# PATIENT PERSPECTIVES MATERNITY NEEDS





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## **BACKGROUND**

The purpose of this engagement was to enable individuals with criminal justice experience to share their views around health themes relating to NHS England's Core20Plus5 improvement approach and support NHS England in reducing health inequalities.

EP: IC engaged with people through surveys. These surveys were co-produced with partners such as NHS England Health & Justice and HMPPS, and were sense-checked by individuals with lived experience of prison and probation.

The EP: IC team encapsulates the lived and learned experience of criminal justice and exists to centre lived experience within justice-based research and consultations. Our work involves direct engagement with those experiencing a system, a service or a process and seeks to present learning in a way that informs organisations, with the overall aim of promoting co-production and improving outcomes for the people and communities they serve.

A peer-led approach was applied to this engagement. Individuals with lived experience of the criminal justice system were trained and supported to gather views from their community and assist with the completion of surveys. A peer-led approach was championed for this work in the hope that it would allow people to overcome any trust, language or literacy issues of those wishing to participate.

As part of a wider piece of work, this report particularly focuses on the experiences of women with lived experience of serving a community or prison sentence while pregnant. Participants who had been pregnant while in prison or on probation were offered the opportunity to take part in two surveys:

#### Core20Plus5 survey

Along with general health needs and attitudes towards health and healthcare, this survey explored four clinical areas within the Core20Plus5 agenda: heart health, lung health, mental health and early cancer diagnosis. A slight variation to this survey was incorporated between prison and probation settings, to reflect specific needs.

We received a total of 1024 Core20Plus5 completed surveys across various settings.

44 participants were either pregnant or had been pregnant while in prison or on probation, or had a baby aged under two years. A sample of pertinent findings from this sub-cohort have been picked out for the purpose of this report.

#### **Maternity survey**

This survey provided information relating to maternity – the fifth clinical area on the Core20Plus5 agenda – and explored the experiences of those who were criminal justice experienced, with variations according to whether these women (who all identified as women from birth) had experienced prison or probation. Seventy-three surveys were completed.

The report is organised by survey. Pertinent data from the Core20Plus5 survey is presented first, followed by the more extensive results taken from the maternity survey.



# **CORE20PLUS5 SURVEY**

# **APPROACH**

Opportunities to participate in the Core20Plus5 survey were advertised in the following ways:

- In participating probation areas, prisons and approved premises
- In community services, such as homeless services, and drug and alcohol services
- Through people with lived experience of prison and probation
- Via social media
- In women's centres.
- Through EP: IC's networks, including other criminal justice services

We used bright, eye-catching posters containing information about the consultation and, to ensure accessibility to as many people as possible, provided a range of methods by which to contact us, including:

- Email
- Text
- Freephone number
- Freepost address

We also included a QR code to allow individuals with access to smart technology to undertake the survey immediately. However, a blended approach was taken in terms of survey completion to support a range of communication needs, allowing participants to choose how to take part. Choices included:

- Independent completion (online or paper-based)
- Telephone interview with our lived-experience team
- Face-to-face interview with our lived experience team
- With the aid of a support worker within a particular accessed service

#### **CORE20PLUS5 SURVEY**

In total, 44 women who had been pregnant or had a baby within the last two years, while in prison or on probation, completed the Core20Plus5 survey. Their perspectives were aggregated with those from all other Core20Plus5 surveys completed in the community, and were included in other outputs from this consultation.

However, this report provides some of the most relevant information to arise in relation to these 44 women, specifically concerning the four other clinical areas of interest: heart health, lung health, mental health and early cancer diagnosis.

# **DEMOGRAPHICS**

#### Gender

All participants identified as women.

