NHS
South East
Clinical Delivery and Networks

Wessex Voices
local healthwatch working together
NHS

What helps and what gets in the way of women seeking maternal mental health support services

June 2022

1. Introduction

Wessex Voices was asked by NHS England South East Clinical Delivery Network for Perinatal Mental Health to explore the barriers and enablers in terms of women accessing perinatal mental health support. With an increase in investment and service expansion, NHS South East was keen to identify and break down existing barriers, broadening access in the future. 'What helps?' and 'what gets in the way?' were the key questions. The specific aims were as follows:

- to understand the barriers to accessing services
- to find out what women thought would make a positive difference
- to hear from the seldom heard
- for the feedback to influence the design of services

The work took place during 2021, in the midst of the pandemic and lockdowns. This report explains how we approached the work, sets out what we heard from women and makes recommendations to ensure all women are able to access support. In addition, we set out some lessons learnt about effective engagement.

2. Methodology

Literature Review

Our first step when asked to carry out engagement work is always to find out what is already known. Our literature review revealed that there had been considerable recent work carried out by Healthwatch across the country exploring women's experience of perinatal mental health services, one of which focussed on those with protected characteristics. We also drew on a systematic review about the barriers to accessing mental health services for women with perinatal mental health illness and a review of ethnic minority women's experiences of perinatal

conditions and services in Europe carried out by Sheffield Hallam University and Sheffield University.

However, it was clear that there was little recent work which focussed explicitly on barriers and on those who hadn't accessed NHS services. The themes which emerged related to

- the need to be asked directly about mental health
- poor awareness of symptoms
- responses being too dismissive - "it's just the baby blues"
- stigma preventing disclosure
- the need for cultural sensitivity
- the need for trusted relationships
- awareness of services and provision of appropriate information
- practical barriers such as the location of support
- the importance of peer support

This informed our work and helped us to frame the questions we asked and the issues we explored.

Defining who we wanted to speak to

A key aim was to try to speak to women whose voices had not previously been heard, and who may not have accessed statutory services in the past. We considered the various ways in which we could access such women and decided to focus our engagement in those areas where people face additional barriers, rather than focussing on specific interest groups. So, we targeted areas described, perhaps unhelpfully, as areas of 'multiple deprivation', more recently and perhaps more accurately described as areas of 'social injustice'. Four areas were identified across the South East of England, avoiding those areas where similar and recent work had been carried out.

How we found women to talk to – in lockdown

The pandemic was a limiting factor and presented an enormous challenge. However, the principles were the same as in all engagement activities. We worked through local and trusted organisations who were already in contact with people we wanted to speak to and we devised mechanisms that made it easy and comfortable for those we wanted to hear from. A significant amount of time was spent identifying local organisations such as food banks, baby banks, community centres, local charities and voluntary organisations. Through our own knowledge and contacts, zooming in on google maps, asking local councils for voluntary services (or equivalent) and lists held in local Healthwatch - we identified 62 organisations.

We developed a flyer to send to organisations with an accompanying explanatory email, and social media publicity which included a paid for targeted social media campaign on Facebook. Getting the words right, and the images right, took time. This was followed up by phone calls to the organisations we contacted to explain the work further and seek their support. We asked if they would as a minimum promote the project to people they worked with, or, more proactively, encourage women to make contact with us. Some organisations also shared with us their views of the barriers women have to seeking support. These are set out in **Appendix 1**.

Opening the Door Flyer

How to talk about mental health

We were concerned that the words ‘mental health’ might be off putting, or simply a phrase some people do not relate to. So, in our publicity asking women to come forward and talk to us, we used ‘mental wellbeing’ and the words ‘low or upset’, rather than ‘mental health’. And in our conversations, we discussed what words the women felt comfortable with or felt were most appropriate and used those words.

How we engaged

We decided against using a survey, believing that conversations would be more appropriate. This meant that each conversation would be different as each woman’s experience was different. This approach was the only way of gaining any deep understanding and insights, which a survey would have limited. We also felt that a survey would be less likely to reach the women we really wanted to hear from.

