colleagues will find coded information (due to complexity of EHR) leads to use of free text fields Use of different EHRs a barrier to between-service communication; clinicians canmiss important information about identification, diagnoses, treatments and referrals |
| Service factors (localand national) – time pressures | Impacts on whether identification and assessment tools are used verbatim, abbreviated or 'approximated'; meaning potentially inaccurate data is entered Free text frequently used for speed |
| Funding, capacity and clinical guidance | The text frequently used for speed |
| Technology – EHR systems | Inhibits information sharing, leading to a service not informed about a MH problem (midwives use of hand-held and paper records were identified as a problem here) |

In Table 2 we summarise details of 11 studies that included primary care in populations that are potentially generalisable to the perinatal period (e.g. no elderly-only populations) and to universal PMH settings. These studies highlight a variety of problems that have been researched, but due to the difficulties in researching medical records, are likely to represent only a fraction of the problems actually present.

Table 2. Mental health data capture problems in primary care-related research

| Completeness – are all expected data recorded? | Symptom severity scores only seem to be recorded in moderate or severe depression (e.g. PHQ-9) |
|---|---|
| Accuracy – does the data reflect the clinical picture? | Codes are poorly mapped across settings |
| Accessibility – are all data available in the EHR? | Lack of shared care protocol leads to missing information Active antipsychotic drugs or diagnoses not always coded for people with severe mental illness |
| Consistency – are data entered or presented in a similar manner throughout the record, across patients, time, clinicians or organisations? | Presentation of code picking list order inconsistent between EHRs and user-dependent (velocity coding) GPs less likely to use diagnostic codes than psychiatrists GPs increasingly likely to code symptoms not diagnoses |
| Purpose – what problems does entering for one purpose or in one setting cause to another? | Clinical → Research/other Free text is invisible to researchers Unknown time element needed in CAS to account for firming up of diagnoses Mild cases missing symptom severity scores CAS for suicide needs to vary between settings CAS for lithium monitoring and outcomes needs to vary between settings CAS adjustment for code variation; code variety may have no meaning and should not be analysed Presence of antipsychotic drugs coded may be dependent onsevere mental illness severity Clinical → other Clinical Duplicated lithium testing due to invisibility of data |

Note: CAS case-ascertainment strategy

Locally, we found some information about problems with clinical data capture in one report from the Specialist Mother and Baby Mental Health Service, SMABS (63). These generally mirror the findings reported in the literature. SMABS aims to prioritise robust and reliable data to inform service development. Currently, limitations include problems caused by changes in SystmOne and limited local access to information from this system. Reporting outcomes data has been problematic due to data not being easily accessible or analysable from SystmOne, build problems for other data recording systems, variable methods of recording data and incomplete data entry. Variations in data inputting are acknowledged and training has been provided to improve quality. The time taken to collect the information required for a triage is increased by the design of the SystmOne unit, as data needed is located in a variety of places. Plans by others to review current data systems across services featured in PMH pathways should lead to recommendations for standardising data sets and key outcome data, to ensure consistency and comparability.

3.20 Social determinants data

Few clinical datasets routinely and universally capture data on social determinants other than ethnicity, age, parity and a postcode that allows an area-based marker of deprivation such as IMD to be derived. Information on benefits, asylum seeking or homelessness may be captured sporadically for some patients. Some clinical holdings are in the process of linking to other routine sources of individual data for research purposes, for example the South London and Maudsley (SLaM) are planning linkage with DWP benefits data (personal communication). Research data can be linked to clinical data for example in the Born in Bradford and Born in Bradford's Better Start cohorts.

Locally, SMABS noted that area deprivation data were not available from their systems and are concerned about not having data to investigate equality of access across CCGs (63). In a benchmarking report (51) we noticed that that recording in categories of accommodation was inconsistent between community settings and inpatient settings, making comparison difficult.

4. Challenges and opportunities

The local reports we reviewed only rarely mentioned inequalities, but where they did, findings were in keeping with the academic literature.

4.1 Common across women and partners

Few studies have examined disparities by protected characteristics for partners. Where 'cultural differences' or 'religious beliefs' have been mentioned, these have not been unpacked further. The only specific example in the literature reviewed was one study that identified differences in time required to conduct assessment (using the EPDS) by language. Although we are unable to determine whether ethnic disparities evident for women apply to partners, we suspect they do. Potentially these disparities could be even more marked, due to beliefs, and perceptions of those beliefs, around pregnancy, birth, and the involvement of men. While women appear to be at higher risk for poor mental health in the perinatal period, evidence indicates a significant burden for partners.