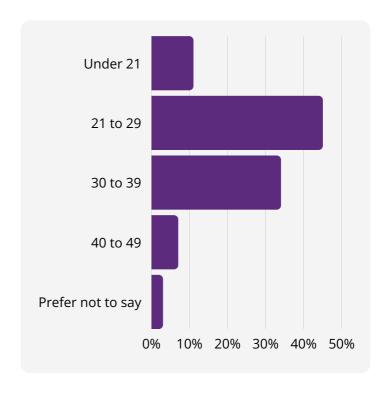
When asked whether they identified with the gender registered at their birth, all participants stated that they did.

#### Age

Of the 44 women who participated in the Core20Plus5 survey, the most common age group was that of 21-29 year olds (45%), followed by 30-39 year olds who made up 34% of participants.

Around a tenth (11%) were aged under 21 and 7% reported being aged 40-49 years.

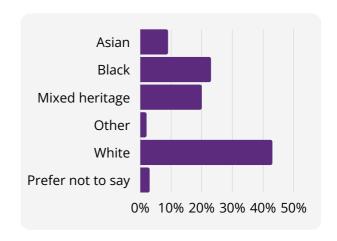
The remaining 3% decided not to declare their age.



#### **Ethnicity**

The most commonly reported ethnicity was white (43%). Over half of participants were from racially minoritised ethnicities (54%) – 23% were black, 20% were of mixed heritage, 9% were Asian and 2% were of an 'other' ethnicity.

The final 3% chose not to declare their ethnicity.



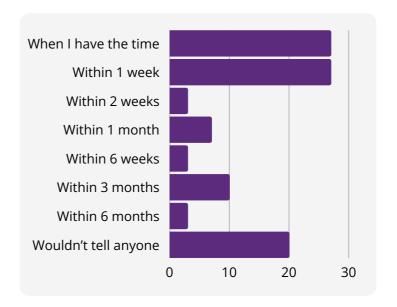
### **HEALTH AWARENESS**

#### **Key learning**

- A fifth of women (20%) stated that they would tell nobody after noticing a new symptom. A further 27% would report it 'when [I] have the time' and 27% would report it 'within 1 week'. Thus, 50% of women would not routinely seek support for a new health need.
- Only 2% of women had ever needed treatment for heart health while twothirds (66%) were unsure when they had last seen or heard something related to heart health.
- 9% had needed treatment or support for lung health and 84% were unsure when they had last seen or heard something about lung health.
- Only 2% of women had needed liver treatment or support and 89% were unsure when they had last seen something about liver health.
- In contrast, 91% reported requiring mental health support and significantly greater awareness was evident around mental health than heart, lung or liver health.



When women were asked how long after noticing any symptom they would wait before consulting with healthcare in prison or their GP in the community, the most common responses were: 'when I have the time' (27%) and 'within 1 week' (27%). Worryingly, a fifth stated that they 'wouldn't tell anyone' (20%).



More than half of women (52%) reported consulting with a GP within the last six months.

However, many were able to identify reasons that they had felt discouraged from seeing a GP previously, the most common of which were:

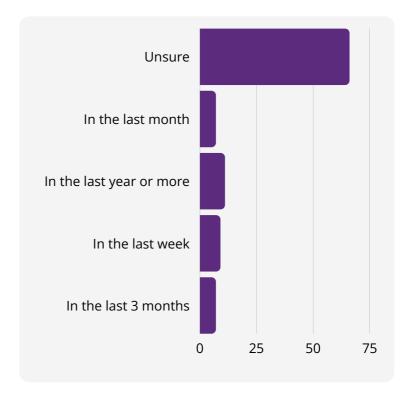
- Worry that they would not be taken seriously due to being/previously being a prisoner (67%)
- Feeling embarrassed to talk about their symptoms (41%)
- Not feeling confident talking about their health (38%)
- Finding it difficult to get an appointment (33%)
- Worry about wasting the GP's time (31%)

#### Heart health

Overall, only 2% of participants had ever required treatment for heart health.

A lack of awareness was evident around heart health, with two-thirds of respondents (66%) stating they were 'unsure' when they had last seen or heard something on the subject.