The work started during the pandemic which posed challenges as no face-to-face engagement was possible. For the interviews we used either video calls via Zoom – or the phone, which tended to result in shorter interviews. At the end of the engagement period, restrictions lifted, and we were able to visit a community centre to carry out face-to-face interviews.

Another difficulty was that the organisations we worked through were operating differently, either remotely or with minimal contact e.g. food banks, and had their own significant pressures to contend with. So, this limited the ways they could promote this on our behalf.

However, working through trusted local organisations was crucial, and we worked hard to identify the most relevant organisations, and then put a considerable amount of time into contacting them and supporting them to help us. This approach was more successful than the targeted social media campaign which only resulted in a handful of interviews. Trusted local organisations were in contact with the women – we didn’t know them. Without this link we would not have reached the women we needed to talk to.

Who we interviewed

We spoke to 14 women from 3 of the 4 areas we had identified:

- 4 from Slough
- 7 from Merstham
- 3 from Portsmouth

The majority were over 35 years of age, with 3 between 25 and 34. 10 defined as White, 3 as Black and 1 Asian. 2 women were single parents, 3 had disabilities, 1 was an ex-offender and 1 had recovered from addiction.

3. Findings

Talking about mental health

All the women we spoke to were comfortable talking about mental health, and had all, to some extent, experienced some form of mental health problem, from mild to severe, not always linked to the perinatal period. Some had accessed different forms of therapy in the past, including face to face and online counselling, art therapy and CBT. Some had not accessed any support for mental health problems. They were all open and uninhibited talking about their experiences and were supportive of and open to the idea of talking therapies in general. This was the case even when, in their culture, mental health was not openly discussed or even viewed as taboo. One woman talked about having “learnt” to open up and another stated that people are generally becoming more comfortable talking about mental health.

One woman said:

“everyone has mental health issues, so it shouldn’t be a stigma”

However, the reverse was also mentioned:

“no one talks about it because they think it’s a weakness”

And several women felt that others:

“had never heard of mental health” or **“are terrified of therapy”**

Is it taboo?

In general, the women we spoke to felt there does remain a stigma, a taboo, around talking about mental health. This was linked to the fear of being judged, that unwanted interventions would follow, that “it” would remain on your records, and that your child might be taken away. This did not necessarily mean that women logically believed that this would be the consequence, but it was clearly a background fear for many, that they would be judged in terms of their ability to care for their baby. The following quotes exemplify this fear:

“I did think at times like I was doing the wrong thing, especially as a first-time mum, that he was going to be taken off me. It’s just a dread thing in the background”

“When I was in the fog, I feared the judgement might be negative”

“I can’t tell her cos they’ll take the baby, that’s really imprinted on our minds”

“I think there’s that fear that I’ll look like I can’t handle it…then someone’s gonna step in…am I going to be judged?

“I think there is stigma…you’re almost too scared to say something”

Tackling taboo, normalising mental health as something everyone is comfortable talking about, is clearly helpful. However, brushing aside concerns as **“it’s just the baby blues”** was also mentioned as problematic, minimising concerns and making seeking help more difficult.

Words to use

We asked women what words they used themselves or thought would be good descriptions. Mental health as a phrase was not necessarily seen as problematic although some felt it was too harsh. The words ranged from the gentler **“sad”**, **“teary”**, **“low”**, **“exhausted”** to the more extreme, **“hating it”**, **“hating the baby”**, **“destroyed my life”**, **“dead inside”** and are represented below in the word cloud:

Barriers – what gets in the way

When asked about the things that got in the way of seeking help, there were many ideas put forward. Some of these barriers had been experienced by the interviewees, some were things that people they knew had experienced, and some were perceptions.

'There for the baby'?