Our findings around inequalities in women are largely consistent with work done in general practice in non-perinatal samples (8). Although there are gaps in our understanding due to an incomplete evidence base, the consistency of findings across studies indicates entrenched inequalities.

It is unwise to draw out explanatory factors from research that does not compare the experiences of women in different groups (e.g. speaks English or not, ethnic minority or not); relying on research from a single perspective carries the risk of essentialising an explanation. This is the reason why we did not draw through some findings from a recent review of ethnic minority women's experiences of PMH conditions and services (34) to causal explanations. These findings related to non-cultural or language-based viewpoints about adopting alternative explanations for symptoms, responding to symptoms, feeling isolated, having a lack of support, having practical barriers and feeling dismissed in the health service. These are, of course, problems that need addressing, but without comparative research we do not know whether they are unequal for disadvantaged women and thus drive health inequalities. There is also a tension between what seems the right thing to do, and evidence of effect. For example while women want health care providers to undergo cultural competency training (34) there is a knowledge gap on the effect on outcomes generally, and in PMH

specifically (65, 66). There is a lack of research on the effect of focus, orientation and content of UK culturally competent care training in effective delivery and outcomes and delivered programs in mental health services do not focus on addressing the actual disparities experienced by ethnic minorities, such as diagnosis (34, 67).

There are significant challenges to overcome in order to reduce disparities at the point of PMH care across settings and services for ethnic minority parents. Many of the identified problems are complex and interconnected, for example the concerns over translated appointments brings up uncertainty over what is appropriate (HCP cross-cultural understanding), and what is being translated (lack of shared understanding between HCP and translators), all in the context of appointments that are too short to explore emotional concerns (service constraints) or are in less than optimal settings. Equally important to consider are the intertwining of structural, interpersonal and institutional racism that construct and perpetuate ethnic inequalities (68). This includes under representation of ethnic minorities in staffing (68), a factor drawn out in the literature we reviewed (34). Improving skills and competencies without addressing root causes may not effect meaningful change. These problems are systemic, and not easily fixed. Health care, as a downstream determinant, obviously cannot solve the social problems that underlie discrimination, but can help prevent further perpetuation. One way of approaching this might be through the concept of proportionate universalism, where services are delivered at a scale and intensity that is proportionate to disadvantage (69). An opportunity exists to collect robust and accurate data to indicate disparities, in order to inform remediation strategies and prediction of need.

We have identified many challenges to a robust and uniform data collection system, such as paper recording and use free text notes with no coding, that require systems change and investment. Routinely capturing data on protected characteristics (ethnic group, English proficiency) that can be analysed alongside robust data on identification and clinical management is key to informing local practice. Routinely recorded clinical data, such as parity and age, can be similarly used as markers of disparity. Other markers of socio-economic hardship are difficult, but not impossible to collect in a standard manner in clinical settings and this should be seen as an opportunity.

In this report we have highlighted a large range of factors that get in the way of monitoring inequality by impacting on accurate and complete data entry. These occur at the macro (supra organisational) through to the micro (data capture event) levels. A major concern for monitoring inequalities is that data might be inputted differently according to social group. As an example, if a practitioner caring for a women with little or no English uses a free-text field to record mental health identification questions, but a clinical code to record the same identification questions for an English speaking woman, when reporting from codes, it appears that the woman with little or no English has not been asked the questions. This could be interpreted as less need (if identification questions are not completed universally and only for suspected emotional distress), or unmet need if it is assumed both women should have been asked. Inconsistencies such as these make understanding the quantity and nature of inequalities very difficult.

Table 3 indicates the categories of social determinants that have been proposed elsewhere for reporting on and monitoring inequalities (36, 70), that we have provisionally adapted to apply to parents and to include an additional concept: partner (non-birthing parent). The table is structured to indicate that all socio-economic and demographic categories can apply to woman or partner, and

the partner may themselves be at a disadvantage relative to the woman. Some of these characteristics (such as age, parity, disability, perhaps ethnicity) are well currently well captured in some clinical systems. Others, such as use of English for the requirement for a translator, may be captured well (i.e. coded) but not reported on, or may not be captured well. Some may not be possible to capture and we include them here to illustrate the diversity of groups at risk of inequality. We stress that there are large gaps in our understanding surrounding determinants other than ethnicity and language. Determinants are only average markers of inequality, for example someone could have a limited formal education but have a well-paid job and access to lots of resources. For this reason, and to improve our understanding of intersectionality, it is generally recommended to capture multiple determinants.