This compares to 9% who had seen something in the last week and 7% who had seen something in the last month.



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Those who could recall when they had last seen or heard any information concerning heart health cited the following locations:

- Leaflets
- TV adverts
- Hospital waiting rooms
- Documentaries
- Discussions with friends
- The news

When asked to list warning signs and symptoms of poor heart health, the two most common signs identified by women were chest pain/tightness, identified by three-quarters of respondents (75%), and tightness in the arms, identified by 16% of respondents. Few other symptoms were highlighted.

"Pain in chest area, tightening in arms."

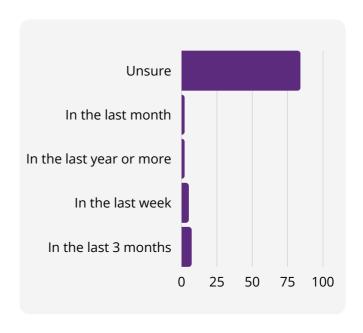
"Pains in heart area, and squeezing feeling."

"Chest pain and arm pains."

#### **Lung health**

A slightly higher proportion of women had needed treatment or support for lung health (9%), compared to heart health.

Again, most were unsure when they had last seen or heard something concerning lung health (84%), with the second most common response being that they had seen something in the last three months (7%).



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- Documentaries
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"Feeling like not getting enough air, trouble breathing, a cough that won't go away."

"Coughing continuously and breathlessness."

"Asthma and similar problems."

"Hard to breath when doing small every day things."

#### Liver health

Overall, only 2% of participants had ever needed treatment or support for liver health and 89% of respondents were unsure when they had last seen or heard any information concerning liver health. Those who could so recall did so by way of:

- Friends and family
- Courses
- Hospital

"Friend had issues with their liver, it was thought it was caused by over use of drugs and medication."

Despite most being unsure when they had last heard something about liver health, the women were able to identify many warning signs and symptoms of poor liver health. The most common responses were liver pain (23%), stomach ache (16%), yellow skin/eyes (11%) and vomiting/nausea (11%). Other, more broad symptoms were also stated, such as redness in the face (11%).

"Yellow skin and yellow eyes."

"Pain in tummy and liver area."

"Pain in liver, vomiting, feeling sick."

#### Mental health

It is notable from the survey results that, compared to mental health, the physical health conditions in question (the heart, lung and liver) among the participants occur with much higher frequency. Mental health awareness is also more evident.

Overall, most women (91%) reported needing treatment, care or support for their mental health, compared to heart health (2%), lung health (9%) and liver health (2%). This represents a noteworthy finding.

For those patients who had needed help with their mental health, three key types of support were identified, as follows:

- Combined medication and counselling (49%)
- Medication only (41%)
- Counselling (10%)

When asked how well they felt that they were coping with daily life, the most common response was that it is 'sometimes hard to cope' (49%). The next most common response, at 44%, came from women who felt it was 'hard to cope most of the time'.

General awareness of mental health was also much higher than that of the physical conditions in question, with a quarter of respondents (25%) stating they had seen or heard something about mental health within the last week. Information came from a variety of sources, including online, GP surgeries, leaflets and television.



## **CANCER SCREENING AWARENESS**

#### **Key learning**

- A third (33%) were aware of when women become eligible for cervical screening.
- Three quarters of women (75%) said they would, or probably would, attend cervical screening the next time they are invited.
- A total of 72% of women did not know when they would become eligible for breast screening. Future intentions were positive, however, with 45% saying they 'probably' would attend when invited and 34% saying that 'yes' they would attend.
- Only 29% were confident they knew how to check their breasts for lumps.
- Only 15% of women knew when individuals become eligible for bowel screening and 15% knew how health services screen the bowel.
- Around half of women (49%) said they did not know if they would complete a bowel kit the next time they are sent one, compared to 15% who said 'yes' they would complete such a test and 31% who 'probably' would.