One of the most often mentioned issues was that services appeared to be there **"for the baby"** and not the mother. This was stated in many of the interviews. Some women felt that their mental health was only relevant if it affected the way they cared for their baby. Many simply felt that the time and attention of professionals was on their child, not focussed on them. There was a real understanding of the time pressures on midwives and health visitors, but nonetheless, this feeling of services not being there for them was strong. Women need to see that services are there for them, feeling they are predominantly there for the baby is a major barrier.

"If she had said 'I have to come for an appointment, let's just go outside, let's do it on a day when your partner's there and I'm not coming to see the baby I'm coming to see you, so we can chat'…….It feels like 'are you OK then?' it feels like an afterthought, that the mum is OK"

The fear of being judged

Linked to the issue of taboo, many women mentioned that they would be reluctant to ask for help because of the fear of being judged. Some women also talked about the shame of not being a good mother. One woman made the suggestion that being able to talk anonymously initially may help overcome that fear of being judged.

Social media

Some of the shame of not coping or not enjoying motherhood was linked to the pressure from social media, showing parents having a great time, with everyone **"happier"** than you and **"being a better parent"** than you.

Waiting lists

There was a perception amongst some that it would take time to get counselling support. One woman had received support very quickly and stated that women should **"know they are priority"**, then they might seek support more. There was also a comment about the NHS being overloaded, signalling that help would not be available.

Who to go to first?

For many, talking to a partner or friends, and for some, family, is a good starting point. GPs and Health Visitors are generally seen as the first point of contact in terms of seeking professional help, but many are not 100% confident about the amount of time they would be given or the response that they would receive. One woman mentioned that although she

went to the GP she didn't really tell the full story, limiting how the GP could respond. There was also mention of the difficulty of getting through reception to speak to a GP and whether GPs were specialist enough to be able to help.

"When you call the GP you have to explain how you are feeling to justify a call back to qualify for an appointment that could be 4 weeks away"

Enablers – what helps

We asked what helped in terms of accessing support. The interviewees drew on their own experiences, much of which had been positive, the experience of others and again, their perceptions. There were positive examples of women being helped postnatally and many ideas about what would help.

Community support

There was a variety of use of community support. Some had used local groups, others not. When used, this support was hugely valued, gaining support from others and also just giving a reason to get out of the house and connect. Homestart and Children's Centres were mentioned and praised several times.
Several women felt that support groups that brought them together with others in similar situations would be particularly useful, for example women with a history of addiction, women who had lost children, or simply women with additional emotional support needs. You would then be with people who really understood.

“I won’t have to explain myself”

“You just want to talk to other mums who are really suffering and all be really open and honest with each other”

A couple of women mentioned that you may not ask for help, even if you’re struggling, but that going to support groups makes it more likely that **“someone will notice”** or **“pick up on things”**. This had happened to a couple of women. One woman also talked about the importance of personal invitations to support groups, not just providing information about when and where. Not everyone will seek groups out, many will need that extra nudge and help to take up opportunities.
However, in terms of seeking community support, some had no idea where to go or where to look, and felt it would have been useful to have been guided towards local groups during their pregnancy. A number of women felt isolated, living away from their families, or having moved recently with no local network of their own.

“I don’t think there was anything out there, or maybe I just didn’t know where to go”

“It was like you’re on a desert island and you just have to survive”

Being asked the right question - in the right environments

It’s not just the question, but the way it is asked, that matters. The interviewees all talked about the way questions are asked as being crucial to their ability to open up. Women want to be asked how they are in a way that is really enquiring, a meaningful question that is not cursory that truly feels like an honest answer is expected. There were many positive examples given of well-asked questions, and also examples where the question felt meaningless

"You get asked once and you say you're fine…asking a number of times maybe in a number of ways, how are you feeling, how can I support you, have you seen anyone today, have you been out…just delve a bit deeper"

There was also mention of the environments that made it easier to feel comfortable talking

- at home, but by yourself – plan the visit well
- in a room that feels comfortable, relaxed and informal, not across a desk
- in a space where you aren't forced to talk but can feel comfortable when you do

And women want the questions that are asked to be non-judgemental. Here is an example that worked well:

"X had this way about her, of making it an all-round question that would fit for everybody, so 'tell me if you have any addictions' - she knows full well because she has the report but she wouldn't make that assumption. So I felt personally that that was a really helpful way because it felt to me that it was my chance to tell my story rather than being told my story by a question"

There were other very positive examples of good questions being asked, a "perceptive" midwife asking "would you like us to help you?", a children's centre receptionist asking "are you OK?"