Table 3. Social determinants of mental health for parents (adapted from PROGRESS-Plus (36, 70))

| 6 | Datell | Applies to | |
|--------------------------|--|---------------|------------|
| Concept | oncept Detail | | Partner |
| Housing status | Instability, homelessness (inclusive definition) | Yes | Yes |
| Ethnicity | | Yes | Yes |
| Migration status | Born in UK, or age at migration (pre or post education may indicate | Yes | Yes |
| Language spoken | Proficiency in English | Yes | Yes |
| Religion | | Yes | Yes |
| Occupation | Employed, unemployed, type of occupation as a marker of social position | Yes | Yes |
| Birthing status | The partner who is not themselves the recipient (e.g. maternity, PMH services) or the focus of some services (e.g. health visiting services) | No | Yes |
| Gender | Gender diversity | Yes | Yes |
| Education | Years of education or level attained | Yes | Yes |
| Socio-economic status | Benefits, income, poverty (at the individual level) Postcode to obtain area-deprivation (less useful than individual data) | Yes | Yes |
| Social capital | Isolation, exclusion | Yes | Yes |
| | eristics associated with discrimination (e.g. age, disability), features of onships (where a person may be temporarily at a disadvantage) | relationships | , and time |
| Relationship status | Married, cohabiting, single | Yes | Yes |
| Age | | Yes | Yes |
| No. of previous children | | Yes | Yes |
| Disability | | Yes | Yes |
| Literacy | | Yes | Yes |

4.2 Specific to partners

The body of evidence reviewed indicates that although some partners (who in the included literature were men) and health professionals indicate that identifying PMH problems in partners may be acceptable, challenges remain and we lack information about acceptability and feasibility in UK services. Partners are not themselves recipients of maternity services or specialist PMH services, and few services exist for partners that are specific to PMH; the majority of support being provided through voluntary and community organisations. Based on existing service provision, it seems likely that the most feasible services for catering to disclosure, identification and management of mental health in partners would be via primary care (GPs) and IAPT, or to be able to access support via employers, although this too would have potential for inequity, varying with occupation and other socioeconomic characteristics. Actively tackling partners' mental health needs would require significant investment in resources, with consideration given to data capture in services where partners do not currently have an EHR. Also relevant is ambivalence by the partner, such as questioning legitimacy of experiences or needs, and feeling conflicted. This ambivalence, together with gendered barriers to mental health help-seeking (indicated in the wider literature on men and mental health) may factor into the relatively lower participation in identification or follow-up seen in the few studies that have examined this.

Some fathers welcome mental health assessment and the potential for this to help normalise experiences and facilitate support however they may feel conflicted about their entitlement to support and have concerns about compromising maternal mental health support (33). The original review (33) has identified challenges that exist at the individual-level, practitioner-level and service-level. This offers a framework for considering barriers and facilitators to identification and disclosure in partners. Several of these resonate with established barriers and facilitators in the maternal mental health literature; others appear to be distinct to fathers (i.e. relating to gender) and to non-birthing parents/partners (i.e. relating to not being the recipient of a service).

Sex/gender is itself a protected characteristic and area for potential inequity. This has been conflated with the protected characteristic of pregnancy/maternity, but both require consideration. For example, men facing inequalities in relation to identification or disclosure may link to them being men but also to them being non-birthing parents. Furthermore, while there is some indication that framing mental health assessment or support around family or fatherhood may be attractive and warrants further investigation, equity of access to others non-birthing parents (e.g. female and non-binary co-parents) must not be forgotten when considering new initiatives (e.g. Dad Pad or fathers' peer support workers) that are targeted to men or male partners. Furthermore, sex/gender has been neglected in relation to birthing parents, with trans and non-binary birthing people often invisible in services, policy and research, but likely at increased vulnerability to PMH difficulties (71).