Women were asked for their views and experiences of cervical, breast and bowel screenings.

#### **Cervical screening**

Only a third (33%) of participants were aware of when women become eligible for cervical screening.

More than half of the women (56%) stated that they had attended cervical screening the last time they were invited, with 18% saying they had not. Some were unsure whether they had attended (10%), while 15% had never been invited to attend.



Positively, when questioned as to whether they would attend their next cervical screening invitation, 49% of women responded with a definitive 'yes' and a further 26% stated that they 'probably' would. The remaining 26% did not know. It was encouraging that no women responded with a definitive 'no'.

Fear that the test may be painful arose as the most common factor discouraging women from attending a cervical screening appointment (39%). Other factors included:

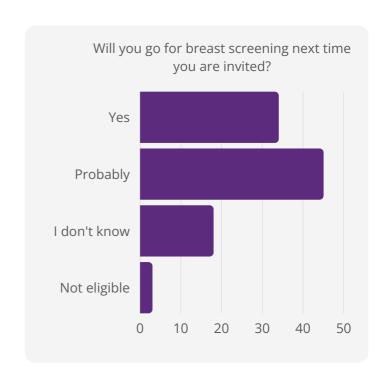
- Fear of what the test might find (15%)
- Feeling too embarrassed (13%)
- Not wanting a man to complete the test (13%)

Overall, 13% of women said that nothing would put them off attending a cervical screening appointment.

#### **Breast screening**

When asked about breast screening, over two-thirds of women (72%) did not know when they would become eligible.

Only 15% had attended breast screening the last time they were invited, but a combined 47% had either never been invited or were not eligible. This is to be expected due to the age of participants. Around a quarter (26%) had not attended their last breast screening and 13% did not know if they had attended.



Thinking about their next invitation to a breast screening appointment, it was positive that the most common responses were 'probably' (45%) and 'yes' (34%).

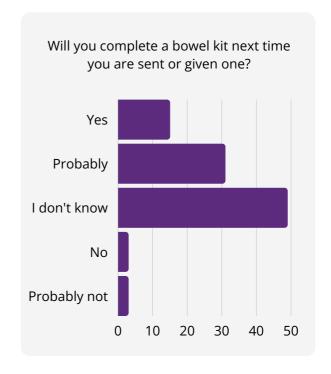
When asked whether they had been discouraged from attending their last breast screening appointment, most women reported never having received an appointment invitation – again, due to the age range of the cohort. However, of those who had previously been invited, embarrassment, concerns around pain, and an absence of breast cancer symptoms were all cited as reasons for non-attendance.

Women were also asked whether they knew how to check their breasts for lumps, to which 29% responded that they did know, 62% were not really sure and a further 8% did not know.

#### **Bowel screening**

Only 15% of women knew when people become eligible for bowel screening, compared to 79% who responded 'no' and 5% who were 'unsure'. Identical results were seen when the cohort was asked if they know how health services screen the bowel.

Greater uncertainty was evident when considering future intentions, compared to cervical and breast screening. Around half of respondents (49%) did not know if they would complete a bowel testing kit the next time they are provided with one, compared to 15% who definitely would and 31% who probably would.



The remaining women responded that 'no' (3%) they would not attend or that they would 'probably not' (3%).

When asked if anything had discouraged them from completing a bowel screening kit the last time they were provided with one, most women reported that they had never received one. This is explainable by the age range of the cohort. However, for those who had not completed their previously received bowel testing kit, reports of not feeling at risk of bowel cancer, having more important worries and experiencing no symptoms were received.

