



Mental health and the journey to parenthood

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Supported by



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Foreword

👉👉 **Everybody wants to hold the baby, but who holds the mum?** 👉👉

Kristy

The arrival of a new baby is a major life event for any family. It can be joyful, exciting, overwhelming and challenging all at once, so it's essential that parents get all the support they need to help them form strong bonds with their children and help lay the foundations for a healthy, happy life for all involved.

In addition to the expected ups and downs associated with becoming a parent, many people experience mental health problems, too. Around one in four women experience mental health problems in pregnancy and during the 24 months [after giving birth](#), according to the NHS Long Term Plan.

Investment in mental health support for parents brings a variety of social and economic benefits, ensuring that individuals and communities are better able to cope with the stresses they face, and enjoy a better quality of life and health. The cost to the NHS and social care of parents not accessing high quality perinatal mental health care is estimated at around £1.2 billion ([per year's births in the UK](#)). According to the National Childbirth Trust (NCT), half of the mental health problems in new mothers go undetected.

In the NHS Five Year Forward View, NHS England committed to providing specialist mental health services for more than 30,000 extra new mothers a year by 2020/21 and has extended this commitment to benefit an additional 24,000 women by 2023/24 in the new NHS Long Term Plan.

How can people's experiences inform future care?

We wanted to speak to people about their mental health experiences before, during and after pregnancy, so that we could hear the stories behind the numbers and learn what's working for people and what needs to improve. We also wanted to help make people's partners' voices heard and to highlight the importance of good mental health support for families as a whole.

Over the last year, our network has gathered views and experiences from women and their partners. Each one of these stories was different and highlighted that every person's experience is unique to them.

Whilst each experience was different, three key issues linked them together:

- **People feel their mental health problems are triggered by a variety of issues:** A range of common triggers can contribute to the development of a mental health problem, such as severe sickness during pregnancy, physical illness, trouble breastfeeding, a traumatic birth experience, and a history of mental health problems.

- **People don't know where to turn for help:** Despite the increased focus on mental health, people still report not being given enough information about the support available and what to do if they need help.
- **People feel scared about how people will respond if they speak up:** Fear still holds people back from speaking up about their mental health. Staff attitudes can also act as a barrier to people expressing their feelings. One of the most common things people said to us about their experience was that in future they would seek help sooner.

By sharing people's stories, we want to highlight the variety of ways in which people's mental health can be affected by the process of trying to conceive and having a baby, to help tackle the stigma that surrounds mental health and encourage more people to speak up.

People interact with a range of professionals on their journey to becoming parents, from GPs, nurses and midwives, to antenatal class leaders and health visitors. These professionals don't just support people with the physical side of becoming parents, they also have a vital role to play in supporting their mental wellbeing.

We are calling on everybody who interacts with prospective and new parents to make more space for people to discuss how they're feeling, and to find out what to do if they need mental health support.



Introduction

There has been [significant investment in mental health](#) services for new and expectant parents in England since we [last looked at maternity and mental health in 2014](#). This is an important move by the NHS and recognizes that the best way to promote lifelong mental health and wellbeing is by ensuring all children have a stable environment in which to grow up.

To help the NHS roll out new services and further improve the broader support offer, Healthwatch across the country have been investigating people's experiences of maternity and mental health.

Our broader research

Between August 2018 and March 2019, thousands of people responded to our research into their experiences of mental health before, during or after pregnancy. We heard from:

- People planning to start a family
- Pregnant women and their partners
- Parents who have had a child in the last three years
- People who have struggled to conceive or lost a baby
- NHS maternity and mental health staff

These stories were gathered through a variety of methods, from online surveys to more detailed fieldwork carried out by Healthwatch in eight areas of England who spoke to nearly 800 people through focus groups and visits to services. We also worked with partners in the voluntary sector to gather views and experiences from groups who often go unheard.

Our main survey was based on [guidance from the National Institute for Health and Care Excellence \(NICE\)](#). The guidance for services sets out what women can expect when it comes to the recognising, assessment and treatment of mental health problems when they are planning to have a baby, are pregnant, or have had a baby. We wanted to assess the extent to which pregnant women and new parents are experiencing this level of support.

The focus of this report

In this report, we will explore what we've heard from 1,738 women about experience of diagnosed or undiagnosed mental health problems during the journey to parenthood. We will also draw on what eight local Healthwatch found when they investigated this issue in their local areas.

It is important to note that those who took part in the research were self-selecting and the sample is not fully representative of the broader population of new parents or those trying to have a family.

However, their thousands of stories provide a wealth of evidence regarding what it's like to face mental health problems during the joyful yet challenging experience of having a baby.

There are common themes amongst these stories, which will be of use to professionals, policymakers and prospective parents. However, what the stories illustrate most clearly is just how diverse and individual each experience is.

Although this report mainly focusses on the experiences of women who identified as having a diagnosed or undiagnosed mental health problem and who are planning to conceive, currently pregnant, or have had a baby in the last three years, we are planning further analysis of our evidence in 2019 to see what more services can learn. For example, exploring the mental health experiences of people who have struggled to conceive or lost a baby, as well as the support available to partners.

Key findings

People feel their mental health problems can be triggered by a variety of issues.

A wide range of causes can result in somebody experiencing a mental health problem. For many people, *mental ill-health is likely to be triggered by a combination of factors*. People shared a multitude of elements that contributed to their conditions, but we noted a few that came up time and again. These are:

- **A pre-existing mental health condition:** Many who shared their stories with us had a history of mental health problems. The level to which this was acknowledged and acted upon by professionals had a significant impact on their experience.
- **Isolation:** Pregnancy-related conditions and symptoms, such as hyperemesis gravidarum (severe or prolonged vomiting), and maternity leave can see women feeling isolated, which can have an impact on their mental health.
- **The physical health of mother and baby and the difficulties they faced:** We heard from mothers whose mental health was affected when they or their baby was physically unwell. Women also shared how some of the difficulties they faced, for example with breastfeeding, could also impact on their mental wellbeing.
- **A lack of empathy from professionals:** People shared stories where they felt that a key trigger in the development of their mental health problem was a difficult conversation or unsympathetic interaction with a health and social care professional.

👂👂 I said at my booking appointment (when you first go to hospital to say you're expecting a baby) that I had a history of mental health issues. They told me there might be support available for me, but it was never mentioned again. 🗣️

Maria

People don't know where to turn for help

If somebody does experience a mental health problem whilst expecting a baby, or caring for an infant, they need to know where to go for support. We heard that for many, simply not knowing where to turn was a key factor in their illness. Women said the following contributed to this feeling:

- **A lack of opportunities to discuss mental health:** Some people had regular conversations about their wellbeing and felt well supported, whereas others weren't asked about their mental health, and/or didn't feel such a conversation was wanted by professionals they interacted with, which affected how confident they felt about speaking

up. People told us that the attitudes of the professionals they interacted with were critical to whether they were able to get the support they needed.

- **A lack of clear information about where to go for help:** Many people said that because they weren't proactively told where to go if they had a mental health problem, they felt lost when an issue did occur, and this slowed them down in getting the help they needed. Others said they would have liked guidance on where to go to speak about issues and fears, such as a traumatic birth, a condition or phobia, but without such signposting, they felt they had to find a way to cope alone.
- **Limited access to support:** Some people got access to help quickly, but others had to wait longer than they would have liked, leaving them feeling unsupported, and, in some cases, seeing their conditions worsen.
- **A lack of understanding about what happens in a crisis:** Many people are unaware of the options available to them should they reach a crisis point. This lack of awareness made some people feel worse because they didn't know if there was anywhere to turn for help.
- **Limited consideration of partners' needs:** We also heard about the impact that expecting and/or having a baby can have on partners, and the need for clear information and support for their needs. In our 2018 [literature review on mental health](#), service user experiences research we highlighted in the report recommended that primary health care services and professionals should adopt a more family-centred approach to perinatal care that includes partners.

“Having a baby is such an intense experience, it’s so overwhelming. It’s an obvious flashpoint for some mental health issues. It would have helped to have a leaflet that said, ‘If you’re feeling down, here’s a number for someone who can help you.’ That kind of preventative work could help stop the cycle I got into. A lot of my decline was driven by the hopelessness – feeling there was nothing and nobody that could help me. Knowing there was support out there would have helped.”

Maxine

People feel scared about how people will respond if they speak up

Many parents find that even when they know they're struggling with their mental health, they feel too afraid or ashamed to speak up. This happens for several reasons, including:

- **Fear that they will be judged as a bad parent:** Some parents worry that if they admit they have a mental health problem, they will be judged by others, or seen as incapable of looking after their children. Many feel they should just be able to cope with every element of becoming a mum or dad, regardless of the impact on their wellbeing.

- **Pressure to have the happiest time of their life:** People spoke about the pressure of living up to personal or social expectations of being a ‘perfect’ parent. Many feel ashamed when their experience doesn’t match up, which puts them off speaking up.
- **Lack of clarity about what feelings are normal after having a baby:** Varied communication about the range of emotions mothers could expect to experience after having a baby meant that some people didn’t feel confident to say that they were having a particularly difficult time or to push for support when they felt dismissed.
- **Inconsistent opportunities to chat about how people are feeling:** Lots of people stated how grateful they were to the professionals who helped them whilst they were expecting/having a baby and that they appreciated the limitations on their time. However, many also said that they would have liked more opportunities to speak about how they were feeling mentally, but these were not always offered. [Our mental health literature review](#) highlighted that while screening tools to assess perinatal mental health in primary care exist, they are not always used consistently.

“I was the first person in my friendship group to have two children. Nobody warns you about what a jump it is. Now other friends have done it they’ve said the same, but at the time I didn’t want to speak up and scare anybody. I didn’t want anyone to think I couldn’t cope. Nobody talks about mental health, nobody wants to say they’re struggling or not coping, everyone expects you to be really happy.”

Amy

Why are we looking at this issue now?

As a society, our views on mental health have changed significantly in recent years.

People are now more willing to speak about their experiences and supporting those facing mental health problems has been stated as a political as well as a clinical priority.

Yet, unlike other areas of health and social care, the [feedback we receive](#) about mental health support continues to be mostly negative, [and it's not just us picking up these concerns](#).