Noticing

Interviewees also talked about how important it is for professionals to notice what is going on, as many women may feel hesitant revealing how things really are. So professionals need to read between the lines and ask questions that may reveal something unsaid. One woman recalled going to have her baby weighed and the social aspect around that, talking to other people, seeing notices and leaflets:

“I suppose if you are struggling you are not necessarily going out asking for help but while you are there people can pick up on things”

An example was given of a receptionist in a children’s centre just asking if everything was alright:

“What’s going on? Are you OK?”

This interaction resulted in a 2 hour conversation, which led to the mother seeking help and going regularly to a group – a transformative moment which **“made a huge difference”**.

Make it simple

There were several mentions of the need to make it simple and easy to seek support. Just having a phone number available, knowing that

“if the baby isn’t kicking you have a number, there should be a number for if you want to talk about how you are feeling”

One mother suggested the Red Book could have a simple message in it about mental health support, as it is a resource all women have and use. There was also a suggestion that women could record how they are feeling in the Red Book, so that this can be looked at during visits, not solely relying on what a mother says in that moment.

Validate

A woman spoke about her difficulties after having her baby, initially being told by friends her feelings were **“normal”** she didn’t seek help for months. Eventually she contacted her GP, saying she didn’t understand why she was struggling so much. The response was positive:

“she said – ‘it is worse for you. You’ve got post-natal depression. It is worse for you’. It just felt good.”

The following quote also shows the power of support that validates:

“X would phone me weekly, we would sit and talk, she wasn’t a worker who judged, she let me talk, she gave positive feedback, she’d say to me ‘you’ve done the work’. I’m very grateful for her”

This validation was the beginning of her recovery.

On the other hand, one woman also mentioned that a history of miscarriage had made her more vulnerable and that she did not feel that this was recognised by her health professionals.

“If you have lost a baby at any stage of your pregnancy there is nothing there to support you”

Time

Time was mentioned a lot:

- **the right amount of time** – many acknowledged that professionals don’t have a lot of time, but this limits the ability of women to feel that services are there for them or that a real conversation about how they feel is actually welcomed:

  "The health visitor is there just for the baby, they ask how you are but they don’t hang around long to hear the answer"

  “They (sic) want to hurry up and move on”

- **how many times** – many felt that the number of visits they receive after having their baby is too few, that you’re **“signed off”** too early, and that

therefore you have to be quite proactive to ask for help. One woman talked about her symptoms appearing after the standard visits had ended:

"If you don't show signs at the beginning you just have to go through whatever by yourself"

- **at the right time** – some mothers talked about their regular visits being at times where the health visitor is more likely to see what is really going on, for example at the end of the day rather than first thing. One woman mentioned that seeing a woman at the end of a long day at home with the baby would give a clearer impression of what is really going on. And one woman talked about the importance of being seen when alone, without the baby.

- **quickly** – being seen quickly, responded to when you need the help, was seen as being important - when the need arises, not several weeks later. Not only is this simply more responsive, but is also part of building trust:

"these women are reaching out, let's get them on board straight away rather than leaving them to the next day"

Practical issues

One woman mentioned that help with practical issues would assist with her low mood. As a single mother, getting support with tasks around the house, or some time to herself was viewed as being central to her mental health. Another woman mentioned that her earlier depression was very much linked to living in a first floor flat and finding it difficult to get out with a baby in a buggy.

Cultural differences

Several women talked about how their cultures do not recognise mental health, where such issues are not spoken about, leading to a complete inability to gain support from within the family.