# **LIFESTYLE**

#### **Key learning**

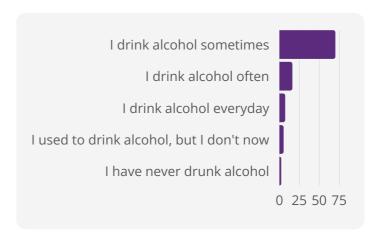
- Seven percent of women drank on a daily basis.
- Seventy-one percent vaped and 16% smoked cigarettes.
- Seventy percent had undertaken no exercise in the last week.
- A lack of money and free time, and poor mental health, were cited as reasons not to undertake exercise.



#### **Alcohol consumption**

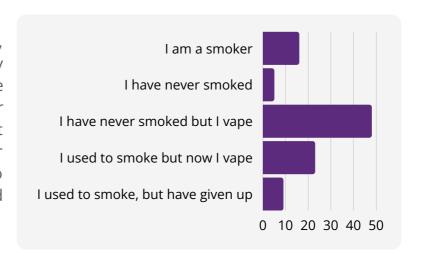
Participants were asked about their current lifestyle choices, including how much alcohol they consumed, their smoking habits and how much exercise they engaged in weekly.

When asked about their use of alcohol, it was determined that most drank sometimes (70%) or often (16%), while 7% drank alcohol every day.



#### **Smoking**

When asked about smoking, 16% of women stated they were current smokers while almost half (48%) had never smoked but now vaped. Almost a quarter (23%) were former smokers but had switched to vaping. A substantial 71% used vapes.



#### **Exercise**

When examining the amount of exercise in which women had engaged within the previous week, 70% stated they had undertaken no physical activity at all. Around a quarter (23%) had exercised once or twice and 7% had exercised more than five times.

We also asked what would motivate the women to increase their exercise levels, to which a third (33%) responded that money was a barrier to exercising and that financial support would motivate them.

"Given discounts or having free access to the gym."

"Having better finances. Money being less of a financial problem."

For 16% of women, it was a struggle to find the time to exercise and having increased free time would motivate them.

"Having more time for myself."

"More free time."

"Need to have time which I don't with everything else to sort."

Finally, 14% spoke of their mental health and low mood impacting the likelihood of them exercising.

"Being in better head space."

"Feel good inside first to want to exercise."

"Less stress with other things."

"Need to be in the mood."

# **MATERNITY SURVEY**

# **APPROACH**

Women currently in prison, prison leavers and those on community orders were asked about their specific maternity needs, using slightly different surveys to reflect their criminal justice experience. Some completed both the Core20Plus5 survey and the additional maternity survey, while others chose one or the other based on their availability and willingness to be involved.

Methods for recruitment were largely the same as with the Core20Plus5 survey, although we also reached out to specialist organisations such as Birth Companions to support our recruitment.

Unlike the Core20Plus5 survey, we also conducted some one-to-one surveys in prison and were able to speak to 7 pregnant women across three prisons that welcomed us:

- HMP Low Newton
- HMP New Hall
- HMP Askham Grange

The results of both the community and prison versions of the maternity survey are presented together below, and differences are highlighted.

In total, 73 women engaged with the maternity consultation, as follows:

- 38 participants on probation orders
- 28 prison leavers
- 7 current prisoners



# **DEMOGRAPHICS**

The following tables provide an overview of all participants across the consultation in terms of ethnicity, age and gender.

We spoke with respondents on community orders reporting to 27 different probation areas across England, and prison leavers from 11 different prisons. While not all areas are represented, we are satisfied that the survey does not focus on any particular area.

#### Gender

All participants identified as women.

When asked whether they identified with the gender registered at their birth, all the participants stated that they did.