Our work on mental health

Encouragingly local Healthwatch have shown that gathering the views of people in need of better mental health support, from teenagers in Bristol to army veterans in Norfolk, can lead to positive change.

In August 2018 we outlined our plans for a multi-year project looking at people's experiences of mental health and the support currently out there to help them.

The project aims to look at people's experiences from childhood to old age, focusing on key moments in life when people need support, and using their stories to inform policy and practice in mental health at a national, regional and local level, and drive the sorts of changes people want to see.

We began this work by reviewing and [publishing a summary](#) of what 34,000 people had already told local Healthwatch about their experiences of mental health to date. During this review, we identified that we had comparatively little insight into people's experiences of maternity and mental health and so decided to look at this issue first

In focus: Scale of maternity and mental health problems

During pregnancy and in the year after birth women can be affected by a range of mental health conditions.

- In 2018 there were [594,080 births in England](#). Around one in four women experience mental health problems in pregnancy and during the 24 months [after giving birth](#).
- According to the [Mental Health Foundation](#), the most common mental health problems experienced during pregnancy and after birth are anxiety, depression and post-traumatic stress disorder (PTSD).
- A review by the [MBRRACE-UK](#) found that maternal suicide is the leading cause of direct deaths occurring during pregnancy or up to a year after the end of pregnancy.

- [Work by the Royal College of Obstetricians and Gynaecologists](#) suggests 7% of women who experience mental health problems during or after pregnancy are referred to specialist care.
- Many women with pre-existing mental health conditions can experience difficulties managing their condition during and after pregnancy.
- Partners can also be affected. [Research by the National Childbirth Trust \(NCT\)](#) found that more than 1 in 3 new dads (38%) are concerned about their mental health.

Policy context

Recognising the scale of the issue and the lack of support available to new parents, in the NHS Five Year Forward View NHS England committed to providing specialist mental health services for more than 30,000 extra new mothers a year by 2020/21.

This target was backed up [with an investment of £365m](#), and in April 2019 it was announced that new and expectant mothers in every one of the 44 local NHS areas now have access to specialist mental health care where they live.

The NHS Long Term Plan, which sets the direction of the NHS for the next 10 years, reinforced the commitment to maternal mental health and set even more ambitious targets, including plans to benefit an additional 24,000 women per year by 2023/24. It also set out a new commitment to provide better support for partners of expectant mothers, in a move that recognises whole families can be affected by mental health problems during the perinatal period.

Against this commitment, NHS England is already providing support to [13,000 additional new mothers a year](#). This is positive; however, the way performance is monitored makes it difficult at a national level to fully understand:

- Who are these mothers and are there any groups missing out?
- Did their partners require any support and, if so, was it made available?
- Did the people get the support they wanted when they needed it?
- What would people receiving support have wanted to be done differently?
- What is the remaining gap between provision and demand??
- Was all the £365m in funding allocated to maternal mental health services?

Without providing answers to these questions at a national level it is difficult to build a transparent picture of whether the changes being implemented are driving the sort of improvements we all want to see.

Existing research backed up by policy reports, such as the [First 1000 days of life report](#) by the Health and Social Care Select Committee has already shown how important it is to mental health in later life to ensure children are provided with a stable environment in which to grow up. We want to help establish whether everything possible is being done to support those who experience mental health problems during or after pregnancy, so that their whole family can overcome any challenges they face.



What our survey respondents told us

- A total of 1,979 people completed our survey in relation to their or their partner's experience of a diagnosed mental health problems before, during or after having a baby, or a mental health problem within this period that wasn't diagnosed.
- 1,738 were women who'd had either a diagnosed condition (1115), or experienced mental health problems but no diagnosis (643). Twenty women identified as being in both groups. 45% of people said they experienced a mental health problem before becoming pregnant, 35% during the pregnancy, and 64% after the birth.
- The remaining 241 respondents included men, and people responding in relation to their partner's mental health experiences.
- 192 (11%) of the women who'd had a mental health problem during the journey to parenthood said their partner had one too.

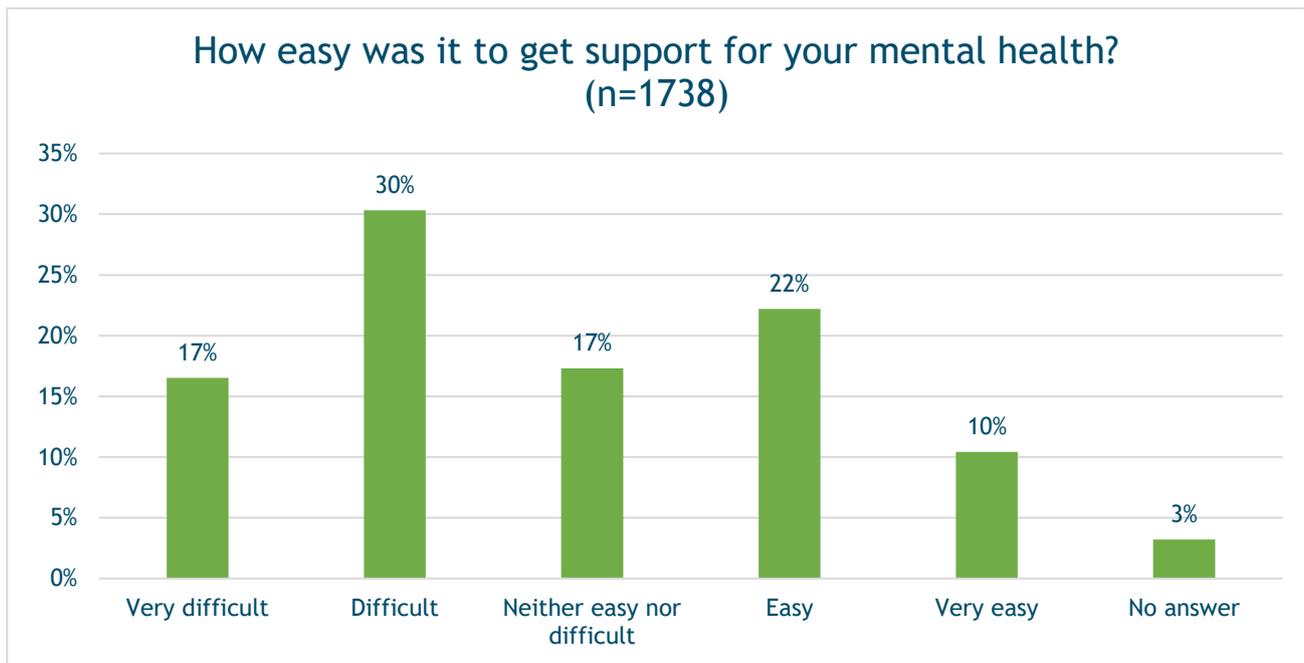
The questions we asked were based on [guidance from the National Institute for Health and Care Excellence \(NICE\)](#) on antenatal and postnatal mental health. The guidance sets out what women can expect when it comes to the recognising, assessment and treatment of mental health problems when they are planning to have a baby, are pregnant, or have had a baby or been pregnant in the past year. We wanted to assess the extent to which pregnant women and new parents are getting this level of support.

“The professionals involved in your care should talk with you about mental health problems in pregnancy and the year after giving birth. They should explain any treatments or support you should be offered so that you can decide together what is best for you and your baby.”
[Antenatal and postnatal mental health: clinical management and service guidance, NICE.](#)

The overall message was mixed with people reporting both good and bad experiences. Indeed, compared with the feedback Healthwatch receive about mental health support more broadly the picture is more positive. However, it is clear the NICE guidance is not reflected in many people's experiences. We found that:

- 39% of the women who said they had a diagnosed or undiagnosed mental health problem prior to, during or after pregnancy told us that they or their partner had received mental health support at some point after conceiving.
- However, a third of women with a diagnosed mental health condition (33%) didn't recall being given any advice at all about maternity and mental health needs at any point, which could also have contributed to the lower take-up of services.
- Overall 38% of women did not recall being given any information and advice about mental health. In terms of specific advice, only 30% of all women recalled being given information about how to take care of your mental health when you have a baby.

- Of the 682 people who said they or their partner received mental health support, 56% received it within one month, and 87% within three months.
- 57% of all women said they felt involved in decisions about their care, whereas 36% did not. For those with a diagnosed mental health condition 63% said they felt involved in decisions about their care, whereas 32% did not. For women with an undiagnosed mental health problem, 45% felt involved in decisions about their care, whereas 42% did not.
- When asked how easy it was to get support for their mental health, nearly half (47%) of all women said they found the process 'difficult' or 'very difficult'.



- When people were asked about the quality of mental health support given by health professionals, such as their GP, midwife or health visitor, their responses indicated that experiences can be inconsistent. A third (29%) said it was 'good' or 'very good', but another third (36%) said it was 'poor' or 'very poor'.

- Of those with a diagnosed condition/a partner with a diagnosed condition, 15% were sure

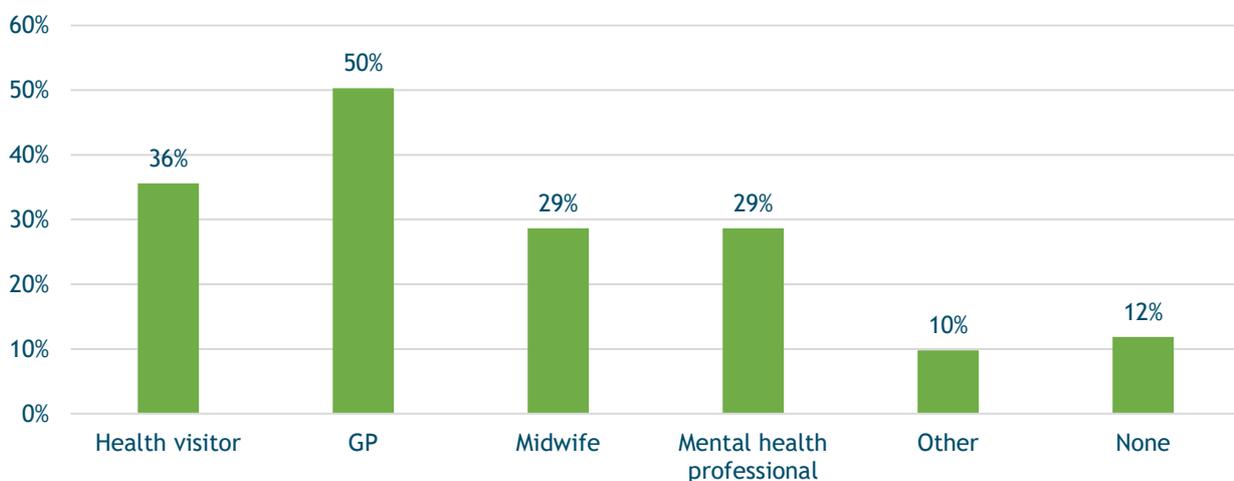
How would you rate the quality of mental health support given by health professionals? (n=1738)



they or their partner had received a formal review within the past 12 months.