“They are not very open about mental health issues. It’s still taboo. There is stigma and gossip”

This also means there is no encouragement to seek support from health services. In one family, needing mental health support was viewed as a weakness, with the solution being to pray or seek religious guidance. This woman had no name for what she was feeling, just questioned, **“why am I not feeling the joy?”** and found no empathy or support from her family.

Two additional issues came out of these discussions. Firstly, a view that black women’s voices are not heard enough. Secondly, that cultural needs should be taken account of and care tailored accordingly. One example being the need to time visits to fit in with cultural traditions. For example, after the naming ceremony, when family visits drop off. Professionals are not expected to know about all specific needs but can and should ask and build these needs into their practice. One woman felt she had been well supported but **“my cultural needs were not considered”.**

Preparation

Nearly all the conversations mentioned, uninvited, the need for better preparation during pregnancy, both for the practical challenges of being a mother, and for the potential of emotional challenges. The interviews asked for help to build up community support networks during pregnancy. Some felt that pre-natal groups that do exist should be better tailored to those with additional needs – an example was given about an exercise to consider life after the birth that actually caused anxiety. Some stressed mentioning the possibility of needing post-natal support during pregnancy, making seeking support more acceptable.

"If told from the beginning that you might need to see a counsellor then you won't be freaked out if it's suggested"

There was a lack of real conversations about how it might be after the baby is born. As one woman said, everyone should be advised:

"You may come out of hospital beaming, or you may not, if you do feel like this, this is who you contact".

Also:

"You get taught how to be pregnant and how to give birth but nobody actually teaches you how to be a mum and how to deal with all the emotions that come afterwards"

Another woman said:

"If the baby isn't kicking you have a number, there should also be a number if you just want to talk about how you are feeling"

One single parent felt **"rushed and forgotten about"** in hospital and ill prepared for going home.

So women need to be prepared during pregnancy to know that mental health problems do sometimes occur, to recognise when there's a problem, and to know what to do – who can help both within statutory services and the local community - and how to make contact. They felt they should be provided with information before it is needed.

Trust

The need for a feeling of trust, safety and lack of judgement were mentioned by almost all the women we interviewed. Trust, safety and not feeling judged comes from the ways in which professionals act, the way services are delivered, and how questions are asked. Seeing the same health visitor / midwife was mentioned several times as this continuity and consistency allows for the development of relationships within which it is more likely that honest and open discussions will take place. Here is an example of a very positive experience:

"The midwife took an interest in what was going on, was there with me throughout my journey, asked questions about how my husband was and how I was, they cared about my whole support network"

and a comment on the importance of continuity:

"For me that's a huge thing to have the same team around you…somebody I could have trusted to share"

There were specific experiences which had led to a complete breakdown of trust. One involved a woman whose past (an ex-offender) had led to a social care referral, which did not in the end necessitate any action. As a result, all trust was lost and this woman remains extremely wary of any engagement with statutory services.

Another involved a history of substance abuse which had resulted in children being removed. Consequently, this woman did not want to engage and felt judged:

"I was met with 'you just take drugs, you're just an alcoholic, you've had your kids removed, you're scum' …it's really scary trusting a professional, that you feel if you say the wrong thing, that instantly you're going to be in trouble"

In fact, the removal of one child led to a relapse:

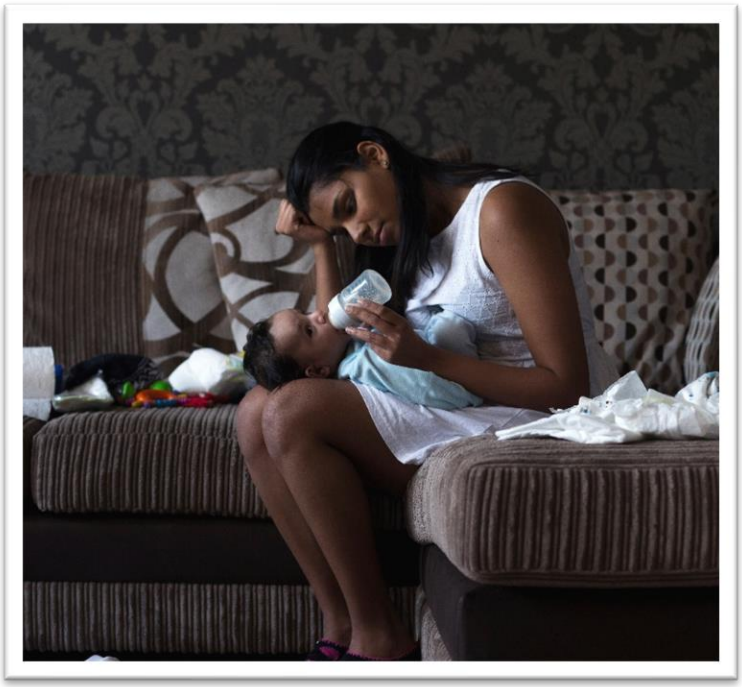
"The only thing I had to fall back on was my addiction"

This was especially significant given the removal of perinatal mental health support as she no longer had the child. Eventually this lack of trust and non-engagement did change, as the result of working with a counsellor who she did not feel judged by and who recognised her struggles to overcome past difficulties.

However, in terms of what good looks like, the following quote encapsulates many of the issues relating to the building of trust:

"The worker was phenomenal, weekly calls, did not recoil at my past, got positive feedback…being asked "do you have any addictions" rather than "you're a drug addict". It completely turned my life around having that support. If I was having a low day I'd text and she would slot me in to the diary. With their support, that's one of the reasons I am sane"

Covid



Given the interviews took place during the pandemic and in part through the lockdown there was also considerable feedback about the effects of the pandemic. For some this was problematic, meaning that community support they would have accessed was not available and that virtual appointments replaced face to face visits. On the other hand, one woman commented **"Everyone was miserable because of Covid so that kind of helped".**

4. Engagement

In designing our mechanisms to gather feedback, we were mindful of who we wanted to reach, and what we wanted to find out about. We had to think long and hard about how to find the women we wanted to hear from, the questions to ask, the look and feel of the publicity material, and how to connect - especially given the pandemic and lockdown. We learnt, or were reminded of, many lessons.

Time and persistence

The importance of investing time and persistence when planning the work and seeking out the people we wanted to talk to. More time was spent on preparation

and finding women than actually carrying out the interviews. So, this element needs to be recognised and resourced.

Known and trusted organisations

Going through known and trusted organisations to find women to talk to was invaluable. This would have been the case even without the pandemic. They were our only route in. Mechanisms such as an online survey may have resulted in a higher number of responses, but would have reached a different cohort, people we probably already hear from.

Conversations v surveys

Also, a conversation rather than a survey was also essential, allowing us to hear deep and rich stories rather than more superficial views. While more time consuming, for this work it was necessary. One of the unintended benefits was also that through these conversations several women expressed an interest in getting involved in ongoing coproduction with services. This would have been less likely had a survey been used.

Social media

Although we did run a targeted social media campaign, it was of limited value. A few responded to it, but our contacts with organisations such as Homestart and other local community groups proved more valuable.

Incentives

The offer of vouchers to all interviewees worked well as an incentive to take part. Offering vouchers also represents a tangible appreciation and recognition of the time given to offer feedback.

What worked best

We contacted many organisations asking that they help us promote the work. Many did that, and some did more than that, proactively finding women to speak to us.

One local Homestart asked their volunteers, when visiting or phoning families, to explain Opening the Door, asking if they would take part. One step further, they asked for consent to pass on their phone number or email address so that we could make contact directly. This worked better than leaving contact details with the family for them to contact us.
The community centre in Merstham, once they opened their doors, invited us to visit during a busy food project, so we could be directly introduced to women. This then led to one of their volunteers making contacts for us and sending contact details for women who would speak to us.