5. Evidence gaps

5.1 Women

There is a gap of basic descriptive information on inequalities for perinatal women which appears to be severely hampered by small sample sizes in quantitative research. This is particularly true for inequalities in management, where fewer women are filtered in. Here, in particular, there is very

little **evidence** by language spoken. There are also several gaps relating to **explanations** for the disparities seen, and for the **effectiveness** of remediation strategies (Table 4).

5.2 Partners

More evidence is needed concerning health inequalities, particularly amongst partners — and examining intersections with other characteristics. Barriers faced by fathers is receiving growing attention, although still limited; the lack of research concerning challenges and opportunities to identification and disclosure with female or gender diverse co-parents and partners limits our understanding concerning inequalities relating to sex/gender and being a partner.

Table 4. Research gaps relating to inequalities in PMH problems for women

| A | | Gap relating to | |
|--|---------------|-----------------|--|
| Area | Evidence | Explanations | |
| Disclosure in women with little or no English | Gap | Gap | |
| Identification or disclosure in refugee perinatal women | Gap | Gap | |
| Identification or disclosure in women with low literacy | Gap | Gap | |
| Identification and disclosure for women with disabilities | Gap | Gap | |
| Identification and treatment disparities for ethnic minority women who speak English | Some research | Gap | |
| The extent to which fulfilling a cultural expectation of happiness about the baby, or needing to be strong, is essentialising | Some research | Gap | |
| Uncertainty about translation accuracy and whether translators make cultural interpretations that are not conducive to the identification of MH problems | Some research | Gap | |
| The reality behind the perception that different cultural understandings of menta health problems would get in the way if case-finding were attempted | Some research | Gap | |
| The extent to which, and for whom, case-finding questions may be culturally inappropriate | Gap | Gap | |
| The mixed nature of the age-related findings relating to identification and disclosure | Gap | Gap | |
| The effect of an increased number of children in the household on identification | Gap | Gap | |
| Characterisation of intersectionality in disclosure, identification and management particularly SES with ethnicity, and parity with age | Gap | Some research | |
| Management by parity, age, relationship status | Gap | Gap | |
| Management by language spoken | Gap | Gap | |
| Management by ethnicity | | Gap | |
| Management by individual and area-based SES | Gap | Gap | |
| Effectiveness of cross-cultural training on mis-perceptions and assumptions related to uncertainties around cultural understanding of mental health problems | Gap | Some research | |
| Effectiveness of other remediation strategies | Gap | Some research | |

Appendix 1. Glossary

Access / uptake - benefitting from available support requires that services be accessed; some people may access services directly (e.g. self-referral to IAPT); however, often when reporting on access/uptake, we are referring to the response to an offer of support (e.g. whether signposting is followed; whether an appointment is attended). Different types of services and offers of support may be available; including specialist services; universal services; voluntary and community organisations; peer support that may sit alongside any of these.

Candidacy - a construct proposed by Dixon-Woods et. al. (2006) (11) to explain the process experienced by people who are disadvantaged when navigating the health service;

"...candidacy is a dynamic and contingent process, constantly being defined and redefined through interactions between individuals and professionals... Accomplishing access to healthcare requires considerable work on the part of users, and the amount, difficulty, and complexity of that work may operate as barriers to receipt of care. The social patterning of perceptions of health and health services, and a lack of alignment between the priorities and competencies of disadvantaged people and the organisation of health services, conspire to create vulnerabilities." (11)

Capture of PMH data - the recording of PMH information on a data system. A system can be paper notes, or an electronic health record (EHR).

CAS (case ascertainment strategy) - the structured method applied to medical records to identify patients with the condition, symptoms or treatment of interest.

identification -

Disclosure is the confiding of mental distress to a healthcare practitioner. **Identification** is the recognition of mental distress by a healthcare practitioner

Disclosure can happen without identification, meaning that distress disclosed is not identified
as such by the healthcare practitioner. Identification without disclosure is less likely, but is
possible.

EHR (electronic health record) - an electronic updateable repository of patient-centred health data. **Essentialising** - attributing a characteristic to a stereotype.