- More than half of all women (58%) told us that they did not have a care plan that considered maternity and mental health needs and 17% replied 'I don't know'. When it came to those with a diagnosed mental health condition, 55% told us that they did not have a care plan in place that considered both maternity and mental health needs. Only 24% of people with a diagnosed mental health condition told us that they did have a care plan in place that considered both their maternity and mental health needs.
- Half of the women (50%) said that just one type of health professional had offered support to them and/or their partner. 36% reported support from two or three, and 7% reported support from four or five professionals.

Which health professional(s) offered you/your partner support? (n=1738)



- GPs were the most likely source of help. Only a third of respondents (29%) reported mental health support from a midwife for themselves and/or their partner. 29% said they had help from a mental health professional, and 36% said a health visitor offered support.
- 48 women (4%) with a diagnosed mental health condition and 158 women (25%) who didn't receive a diagnosis for their mental health problem said they did not get any professional support at all.

Our findings versus NICE guidance

As these findings highlight, NICE guidance regarding the mental health care women should receive when expecting or after having a baby is not always being followed.

For example, the [NICE guideline on maternal mental health](#) says that there should be a written care plan for any women with a mental health problem in pregnancy and the postnatal period, including how outcomes of treatment will be routinely monitored. We heard from women who either did not have a monitored plan in place or weren't aware that it existed.

NICE also recommends the provision of relevant information on mental health, and discussion regarding the benefits and harms of treatment and of no treatment. Again, we found that not everybody experienced the standard of care they should expect, with many women not recalling being given any advice or information about maternity and mental health.



What care people should be able to expect

In addition to the NICE guidance there are currently five [NHS mental health 'care pathways'](#) that women might need to use at different times during their journey to parenthood, depending on their individual circumstances.

- Women with a diagnosed serious mental health condition before pregnancy should be offered pre-conception advice.
- Women who are pregnant and are receiving treatment or care for their mental health should have a care plan taking this into account ('specialist assessment').
- Women becoming seriously mentally unwell during pregnancy or in the time after birth (now in the two years after birth, although until recently, in the year after birth) should have an emergency assessment.
- Evidence-based talking therapies should be available to new mothers.
- When necessary, in serious cases of mental illness, care in an NHS Mother and Baby Unit should be available.

The 'I' statements

The National Collaborating Centre for Mental Health has already done extensive work, in partnership with people who use services, to set out what good care should look like for women with a diagnosed mental health condition at any time before, during or after pregnancy. This is [described through a series of 'I' statements](#):

- "I know that during pregnancy and post-pregnancy check-ups, I will be routinely asked about my physical and mental health, as well as the health of my baby. If I am worried about my mental health, I will be able to discuss my concerns with someone in a supportive environment."
- "I know that if I experience a mental health crisis, it will be treated as a medical emergency, and I will have prompt access to assessment and treatment."
- "I know that if I need care in hospital for a mental health problem, I can stay with my baby in an MBU and will be able to go there as soon as possible."
- "I know that if I am planning a pregnancy and have a severe mental health problem, I will be able to be seen for preconception advice in my local community so that I have the information and advice I need to plan my pregnancy effectively"
- "I know that if I need a specialist assessment I will be seen quickly and know the outcomes and next steps for treatment and care."

- “I know that if I have a mental health problem during or after pregnancy, it will be treated with the same urgency as a physical health problem. This means that I will be able to receive the right care at the right time, based on my needs.”
- “I know that I will have a choice of a range of NICE recommended treatments, including psychological interventions, and, with the help of staff, will be able to make decisions that are right for both me and my baby.”

As we explore some of the experiences people have shared with us and the themes emerging from our findings, it’s useful to consider the impact of situations in which the expectations set out in these statements have and have not been fulfilled.



What would people have done differently?

People with a range of experiences responded to our survey. This included women with pre-pregnancy mental health conditions, and women for whom a new or additional diagnosed condition arose during pregnancy or after the birth, including (but not limited to) antenatal depression and anxiety, and postnatal depression.

These women therefore represent a complex mixture of needs and possible care pathways. They are also drawn from all parts of England and so are giving feedback on different services, delivered at different times, though their most recent birth experience will have been in the last three years.

What we heard from them echoes recurrent themes in what women have said in previous surveys, such as NCT's [‘The Hidden Half’ report](#).

In our research we asked people, considering how their mental health has been supported during their journey to parenthood, what they would have done differently. Below is a summary of their responses.

Factors that made an experience more positive

Some were entirely happy with the care they received thanks to:

- Good care from professionals

We heard about the professionals who made people feel well supported at the various stages of their journey to parenthood.

“Nothing. I received amazing care both during my pregnancy and still now and my baby is 7 months old. I couldn’t have done it without the professionals who have supported me so brilliantly.”

“My mental health has been really well supported during and after my pregnancy. I feel incredibly lucky to have received such excellent support from all professionals involved.”

“My community midwives were amazing and supported me hugely. Went above and beyond.”

“Nothing at all I got amazing support from all the professionals even now almost 4 weeks after pregnancy I am still getting support. Such an amazing team behind them I love them so much, we have a brilliant NHS team within antenatal.”

“The health visitor provided great support.”

- Staff bearing their mental health in mind and proactively asking how they were

People told us about the difference it made when staff made the effort to check in with them about how they were feeling.

“Whilst I was upfront about my mental health problems at my previous booking appointment, I failed to seek further help when my mental health deteriorated during my pregnancy. I was lucky that the midwives and my health visitor, being aware of my history, did keep a slightly closer eye on me.”

“I feel that I was lucky to have a fantastic midwife who recognised that I might be at risk of low mental health based on my history, and always made a point of checking in with me. She noticed my mental health was poor in the immediate days following birth and was incredibly supportive. I owe her a lot for the advice and support she gave. I also feel very lucky to have a GP practice which has always been a safe place to discuss my mental health.”

- Support being provided in what people felt was a timely fashion

We heard about how important it is for services to respond quickly when people speak up about a need for mental health support.

“I had mental health issues with anxiety before pregnancy and I also saw a mental health midwife during my pregnancy. I visited my GP quite soon after giving birth as I was feeling overwhelmed with anxiety. I was referred very quickly to the correct people to help and I got the treatment I needed without taking medication.”

- Successful referral to perinatal support

People told us about the positive impact of having access to specialist perinatal care before and after giving birth.

“I was lucky enough to be under the perinatal mental health team during my pregnancy due to suffering from depression in the past. Although my mental health was good during my pregnancy, the team [contacted] me once a month just to check in and were involved in drawing up my birth plan. Their [involvement] also meant that I received instant support after my baby was born when my mental health deteriorated. I received a visit every fortnight and this support continued until my son was a year old. I was also referred to a clinical psychologist in the Infant and maternal mental health team who started seeing me when my son was 7 months old once a fortnight. This support is still ongoing, even though my little boy is now nearly 2.”

What would have helped?

For others, the experience was less positive. People said their experience would have been better if:

- If everyone involved had a greater understanding of the impact of becoming parents on people’s mental health

People spoke about the damaging impact they felt it had when professionals they interacted with weren't equipped to support them with a mental health problem. People talked about staff dismissing their feelings, underestimating the severity of how they were feeling and not wholly understanding the condition being presented to them.

"I asked for help at 37 weeks from my GP as I have a history of depression. I was told I was just tired or hormonal and to stop working. I felt so dismissed by this that I did not feel I could ask for help again even from my allocated mental health midwife. I had my daughter 5 weeks later by which point I was in a bad place and after a traumatic birth did not bond with her at all. I went for my pre-arranged review hearing with the mental health midwife and broke down to her about how I felt. After that I got proper help, but I feel I lost the first 6 months of my daughter's life due to the unhelpful approach of that GP. I felt I had tried to do the right thing by speaking up early and was ignored. Better pre-natal depression awareness could have made a huge difference to my journey and stopped things getting as bad as they did."

"There is nothing I could have done differently. I did all I could to explain to the GP and any professional that I didn't feel well and recognised my symptoms, but the GP dismissed them as baby blues. I was direct, clear and insistent but this made no difference. Consequently, I suffered for longer and my baby suffered through my lack of bond with him. Local midwives were great."

"Ask for help but you aren't able to do that when you're mentally very unwell it's a catch 22 situation. So medical professionals need to RECOGNISE when people need help & action it."

"I don't know what I could have done differently; if the service and/or awareness isn't there then what can you do?"

"Mental health is paramount in pregnancy, birth and parenthood, but it seems to get forgotten until it becomes POST natal depression. A mother's mental health is a crucial factor in birth. I'm currently battling with it in the first trimester of my third pregnancy. My last midwife appointment I wasn't even asked how I was feeling, physically or mentally."

"I was asked once by a consultant if I ever felt low during pregnancy and I denied this, I had a previous episode of depression. Now looking back, I should have said yes. At the 6 week check I said to the GP that I felt very emotional and not how I had felt after my previous pregnancy/birth. He said to just wait it out and see. It then took me another 5 months to go back to the GP about this issue."

"I didn't even know I was experiencing depression after having my first baby. I would have made a young mum like myself aware of the symptoms and how to deal with them because it broke me in so many ways and led to more complicated mental health issues. Now that I'm having my second and I'm recognised as already having issues with BPD

depression anxiety and ADHD, the mental health team at my local hospital have been more than accommodating. Had they given me the advice prior I could have avoided it all.”