Principles of effective engagement

We also adhered to the important principles of patient and public involvement – see **Appendix 2**.

5. Conclusions

The women we spoke to were not uncomfortable talking about mental health problems and yet, stigma and fear persist. A number of barriers to accessing help were apparent, the most significant being the view that services are there more for the baby than for the mother. The fear of being judged, and the shame of not being a good mother remain. Women also felt that if they asked for help they may not get it, with services overwhelmed and waiting lists long. Drawing on their own experiences they stressed the importance of knowing what is available in the community and the need for questions to be asked in the right way. For those not confident to open up, the need for others to notice and act was mentioned. Clearly, it needs to be simple to ask for help, and women need to be prepared during pregnancy for the possibility of mental health problems and informed who to contact. This is not just to make it easy to find help, but to normalise the issue. Cultural sensitivity is also crucial, tailoring services to specific needs. An overriding issue is that of trust, which enables honest conversations. Continuity of care and being non-judgemental are key to this.

In terms of engagement, working through local, known and trusted organisations was the only way to reach the women we wanted to speak to. This will also apply to reaching women to access services.

6. Recommendations

The message

1. Continue to destigmatise mental health, reassuring women that they will not be judged and that no harm will come from seeking support for mental health problems.
2. Provide information that stresses that services are there for mothers, not just for babies.
3. Inform mothers that they are priority, that they will not languish on a long waiting list if they need help.

The response

4. Ensure GPs and Health Visitors respond positively and consistently to requests for help, offering appointments that allow adequate time during the postnatal period, then securing the support needed. Ensure that those who do not overtly report problems are not ignored - notice concerns where mothers do not reveal the problems they are experiencing.
5. Do more to ensure that questions to probe mental health problems are asked appropriately, multiple times, and that questions are meaningful and enquiring, not cursory, making it more likely that an honest answer will be forthcoming.
6. Validate women's experiences, and don't brush aside concerns as "normal baby blues".
7. Ensure requests for help are responded to swiftly, building trust and confidence.

Prepare

8. Normalise seeking help, letting women know in advance of giving birth that mental health problems happen to many people during and after pregnancy, ensuring they know what to do and where to go if they need support. Provide clear and simple advice about where, why and how to seek help in the Red Book.
9. Work with the local voluntary sector to:
    a. help women to establish support networks in the community during pregnancy, so it is there when needed.
    b. ensure personal invitations rather than simply expecting women to take advantage of what is available.
    c. ensure this support is tailored to specific needs, linking mothers in similar situations so they can better understand and support each other.

Build trust

10. Explore and be aware of women's personal stories and individual concerns that may affect their level of trust and wish to engage with services, to respond accordingly. Extra efforts will be needed to build a relationship of trust.
11. Provide consistency and ensure the same faces to build relationships of trust.
12. Train staff in cultural differences and ask families what their cultural rituals are. Then tailor support to specific needs.

Engage

13. Engage women to access services in the same way we engaged for this piece of work – invest time, be persistent, reach women through the organisations they are already in contact with, use personal contacts and invitations, and incentivise.
14. Invite the women who took part in Opening the Door to work together with staff on improving access.

7. Acknowledgements

Thanks to the women who took part in this work, for giving their time and for sharing their experiences – both positive and negative - openly and honestly. Lived experience is invaluable to understand what works well and less well, and to enable services to be shaped and tailored to meet diverse needs. We hope your involvement will continue.