Father - the person identified as the father of the baby, regardless of biological connectedness or parental responsibility; this term is used when describing evidence relating specifically to fathers (language taken from the good practice guide - (72))

Identification strategy -

an identification strategy is used on a universal basis in the UK, i.e. all women are asked about their mental health; this happens at the first formal antenatal appointment ('booking' visit; usually 8-14 weeks and conducted by a midwife) in maternity services and at a postnatal visit (usually 6-8 weeks and conducted by a health visitor), although there is an expectation for continued discussion of mental health and wellbeing at each contact; the booking visit involves taking the mental health history and also, if felt warranted, assessing for current depression and anxiety symptoms (using ultra-brief case-finding questions: Whooley questions, Arrol question, GAD-2; followed by longer severity score instruments where indicated, i.e. PHQ-9, EDS, GAD-7);

- disclosure and identification could also happen outside of these formal assessments, e.g. a
 person may make a disclosure concerning their mental health or a health professional may
 pursue identification in response to observing symptoms (e.g. behaviours, comments) or act
 on information provided by others; as well as maternity and health visiting, primary care
 professionals (e.g. General Practitioners) may be involved here.
- an identification strategy is not yet in place for partners in universal services or in specialist PMH services; however, the NHS Long Term Plan commits to evidence based assessment of partners of those accessing specialist PMH services and (future) maternal mental health services (formerly known as maternity outreach clinics); some voluntary and community organisations offer mental health assessment to partners, as do parent-infant relationship services; practitioners in some universal services have also reported signposting partners (e.g. to GPs, IAPT) where concerns are indicated (e.g. through discussion with either parent).

Inequity / inequalities / disparities - worse outcomes across individuals in a population or between different population groups that are due to social, economic or demographic differences that are both avoidable and unfair (7). See also Social determinants of health.

Intersectionality - the intersecting or overlapping effects of, for example, ethnicity, socio-economic status and other characteristics that contribute to social identity and affect health.

Partner - the person identified by the woman/mother as their partner; this could be any co-parent including a father, co-mother or co-father (language taken from the good practice guide (72)); although we use the term partner here, we recognise that some co-parents will not be in a current relationship with the women (birthing parent) and individualised language is needed in communication with families.

PMH (perinatal mental health) disorders/problems - any mental health disorder or problem during pregnancy or the first year following birth; this may include a mental health problem that is preexisting (i.e. continuing or recurring in the perinatal period) or new onset; examples include depression, anxiety (unspecified), OCD, social anxiety, PTSD, puerperal/postpartum psychosis.

Services (examples)

- Universal services these include maternity services, health visiting services, and GPs ·
 Specialist PMH services inpatient and community services that provide care to those with
 moderate-severe mental health needs in the perinatal period; they also provide
 preconception counselling (information and advice) for women with a current or previous
 serious mental illness
- Specialist maternity services these may include: specialist mental health midwives; bereavement midwives; clinics for those with fear of childbirth or who have experienced a
- traumatic birth (e.g. 'Birth Choices', 'Birth Afterthoughts'; these may be in the immediate aftermath of a traumatic birth or in a subsequent pregnancy)
- Adult Mental Health Services (AMHS) e.g. Improving Access to Psychological Therapy (IAPT) services (a primary care AMHS); Community Mental Health Services (secondary care AMHS)
- Parent-infant services
- Neonatal intensive care units (NICUs)

- Gynaecology services these potentially could be relevant (e.g. concerning traumatic birth or assisted conception)
- Voluntary and community organisations these may include national or local organisations providing support for a range of needs, e.g. PMH, parenting

Social determinants of health (SDH) - social, demographic and economic-related characteristics of individuals and populations that are related to systematic variation in health and health care. In this report we have applied a condensed version of the PROGRESS-Plus organising structure to indicate population groups focused on women at risk of disparity (70). In its original form, PROGRESS refers to Place of residence, Race/ethnicity/culture/language, Occupation, Gender/sex, Religion, Education, Socioeconomic status and Social capital. Plus refers to: (1) personal characteristics associated with discrimination (e.g. age, disability); (2) features of relationships (e.g. smoking parents) and (3) time-dependent relationships (e.g. instances where a person may be temporarily at a disadvantage) (36). See also Inequality.

Socio-technical framework - the design of a system that integrates social (individual, organisations and community) with technical (hardware, software) viewpoints.

Timeframes - traditionally, the perinatal period in the context of mental health refers to the period from conception until one year following birth; the NHS Long Term Plan calls for services to be extended until two years following birth.

Woman/ mother - the person who is pregnant or has given birth (sometimes referred to as the gestational parent or birthing parent); this is the 'index patient' of a maternity service or specialist PMH service, and may include a trans man or non-binary person (language taken from the good practice guide (72)); in contrast, health visiting services are focused around the child.

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