“I have bipolar. This was undiagnosed until I got postpartum psychosis after my second child. I had postnatal depression after my first child and supposedly had a care plan in place, but this did not pick up that I am bipolar or provide any support after I moved house when I was 8 months pregnant. It would have been helpful if I had been referred to a support group when I moved, and it would have been helpful if bipolar had been diagnosed earlier as this massively increases the risk of PPP [puerperal psychosis – a serious mental health condition following childbirth].”

“More advice and support for the first six weeks after delivery. Any discussion of my mental health at 6-week GP check-up and/or 6-week health visitor appointment.”

- If there had been more opportunities to discuss their mental health

We heard from people who would have liked to talk about how they were feeling but didn't have the chance to do so. People said that it would have helped if professionals had been proactive in asking about their mental wellbeing.

“It was never mentioned by anyone, My GP told me to stop taking my medication as it was harmful to the baby, but it was never then followed up on or asked about. I struggled massively with my mental health whilst pregnant but didn't know if support was available or who to ask.”

“I had to actively reach out for support. There were *zero* questions about my mental health in the 6 week check despite having PND with my first child. I was offered online support through iTalk which I didn't find useful. I have paid for private therapy.”

“I would have wanted someone to ask me specifically about my mental health - no one did and as a result I suffered silently for months and months before reaching breaking point. It was awful, and heart breaking and I missed out on so much with my baby as a result.”

“During my pregnancy I told my midwife about previous diagnosis of anxiety disorder and received no help. After birth I felt v depressed but my HV (health visitor) just gave me a scoring survey, talked over me and I didn't want to speak to her. Next time I would request a different HV.”

- If they had been listened to

People said that in retrospect they wish they had sought help sooner or been more forthright in asking for support, as professionals did not always spot that they were struggling or take the action they wanted when they shared how they were feeling.

“I would have tried to get help earlier in my pregnancy.”

“I would speak out more about my concerns earlier. Rather than letting [them] build up and build up and lead to the depression and anxiety I personally suffered.”

“I would have called my health visitor sooner. She had completely forgotten about us!!”

“I would have asked for a specific check to be set up if possible for me on regular occasions after the birth of my son. I have a history of mental illness and it was difficult to distinguish between baby blues and PND.”

“I would have been more insistent when asking for help rather than being allowed to be fobbed off, as if I had been given appropriate support when I first was struggling I may not have become so unwell and not only myself, but my child and partner would be far, far better off.”

“I wouldn't have relied on my health visitor to spot that I wasn't right, I would have gone to my GP straight away. The health visitor just asked a set of questions and didn't actually use her eyes or ears to see that I wasn't well.”

“I would have alerted my midwife more to the potential problems I might experience considering that I had an eating disorder as a teenager.”

“Challenged midwife who referred to previous suicide attempt as 'Attention seeking'”

- If there had been greater availability of support and clearer signposting

We heard about the difficulties some people faced trying to access services, and about others who were promised that they would be contacted about getting support but never received a call.

“Nothing - I was very supported whilst in hospital and when I came out had great support from my midwife, then health visitor. It was after that all stopped that I began to struggle and found that accessing services was difficult.”

“I had to chase up my referral to psychology during my second pregnancy and during that time my anxiety became worse. After I had my second child I got a referral for CBT through iapt, again I had to chase that up a bit, but what was tricky was sorting out childcare, so I could attend appointments as I couldn't bring her. I couldn't afford a babysitter at that point. In the end a relative helped, but it made things more stressful.”

“I was given very little support, the only option I had was to phone the self-referral counselling service, to tell them I had a child under 1 and I would be prioritised, however I never had a call back. So, I would have made this process better and make sure the people self-referring are seen!”

“I was offered no support for my mental health during or after pregnancy. I was discharged by my psychiatrist during pregnancy and referred to the perinatal psychiatry

team, but there was no perinatal psychiatrist at my hospital or in my area, so I was left with no one. I had psychosis after the birth and was visited by a mental health nurse 3 days later. He referred me to the psychiatry team, but the referral never made it to my GP and was not followed up by the hospital. My GP and health visitor tried to support me, but it was only when I reached crisis point two years later that I finally received support after admission to A&E. Before that time, I had waited 8 months for talking therapy and my GP had tried changing my medication but despite my pleas refused to refer me to the CMHT.”

“I was diagnosed with postnatal anxiety and mild personality disorder by my health visitor. She said someone would contact me but after a few weeks with no contact she said it would be best for me to refer myself to healthy minds Worcestershire. Which I didn't as I didn't feel like ringing them myself. In the end I began to slowly feel better and haven't received any treatment or follow up from my health visitor.”

“Nothing. How could I have done anything differently? My mental health was ignored antenatally, despite being open about my history of depression. My birth was traumatic. There was no relevant handover when I was discharged back into the community postnatally, my current and mental health history was ignored by midwives and health visitors. When I complained about my care I was, to coin a phrase, "mugged off". Only at my son's one-year check did the health visitor listen and set the wheels in motion for support, after that point I received excellent care.”

- If more information had been available about mental health and the support available

People told us that they would have felt more empowered when it came to getting help if they had better access to information. We heard about the difference this could have made to how long people lived with a problem before finding help.

“Provide more info about postpartum mental health and risks. What to watch for. Help everyone differentiate between just tired vs [specific conditions].”

“If I knew that pre-pregnancy/during pregnancy mental health support was available I would have accessed it - I would have then known about my options before living in a very difficult state for some time before accessing help.”

“[I would have] told more pregnant people and new mums in my local area to seek out mental health support - I am lucky to live in an area where it is available and works very well.”

“I would have been more forceful and made my GP refer me before I got to 32 weeks pregnant. They wrongly told me I didn't have to think about my bipolar disorder impacting my pregnancy when I went to an appointment at around 12 weeks pregnant. Once I got referred the support was excellent.”

- If people had been able to keep seeing the same staff members

We heard from people who believe that continuity of care would have helped make sure their problems were spotted and addressed more quickly and effectively.

“I would have begged not to have had multiple changes to my midwives and health visitors so that it could have been picked up.”

“My appointments with the midwife were so brief and rushed I did not feel I could discuss how I was really feeling. I saw a different midwife each time, had I seen the same one throughout maybe either they would have noticed a change in my mood or I would have trusted them to open up.”

- If professionals were better equipped to take people’s personal circumstances into account

We heard about how important it is that there is appropriate support for everybody, no matter what route they take to becoming parents.

“The NHS doesn't know how to appropriately support lesbians and their partners around mental health both during the fertility process and postnatal. We have to access private treatment and there is no thought given to partnerships and integration between the NHS providers and private providers to support the mother. Generally, with provision there is some underlying homophobia, so the trust isn't there to seek support. There are so many cuts to pre-natal provision I don't know what I would have done if I couldn't have afforded the NCT classes. The peer support from other mums has had the most powerful positive impact on my mental health. There was some provision locally, but I was given such short notice that organising the time off work would have been very difficult, and my partner wouldn't have been able to be there (this is really important), plus some of the sessions seemed influenced by local policy rather than the needs of the mother. Support that isn't specifically about mental health but that enables friendships is a really important part of the picture as it leads to peer support.”

Other experiences of note

Below are several additional factors that affected people’s experiences.

- The impact of fear

Some people told us that they were reluctant to speak up about their mental health for fear that they would be misunderstood or judged. We heard from people who said they worried their mental health would be misunderstood as an inability to look after their child.

“The biggest fear was that if I spoke out about how I was feeling they would take my baby away. I didn’t have any faith in my health visitor and the thought she might have to

be involved in our life lead to more anxiety. Although care was available when asked for there is still a huge amount of stigma attached to asking for help.”

“I was afraid of being honest about my feelings in case I ended up with unneeded pressures, such as social service.”

- The impact of poor support

We also heard from people who shared the long-term effects of a poor experience of accessing mental health support.

“I seriously considered not having more children because I felt the support was so bad.”

“I was treated appallingly after my first child at my six-week check and was refused to be seen due to being 'late' for the appt (I wasn't; the surgery has since apologised and changed their policies). This check did not ask any questions about my mental state, but I had lost confidence in the practice due to the negative experience towards a new mother who was already struggling to get out of the house...”

- Taking medication for mental health conditions

We asked women with a diagnosed mental health condition their experiences of advice - for them and their partner - about continuing or stopping medication before they became pregnant or after conception.

Some were specifically given information about the benefits and risks - for them and their baby - of continuing with their medication. Others, however, reported being given conflicting advice, and this came up particularly in relation to the drug sertraline.

We heard from women who decided to discontinue all medication, sometimes without being offered or seeking any medical advice, and sometimes going against the advice they were given.

As with all our findings, we heard from people who'd had a real variety of experiences, highlighting a need for greater consistency when it comes to the support and information offered to new and prospective parents.