Thanks to the following organisations who promoted Opening the Door and helped us find women to talk to:

Brighton

- Brighton Unemployment Centre, Families Project
- Brighton Food Bank
- Brighton Women's Centre
- Fulfilling Lives
- Oasis Project

Surrey - Merstham

- Merstham Community Facility
- Raven Housing Trust
- Stripey Stork
- Surrey Ethnic Minority Ethnic Forum

Portsmouth

- Fratton Community Centre
- Solent Mind
- Connors Toy Library
- Solent Talking Change
- Health Visitors

- Homestart Portsmouth
- Solent NHS

Slough:

- Healthwatch Slough
- Slough Voluntary Services
- Homestart Slough

8. Contact us

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sarah.peters@helpandcare.org.uk

9. Appendices

1. Insights from workers in local organisations
2. Engagement principles
3. Additional links and resources

Appendix 1

Insights from workers in local organisations

Workers in the organisations who helped us find women to speak to mentioned the following issues which, in their opinion, form barriers to seeking support:

- if you already have lots of connections with "the social" you don't want to talk to services
- a lack of a sense of agency, people just "put up with it"
- the fear of having children removed
- now knowing the services are there
- not being aware of your mood / not recognising unhappiness
- the fear of being judged
- being told "you're doing ok" – not helpful
- having to wait 2 weeks for a referral
- the fear of being offered drugs - not helpful if you have a history of substance abuse

Appendix 2

10 Principles of Effective Patient Involvement, as applied in Opening the Door

No.	Principle	Check
1	Be open and honest about what is / is not possible	We were clear that we were seeking views that would impact on barriers to services and that views would influence the design of services.
2	Communicate clearly in easy to understand plain language	Our publicity was not wordy, with carefully chosen images. Translations were offered if necessary.
3	Listen and act on feedback	This will be the next step and an initial response is included in this report.
4	Be accessible	Using local trusted organisations enabled accessibility – we went to our interviewees.
5	Involve as early as possible	The work took place at a stage that will allow feedback to have an influence.
6	Base relationships on equality and respect	Using a third party (Wessex Voices) allowed equality and respect during the interviews. The aim is to continue involvement on a similar basis.
7	Seek the views of those who experience the greatest inequalities and poorest outcomes	This was the fundamental purpose of Opening the Door. We partially achieved this.
8	Allow plenty of time	The project allowed interviews to take place over a period of several months, reflecting the challenges especially during the pandemic. There was a focus on quality, not wrapping up the work quickly.

9	Review, evaluate and publish the impact	Planned for early 2022, including an invitation back to those who took part to continue their involvement.
10	Allocate appropriate resources and support so engagement is effective	While the financial resources applied to this work was minimal, staff commitment allowed the work to be effective.

Appendix 3

Additional Links and Resources

Fulfilling Lives

https://www.bht.org.uk/fulfilling-lives/

Fulfilling Lives South East, led by BHT Sussex and supported by a number of voluntary and statutory sector partners, provides intensive and tailored support to people with multiple and complex needs, helping the most vulnerable and hard to reach

Another Mother Story

https://www.anothermotherstory.com

South Asian women's experience of motherhood

10. Feedback from NHS South East Clinical Delivery and Networks

We are really pleased with the Opening the Door report particularly as it was carried out during the Covid pandemic including periods of lockdown. The findings help to confirm for us some really important messages about the difficulties facing women living in adversity which impact on their willingness and ability to engage with services.

The first is the stigma surrounding mental health making the women fearful of being judged or even that their baby would be taken from them if they mentioned mental health problems. Reducing stigma is not just an issue for health professionals, it is a problem for the whole of society and we all, individually and collectively, have a responsibility to challenge stigma around mental health wherever we see it be that professionally or in mainstream or social media.

It is clear that a local personalised approach works best with consistent staff who know how to ask the right questions. Support groups for women who are in similar circumstances can be more acceptable and women also wanted services which were there for them not just the baby. Services which are easy to access without long waiting lists are important.

Training to all staff not just on what questions to ask but how to ask them, as well as relevant cultural awareness training, is also important.

The South East Perinatal Mental Health service will share the Opening the Door report widely to ensure that both those who commission and work in services that support these women can read the messages. There will be a continued commitment to ensure that all of the stakeholders in the perinatal mental health pathway have an opportunity to recognise perinatal mental health problems, to talk to women about them and to understand cultural differences to ensure that no groups of women are left out whatever their circumstances.