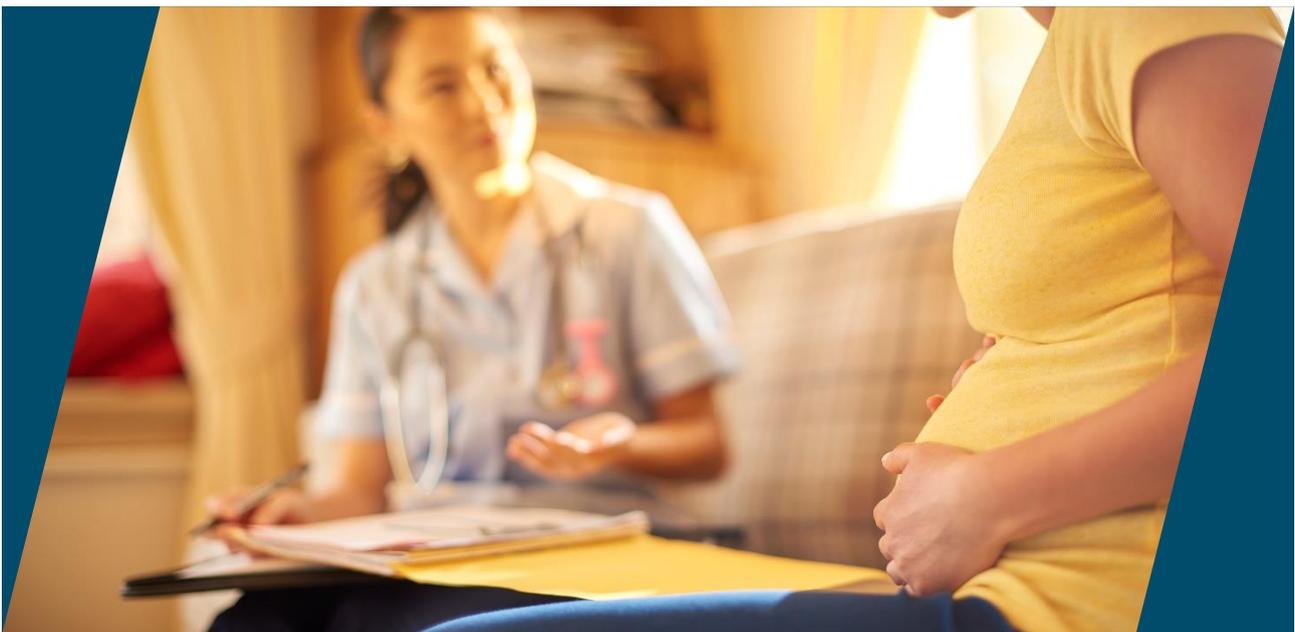
“I got prenatal depression & was prescribed Sertraline with great results.”

“I was on sertraline for depression. I was originally told that coming straight off it would affect me greatly, mood swings etc. And that I shouldn't get pregnant whilst taking it. When I found out I was pregnant at 5 weeks (surprise!), I went straight to GP for advice. She didn't know what to do about sertraline, so went to phone a midwife and would call me when she had more info. She later called to say that I should stop taking sertraline immediately, so I did. Few weeks following were hard. Mood swings from going straight off the anti-depressants, plus all the added, 'I'm pregnant!' hormones, I had a really tough first 2 months. Thankfully, I'm now in a good place after months of therapy, where

my husband was able to look after me and talk me through my bad days. When I spoke to a second midwife at my 25-week check-up, I told her about this experience, and she informed me that many mums continue with sertraline during pregnancy, and that I should never have been taken off it to start with. Funnily enough, that set me off again. I was in tears! I'm coping fairly well without it, and so won't go back on it now, but I'm so annoyed that the first few months of my first pregnancy were so stressful.”

“I had been taking Citalopram 20mg for 5 years prior to conceiving. Before trying to conceive I asked my GP for advice on the impact of continuing the medication during pregnancy. I was referred to a psychiatrist. I received good advice in the appointment, informing me of the risks and benefits.”

“When my child was 18 months old I requested a referral to counselling as child had received special needs diagnosis and I was very anxious. I waited 8 months on waiting list for CBT but was then discharged without treatment as they said my needs were too [complex]. I had a breakdown due to this disappointment and then had to go back on medication. I did not receive any advice about breastfeeding with regards to bipolar and had to research online, and there was very little information. I decided not to breastfeed due to wanting to avoid sleep deprivation and post-partum psychosis.”



A local perspective on maternal mental health

As part of our research, we commissioned Healthwatch in eight areas of England to explore local people's experiences when it comes to mental health support during the journey to parenthood.

Healthwatch in [Leeds](#), the London boroughs of [Croydon](#), [Lambeth](#) and [Sutton](#), [Shropshire](#), [Torbay](#) and [Wakefield](#) used a range of methods to gather people's experiences - including the national survey, locally developed surveys, focus groups and visits to groups and events. The findings of this work broadly reflect our national findings and incorporate the views of nearly 800 people.

The research undertaken by local Healthwatch did find examples of good care and support. For example in Shropshire, [78% of those the local Healthwatch spoke to](#) felt involved in decisions about their care.

However, those who shared their views with us also raised concerns when it came to:

- Not feeling able to seek help because of fear and stigma
- A lack of opportunity for new parents to raise their mental health concerns
- A lack of information about where to get help
- Limited access to the right support

Those Healthwatch spoke to also emphasised the importance of having trust in professionals so that they feel comfortable sharing their concerns, and of the role that being supported by the same healthcare professionals over time can play in building this trust.

Peer support was also something people said they valued because it enabled them to speak to and socialise with other mothers and provided much-needed reassurance.

Healthwatch's research also highlighted the importance of understanding and responding to the wider circumstances in an individual's life. For example, in Leeds Healthwatch ran a focus group with 18 women who, not only have experienced a mental health problem, but also have at least one child with a learning disability.

“Getting a diagnosis of your child's learning disability is a huge shock and involves a huge amount of guilt - but there is no support, you're just left on your own. It's very isolating.”

Story shared with Healthwatch Leeds

The women not only faced the challenges that other mothers have told us about, but they could also struggle to get help with their additional needs. For example:

- Most were not systematically told by healthcare services about the organisations that support parents who have children with a learning disability.

- Only a few women were able to access a health visitor with specialist training in learning disabilities. Many felt that their standard health visitor was “out of their depth” and, as a result, women were left feeling isolated.
- Health professionals rarely asked them how they were coping during this particularly stressful moment in their lives. Some women also felt that, because they were looking after their child, time pressures were too great for them to access support.
- The way health professionals talk to parents can affect their wellbeing. It was commonly felt that health professionals focused on the problems associated with their children’s health conditions, rather than viewing them as a positive addition to parents’ lives. This attitude could be emotionally unsettling for parents at a very vulnerable moment in their lives.



Spreading the availability of peer support

Through this work we have identified several positive approaches that have already been used to improve mental health support for new and expectant parents.

For example, the National Collaborating Centre for Mental Health 'I' Statements referenced earlier are a brilliant example of working with patients to develop a set of easy to understand expectations around what care should be delivering.

There are also many other initiatives being rolled out as part of the reforms in the NHS to address shortages in staff, improve support and to give people a greater say in how services are designed and delivered. For example:

- The South London and Maudsley NHS Foundation Trust's Think Family initiative created [a set of leaflets](#) for children whose parents are admitted to a mental health ward to help carers start conversations with children about why their mother had been taken to hospital, through providing age-appropriate written information.
- Lancashire Care NHS Foundation worked in partnership with women with experience of perinatal mental illness all the way through the development of its Ribblesmere Mother and Baby Unit, which opened in October 2018. They were part of the team that met with the architects for the unit, directly influencing the layout of the ward, the décor, and obtaining the lease for a house for partners to stay in, in the grounds of the hospital. The Trust team also worked with women on information leaflets and a booklet about Ribblesmere, and on interviews for staff for the unit and the outreach and community teams. Peer support workers are employed to work on the ward with mothers and families who have been admitted, and in the community.

However, considering people's feedback about the need for more opportunities to talk about how they're feeling and to seek advice, we have chosen to focus here on peer support, as an increase in provision could play a key role in helping fill this gap.

Peer support services [offer a range of benefits for both patients](#) and NHS providers generally, but particularly in mental health.

Whilst people who fed back to us value the help they receive from professionals, they also clearly want more than just clinical support. People want to be able to talk to someone who has been through a similar experience, someone who can show them empathy and give them encouragement that they will be able to overcome or manage their mental health problems and conditions.

Parents in Mind

A good example of what can be achieved through peer support is 'Parents in Mind', a programme run by the National Childbirth Trust (NCT) and funded by the Department of Health and Social Care.

Working with the Institute of Health Visiting, the programme trains local volunteers to support women experiencing emotional health difficulties in pregnancy and within the first two years after birth.

It primarily offers help to those at the lower end of mental health need, i.e. those experiencing low mood, anxiety or general poor mental health.

One of the main aims is to reduce isolation within the community by providing a safe space to talk and good quality support from a trained volunteer who can offer a listening ear and non-judgmental support. They are often able to draw on their own experiences to help women to develop coping strategies and to access additional local services.

Peer support has often been seen as a way of supporting those who are experiencing lower level problems and perhaps don't have a formal diagnosis, but the evidence people shared with us

In focus: Access to specialist Mother and Baby Units (MBUs)

When a diagnosed mental health condition develops to a point where a mother may need specialist care, it may be necessary for them to spend time in a [Mother and Baby Unit](#). These units provide specialist care and treatment for mothers with their babies when they are suffering from a mental health condition.

Severe mental health conditions that may require this level of support can include bipolar disorder, schizophrenia, postpartum psychosis and other psychotic illnesses. Mothers can also be admitted for treatment for severe depression and anxiety disorders.

Some women told us that they found these units to be life-saving:

“Thumbswood mother and baby unit was literally a life saver for me and my son. It deserves all and any funding that is available.”

“It is vital to give women information about what mental health services are available whilst they are pregnant as I was ill for a while before we accessed support not knowing what support was available. When the crisis team was eventually called - although they were lovely they tried to manage me at home (not having perinatal expertise). This prolonged my difficulties - when I finally saw a perinatal doctor he advised going to a mother and baby unit and I started getting better in as little as two days in that placement. The unit saved my family and I could not have been more grateful for that wonderful, wonderful service. It was a lifeline. Sadly, there are not enough beds for all the women who need their services. I feel very grateful and fortunate.”

“The care I received at Coombe Wood mother and baby unit was amazing. The local 'care coordinator' didn't read my file before coming to meetings at Coombe Wood and was often late and had no idea what had happened to me. Furthermore, she had no experience

maternal mental health. On my discharge from hospital I had a period of one to one support which was very good.”

However, we also heard from people who couldn't access this vital care when they needed it.

“Was basically told there was no hope for me other than taking medication. It took around 3 months to even get a referral or a proper assessment. I was told there were no beds available if I were to go to a women's mental health unit for maternal care.”

As illustrated in this example, one of the main issues in recent years has been the lack of available beds in such units and how far families may have to travel to access them.

Estimates suggest that between [1 and 2 out of every 1000 new mothers will be affected by post-partum psychosis](#). Similarly, there are [roughly 8,000 women every year in England who suffer from bipolar disorder](#) who may struggle to manage their condition whilst not being able to take their medication due to their pregnancy.

In 2014, when Healthwatch last looked at this issue, there [were just 17 mother and baby units in England with a capacity of 122 beds](#). Investment has increased the number of units to 19 and NHS England has plans to increase the number of beds available by 49%. However, given the scale of the issue, it's important that policymakers continue to monitor the issue to make sure everybody gets the help they need.

Involvement of patients in Mother and Baby Units

In [a blog on the NHS England website](#), Zoe Gibson shares her experience of being treated at a Mother and Baby Unit and then using her experience to help mothers in a similar situation. She says that peer support workers are a 'symbol of hope' for patients as they show that recovery is possible.

Zoe and other peer support workers work side by-side with mothers to listen, support and encourage them in their recovery. They are present at admission, discharge, handover, ward rounds, case reviews, training sessions and staff meetings and act as the patients' advocates.

She says: “Peer support was the one thing that I felt was missing from my care when I was unwell. I still remember feeling desperate for evidence that women who had been admitted to an MBU had got better. I longed to have access to someone who could offer comfort with a true understanding of what I was going through and could answer the questions that were constantly whizzing round my head, causing me so much anxiety. This is why I feel very privileged to now be a peer support worker.”

Stories like Zoe's demonstrate the hugely important role people who have experienced mental health problems as new mothers can play in supporting others to get the right help and recover.

Peer to peer perinatal support group

Funded by Homestart and Sutton Mental Health Foundation (SMHF) and led by individuals with a personal experience of perinatal mental health, this group was created to give parents in Sutton a space to talk and learn from each other. The group came about following meetings between all professionals in the Sutton Borough involved with the care and support of families and children in the perinatal period who spotted a gap in the support available.

SMHF supports adults experiencing mental health issues from the age of eighteen who are not in residential care, and Homestart provides support for families who are struggling and have children up to the age of five years old. These two organisations hadn't worked together before, but together brought great expertise in supporting people through building connections.

The group aimed to improve mental health for women by reducing isolation and stigma, as well as improving the relationship between parent and baby by changing the way parents feel about themselves. An eight-week programme of meetings proved helpful for the women who came along, and saw some mothers forging relationships that will continue outside of the group. This period highlighted issues to consider when running this kind of group, including how structured versus free-flowing sessions should be to ensure everybody gets what they need out of them.

Steps are now being taken to try to secure funding so that this group can continue.

What it's like to be a peer support worker

“Little did I know when I signed up to be a volunteer peer supporter that it would be such an emotional rollercoaster.

“I don't think I truly appreciated or understood the cleansing, yet often soul-searching, process that I was going to participate in on a weekly basis with a bunch of strangers that had three things in common: women, mothers and we have all experienced an episode of postpartum or antenatal mental health difficulty.

“However, I quickly learnt that there was more to us all than that. Tea and cake bonded us, and tissues and tears led us to be solid friends. Our mental health in pregnancy or early parenthood is the invisible thread that links us, but our joy and mutual love of being able to guide each other through our journeys are the glue.

“From the offset, I think the fear of the unknown was the biggest fear we faced. I didn't want to get it wrong, I didn't want to mess it up and upset any of our ladies. When I began training, I didn't know how to start, how to listen, didn't know how not to butt in and make it all about me. I shouldn't have worried: I have been exceptionally lucky to have been guided by such a wonderful trainer with her gentle yet firm humour. My manager too, with her kind trusting belief and of course those who I've met through the programme.

“We have been through the mill as a group of mums and all of us have reached this point in our lives after difficult yet different journeys. But we have made it to the end of our intensive, thought-provoking training together and I know we are all the stronger for it.

“For me, the overwhelming factor in this whole process was that I just wanted to help. I just wanted to be able to help one mum go through a terrible time and not be alone. I wanted to be able to reach out and just let one mum know she had someone by her side. Yes, she was still going to be going through a horrid time. But she wasn’t alone. Like I had been.

“Fast forward 10ish weeks and we are “live”, and it works! Our ladies are making slow and steady progress – we laugh, and they cry, together. The ladies have bonded and grown, and our smaller volunteer groups have also bonded further as well. We’ve learnt that anything goes in a session: we are facilitators of recovery. We start each week at the precipice of a mountain and gently nudge the snowball of conversation. Sometimes an avalanche of issues arises, and we work through them at a fast pace. However, sometimes we work through at a slow and steady gentle pace chatting about baby’s growth spurts, sex, what to cook for tea and all sorts more. We refer to other services, offer practical solutions, hold babies, pass tissues, but most importantly allow space and an ear for our ladies to spill and process their week.

Through volunteering with parents in mind, I’ve found my place in the world and I finally feel that my PND was for a reason. It’s empowered me to be me. It has no hold over me now: it helps define me, but I’m not defined by it anymore.” Peer Support Worker, Parents in Mind NCT.

The importance of consistent support

Through our broader work, we have identified several important messages about people wanting to see the same individuals providing support over time.

The desire for continuity is often driven by an individual's specific needs at that moment in time. Often for a one-off issue or new concern, people are more focused on seeing any appropriately trained professional quickly.

However, when it comes to an ongoing need continuity becomes more important. This was reflected in the feedback about maternity, where parents-to-be expressed the importance of continuity of support in helping spot mental health problems and provide speedy support to prevent issues escalating.

When continuity of care is discussed in primary care the system often interprets this as people wanting to see the same GP. Yet, feedback shows that people are happy to see the most appropriately trained individual. So, if they need an appointment to check up on their diabetes, they are often more interested in seeing the specialist nurse at the practice who has more time to spend with them and often has more specific up to date knowledge.

In maternity and mental health, those who had the same midwife throughout felt that this was a positive experience. Our [literature review](#) also highlighted that women are more likely to disclose mental health symptoms when they have support from a familiar, trustworthy professional. However, people also recognised how stretched services were and several talked about other ways they could get continuity of support, particularly around their mental health needs, such as from other parents who had been through a similar experience.

[As part of the changes taking place in the NHS](#), 'Continuity of Carer' teams are being developed and launched across the country - with the aim that in 2019, 20% of pregnant women will be offered the opportunity to have the same midwife caring for them throughout their pregnancy, during birth and postnatally. Women who have the same healthcare professionals supporting them during pregnancy [are more likely to achieve better health outcomes](#). The introduction of these teams marks a positive step in helping make sure parents' wellbeing is monitored and issues addressed.

In their feedback people also suggested that the greater use of peer networks could:

- Encourage more people to speak up and seek help sooner by showing how common mental health problems are amongst new and prospective parents.
- Make the process less scary by offering an alternative to seeing a clinical professional.
- Potentially reduce referral times for support by providing expanded resource.
- Support prevention by providing an intervention before problems get worse.

- Relieve pressure on the workforce and increase the availability of more people who can support new parents.

Whilst there is lots of potential in peer support it is important to remember that it is not free. Any such services introduced must be properly funded and be part of a wider and more comprehensive offer of support. It must also be made clear where such services are introduced, that they are not a replacement for care from health professionals but offer something that professionals cannot.



Reflections and recommendations

We started this work with the aim of helping the NHS understand how well it is currently meeting the mental health needs of new and prospective parents, and to support policy makers and health practitioners to continue to improve.

We acknowledged the significant financial investment being made in this area, and the policy emphasis that has been placed on tackling the issue in both the Five Year Forward View and in the new NHS Long Term Plan.

We also recognised the progress this has delivered in terms of rolling out new specialist services in every part of the country by April 2019 and in reaching 13,000 additional mothers a year through this support.

Whilst it is clear that significant progress has been made, the process of analysing the thousands of personal and complex stories that have been shared with us over the last few months has reinforced why it is so important to look beyond the numbers to understand the work that still needs to be done to support people's individual experiences of mental health problems during the journey to parenthood.

We hope that the research we have carried out and the key messages we have highlighted are of use to both professionals and the public. As well as the specific findings, the work has left us with several overall reflections and recommendations.

Recommendations

As well as sharing their experiences, people also put their ideas for change forward. We have grouped these together into recommendations for individual services / frontline professionals, as well as a series of suggestions for national health leaders and policymakers.

For frontline services involved in supporting mental health care in maternity

Services should look to increase awareness and adoption of the NICE guidelines and the 'I Statements'.

These have been produced with parents and provide an excellent starting point for setting clear expectations for service users and staff and can help reassure people it is OK to seek help.

Using the statements will help professionals make every contact they have with people expecting or who have had a baby count. These are vital opportunities to find out how people are feeling and share information about support available.

The I Statements also provide a practical and meaningful framework against which services can review whether the quality of care being provided is meeting people's needs.

Ensure staff are trained and given the time to build rapport with people and to spot common signs

We heard that continuity of care plays an important role in supporting people's mental health during the journey to parenthood, but we also recognise that it is not always possible for somebody to see the same staff members at every stage of their care.

It is therefore doubly important that all staff involved - whether they are a midwife, GP or health visitor - have the skills and confidence to ask sensitive questions about people's emotional wellbeing and have the time to pick up on subtle changes that might indicate somebody is perhaps not coping as well as they say they are. We heard during our research about the damaging impact poor staff attitudes can have on people's willingness to speak up, so it's vital that every new or expectant parent is treated appropriately.

Ensuring staff have the training and time they need to speak to people effectively, is the best way to ensure services enable women to feel heard and for women to trust staff enough to speak up. This would also help people feel that when staff ask questions about their emotional wellbeing these come across as genuine and not a 'tick box' exercise. It would also help make sure problems are spotted early and referrals to specialist services made as soon as possible.

Make it the norm for feedback to be sought and applied continually

This evidence base can be used by services to assess how well they are meeting people's needs, to spot problems early and make incremental improvements.

It can also be used by individual practitioners to draw on during official learning processes, including revalidation.

Avoid making unilateral changes to services and make sure you work with the local community.

When providers or commissioners plan to change the services on offer or to introduce new services, it is vital that both prospective and new parents, as well as previous users of the service, are involved in the development process.

Key local stakeholders including local Healthwatch, the locally-based NHS Maternity Voices Partnerships and local voluntary sector organisations, such as NCT, can help services reach out and engage with communities.

For health leaders and policymakers involved in shaping mental health care in maternity

Make the current and future workforce gaps in maternity, and other areas like health visitors, a key focus of the NHS People Plan to help give every child the best possible start and ensure parents have a positive engagement with the health service.

Among the suggestions put forward by those who took part in our research was the need for greater emphasis on continuity of support rather than a shifting cast of different professionals. The roll out of Continuity of Carer teams, which aim to offer women the choice of being supported by the same midwife during and after pregnancy, [and other NHS reforms](#) will help to support this need.

Where this is not possible, the wider workforce needs to have enough capacity to spend time with each patient to fully consider their emotional as well as physical health needs.

As well as addressing the existing gaps in the clinical workforce, the People Plan should look to greatly increase the provision of peer support.

Many of those who took part in the research said they wish they had more opportunity to speak with others who had been through similar experiences.

They suggest this might help people seek help earlier, as it is perceived as less intimidating and stigmatized than seeking help from a health professional. It could also help to significantly increase the range of services on offer and help those who need more significant interventions get support whilst they wait for it.

Support the NCT's call for better health checks post-birth for mothers.

Many of the stories shared with us highlighted how parents felt that all the focus of health professionals' post-birth was on the baby. Indeed, we heard several explicit calls for the six-week health checks mothers attend at their GPs to incorporate a greater focus on mental as well as physical health. These checks are not routinely offered by all GPs.

People also stressed how there needed to be a greater focus on mental health of the whole family. We therefore recommend that the NHS examines whether health checks could be extended to cover partners as well.

Broader consideration of the needs of partners

In December 2018, just ahead of the publication of the NHS Long Term Plan it was announced that NHS England would be increasing access to help for partners of women experiencing a mental health condition during pregnancy.

The feedback we received from many women makes clear that taking a whole family approach to providing support would be welcomed. However, it is also important to remember that it may possible for the partner to be the one who develops the mental health

problem and they need to have similar access to help to prevent their condition affecting mother and baby.

We therefore recommend that NHS England considers how they can ensure that access to support is being provided to partners where a mother is not experiencing a mental health problem.

A better way of measuring people's experiences at a national level

To monitor whether the new investment in maternity and mental health is driving the sort of improvements people, and the NHS, want to see, NHS England should report on a broader range of indicators than just the number of additional women receiving help.

Amongst these we would like to see:

- (a) Demographic data on those receiving help presented alongside the demographic data for all those having children.
- (b) Reporting on the type of condition for which they are receiving support.
- (c) Reporting on whether patients and partners have a care plan that covers both mental health and maternity needs.
- (d) Reporting on waiting times between referral and getting additional support.
- (e) Introduction of a qualitative assessment for patients on their experiences of getting support to build a rich picture of how services are helping and where they need to improve. This could be delivered through representative sampling.

It is highly likely that this data is already being captured at a local level, but without these improved metrics being captured nationally neither the NHS, nor independent bodies such as Healthwatch, will be able to look at the overall improvement of care and see whether the system's efforts are making a real difference to people.

Reflections

- **The balance of positive v negative feedback**

Firstly, it is worth noting that the [feedback we receive](#) about all mental health services generally stands out from other areas of health and social care because it is overwhelmingly negative.

In this context, the fact we received positive experiences about maternity and mental health services suggests the emphasis on the issue is making a broad difference.

But there is still significant room for improvement.

- **National policy is moving in the right direction, but resources and consistency is key**

The evidence also suggests that the policies and guidance in place at a national level, that have been developed in partnership with service users, still chime with what people want in terms of support. However, they are not being applied consistently across areas or even within services themselves.

This could be in part down to more general pressures which patients are reporting across all services [as starting to impact on the level of empathetic care](#) they receive from health professionals.

This is a key to improving people's experiences of health and care. From the stories people shared with us it is clear the difference that compassionate, consistent care can make but building trust between professionals and patients requires both skills and resources.

- **A reality check on fear and stigma**

With such an increased focus on talking about mental health in society more broadly, it can feel at times as though stigma is on the wane. But stigma exists in two forms, both in how others react to us and how we think they will react.

When we asked those who took part in our research what they would do differently if they were to have another child we intended to find out what they wanted the NHS to do differently.

However, they overwhelmingly said they themselves could have improved things by reaching out earlier. This suggests that fear and stigma remains a significant barrier to seeking help.

In their feedback people spoke a lot about feeling fearful about what would happen if they spoke up. Some told us that they worried that having a mental health problem would mean they were seen as unfit parents. [Research conducted](#) in partnership with disabled parents, including those with mental health problems, highlighted how important it is that services recognize parents' strengths and capabilities and provide support that helps families stay together.

- **More work needs to be done to understand who is not accessing support**

One of the key questions we asked right at the beginning of this work was who are the 13,000 more women each year who are getting maternity and mental health support from the NHS. Without more detailed demographic data being collected, it is difficult for the NHS to assess whether the services on offer are meeting the needs of a range of different communities.

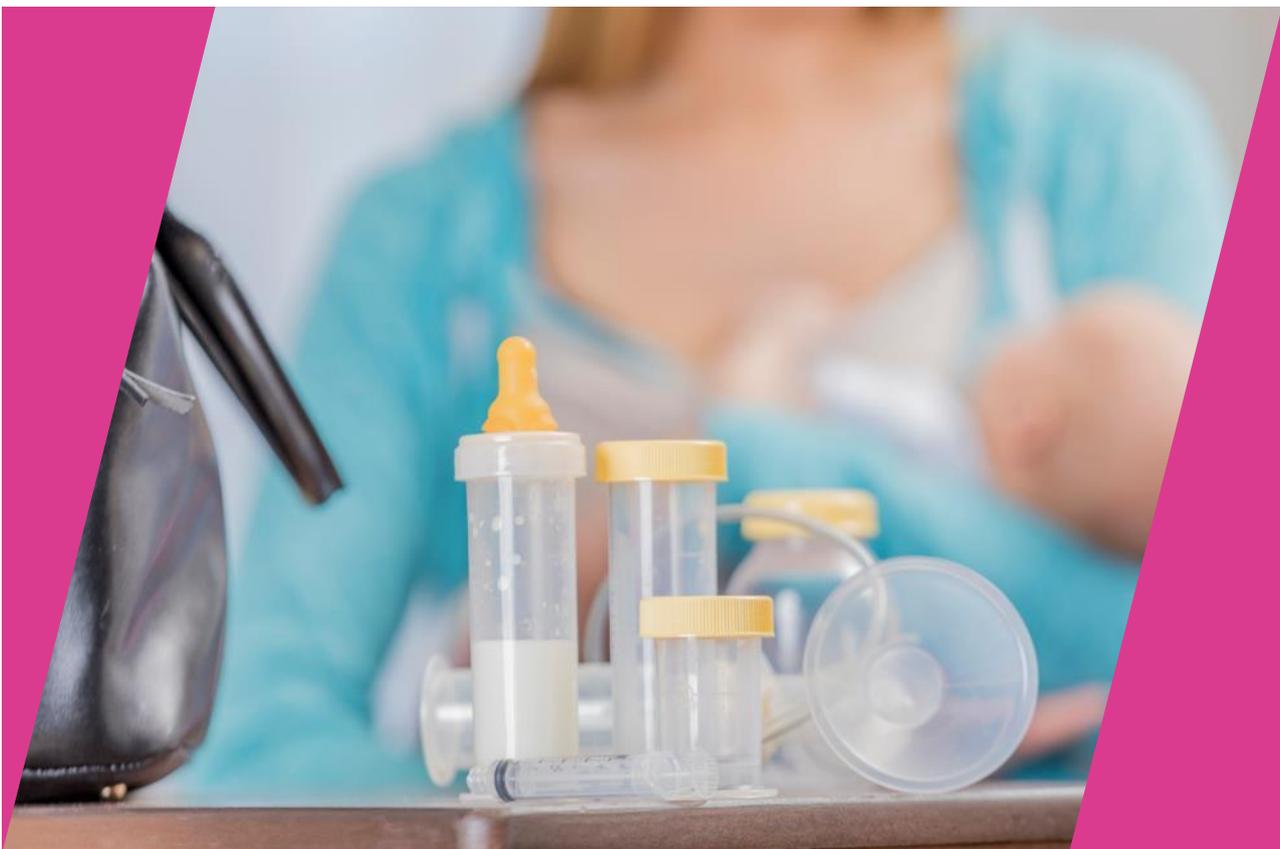
In our research, we worked to gather experiences from people across society. Of the 1,738 women with a diagnosed or undiagnosed mental health problem we heard from, 97 were from Black, Asian and minority ethnic (BAME) groups. This highlighted some of the factors that can make a women's experiences of expecting and having a baby different when they come from different sections of the community.

In response to the question ‘What would you have done differently?’ one woman said:

“I don't know, I don't go out much or know many people, I am new to the country and don't know how things work. It was also my first baby.”

Findings from the [Inequalities in Infant Mortality](#) work programme at the National Perinatal Epidemiology Unit (NPEU), Nuffield Department of Population Health, University of Oxford highlight the importance of ensuring that pregnant women from BAME communities - some of whom will not have English as a first language - understand information and advice given to them by health and social care professionals. Not doing so will be a significant barrier to seeking and accessing mental health support. Meanwhile, in a study that aimed to investigate factors associated with experiencing antenatal depression and developing subsequent postnatal depression, women from BAME communities were twice as likely to experience antenatal depression than white women.

It's vital that more is done to understand who is and isn't accessing the support available and why, so that the NHS can make sure it gets services right for everyone.



Thank you

Thank you to all the nearly 200 individuals and organisations who helped encourage prospective and new mothers to share their experiences with us by sharing our survey.

With particular thanks to:

- The Maternal Mental Health Alliance
- NCT
- The Maternal Mental Health Network
- Care Quality Commission
- Mumsnet
- National Maternity Voices and local Maternity Voices Partnerships
- Healthwatch Croydon
- Healthwatch Lambeth
- Healthwatch Leeds
- Healthwatch Shropshire
- Healthwatch Sutton
- Healthwatch Trafford
- Healthwatch Torbay
- Healthwatch Wakefield

About us

Healthwatch is the independent champion for people who use health and social care services. We exist to ensure that people are at the heart of care.

We listen to what people like about services, and what could be improved, and we share their views with those with the power to make change happen. We also help people find the information they need about services in their area.

We have the power to ensure that people's voices are heard by the government and those running services. As well as seeking the public's views ourselves, we also encourage services to involve people in decisions that affect them. Our sole purpose is to help make care better for people.

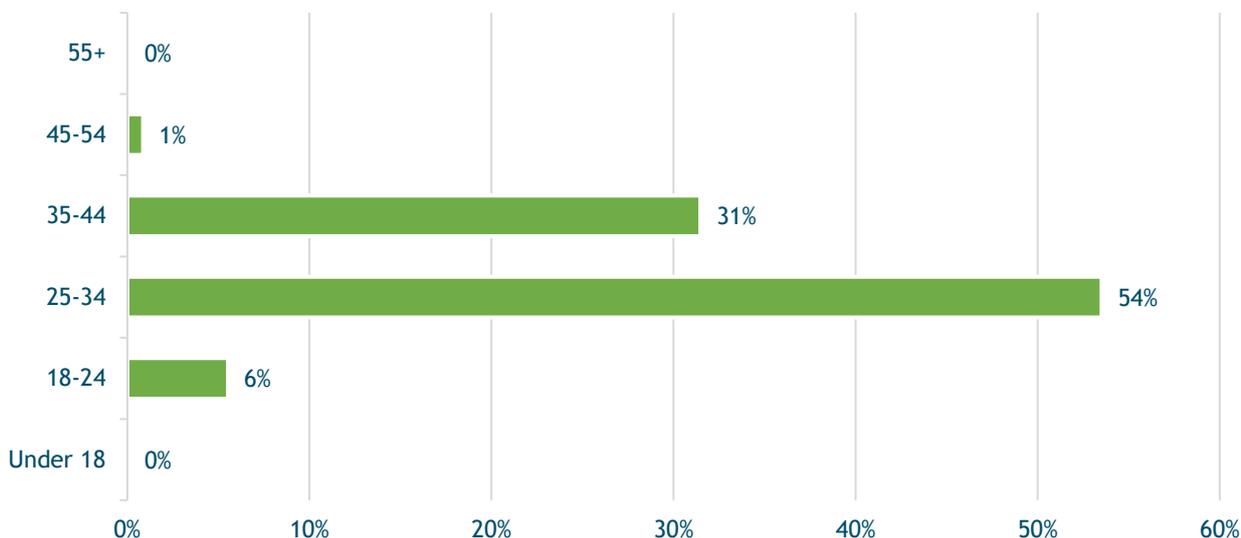
Role of local Healthwatch

There is a local Healthwatch in every area of England. They provide information and advice about publicly-funded health and care services. They also go out and speak to local people about what they think of local care, and share what people like and what could be improved with those running services. They share feedback with us at Healthwatch England so that we can spot patterns in people's experiences, and ensure that people's voices are heard on a national level.

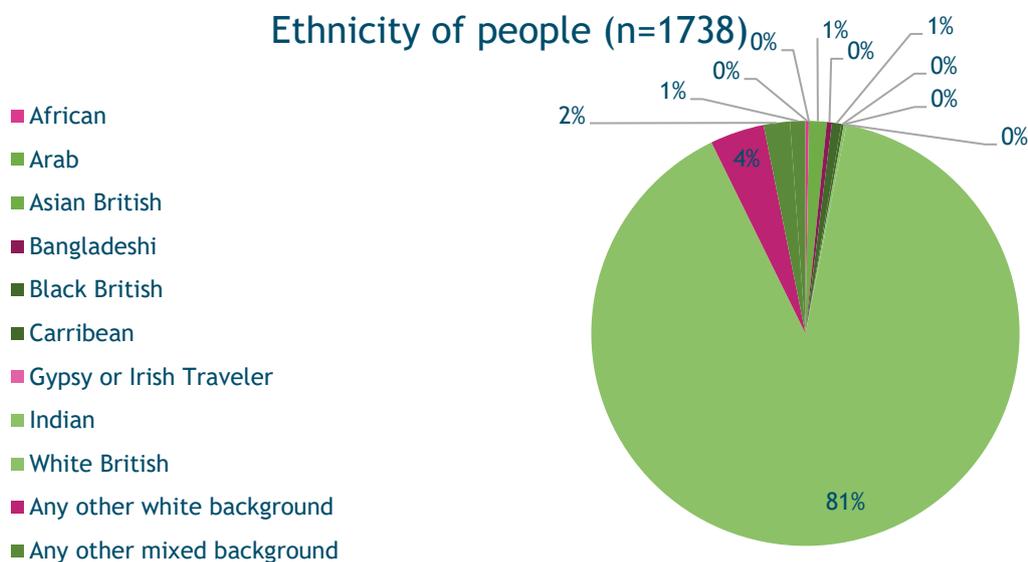
Annex A - Who responded to our survey

The following section outlines who responded to our survey between 2 August 2018 and 28 March 2019.

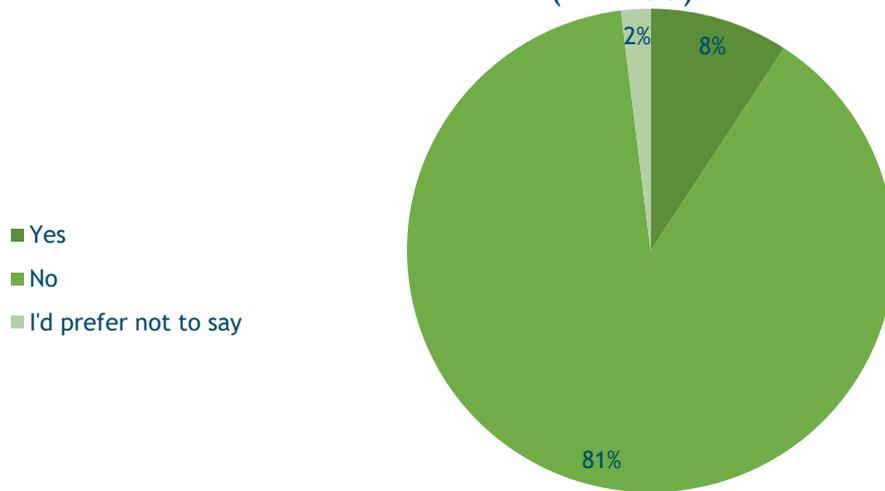
Age of people (n=1738)



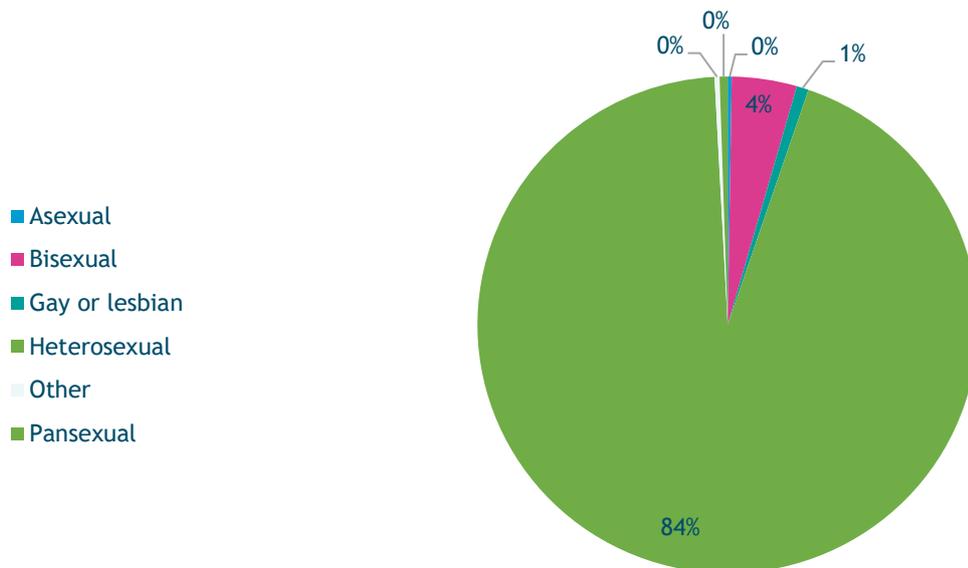
Ethnicity of people (n=1738)



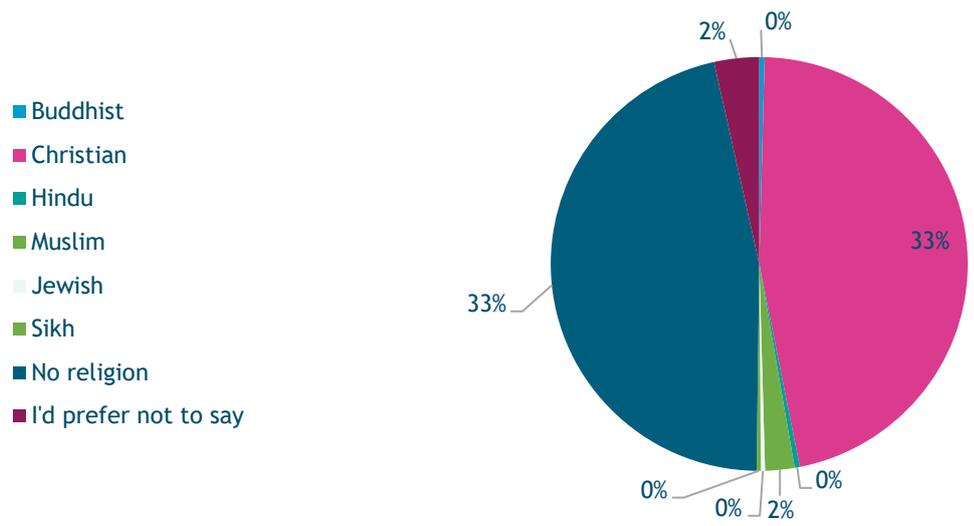
Do people consider themselves to have a disability? (n=1738)



Sexual orientation of people (n=1738)



Religion of people (n=1738)



healthwatch

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