#### Age

AGE RANGE	COMMUNITY ORDER	PRISON LEAVER	CURRENT PRISONER	TOTAL	% OF TOTAL
Under 21	6	3	1	10	14%
21 to 29	17	13	3	33	45%
30 to 39	10	8	2	20	27%
40 to 49	5	4	1	10	14%
TOTAL	38	28	7	73	100%

#### **Ethnicity**

ETHNICITY	COMMUNITY ORDER	PRISON LEAVER	CURRENT PRISONER	TOTAL	% OF TOTAL
Asian	5	2	0	7	10%
Black	10	6	1	17	23%
Mixed	12	4	0	16	22%
Other	1	0	0	1	1.5%
White	10	15	6	31	42%
Prefer not to say	0	1	0	1	1.5%
TOTAL	38	28	7	73	100%

Looking at those on community orders, we also note that:

- the average length of time on probation was between three and six months
- 71% were pregnant at the time of completing the survey
- 74% of those who were pregnant were in the first 20 weeks of pregnancy
- 11% had been pregnant in the last two years but did not have the baby
- 16% had older children, the average age being nine years

Looking at those who had left prison:

- 17 months was the average length of time spent in custody
- over half (57%) had been released between one and six months previously
- 38% were pregnant at the time of the survey
- one had been pregnant but not had the baby
- 19% had older children, the average age being 12 years

Where possible, quotes have been included to enable the direct voices of individuals to be heard.

Points of interest are illustrated throughout.



# FEELINGS AROUND PREGNANCY

#### **Key learning**

- The most common feelings expressed about being pregnant were excitement, nervousness and fear. Women in the community tended to experience more positive emotions than prison leavers, with the exception of those currently in prison who seemed more positive overall.
- Those living in the Mother and Baby Unit (MBU) at the time of the survey were mostly very positive about their pregnancy and baby.
- Reasons for feeling fearful largely related to social services involvement and the judgement of others.
- In the community, women learnt the most about pregnancy and birth from family and friends.
- 39% of those on probation and 19% of prison leavers knew they were pregnant at the time of their arrest.
- Low numbers of women recall being asked about pregnancy by the police: 8% of those on community orders and 14% of prison leavers or current prisoners.
- 34% of those on probation orders and 38% of prison-experienced women felt the need to conceal their pregnancies.
- All the participants who felt the need to conceal their pregnancy spoke of being 'scared' or 'worried' of what the situation would mean for them.
- 71% of prison leavers were not offered a pregnancy test on arrival in prison, dropping to 20% for current prisoners.
- Consistent worries for those in prison and on probation were experienced around mental health, keeping healthy, the health of the baby and childbirth.
- More than maternity-related needs, prison leavers spoke about how accommodation and finances were primary concerns for them on release.



#### Feelings about pregnancy and being a new mum

As part of the maternity survey, the women were asked how they felt about being pregnant and being a new mum. It was evident – and a content analysis of words written supported this – that fear and anxiety were the dominant emotions. This was certainly true for prison leavers, who responded with very few positive emotions.

Those in the community, however, referred to feelings of excitement, while those currently in prison described a sense of hopefulness about the pregnancy.

"I feel overwhelmed with love and can't wait to be a mum again."

"I feel overwhelmed with love and can't wait to be a mum again." Interestingly, when considering the emotions of fear and anxiety, the women were fearful of childbirth and of what kind of mother they might be, but also spoke of their fear of losing their babies, of social services involvement, and of remaining in prison for years post-birth. These were overwhelming feelings for many women.

"Stressed, worried I'll have my baby in prison and they may take him away."

"Very worried and anxious and depressed as was facing a long stretch in prison."

"Was daunting/ scary/ the whole birthing with officer/ having restrictions and fear of not being with baby the whole time."

"Scared and thought I would be in trouble being pregnant at end of sentence, scared I would have it while in prison as found out [I was] pregnant when I was in prison."

"Nervous in case I lose it again and I'm getting older now too."

"Scared as don't want to lose the baby to any agency."

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Using a tick box approach, we asked women to cite their main concerns. The table below presents the main worries for each cohort – prison experienced and community order.



WORRY	SURVEY	YES
Your mental health	Prison leaver Community	95%
Keeping yourself healthy	Prison leaver Community	100%
The health of the baby	Prison leaver Community	97%
Relationship with the baby's parent/family	Prison leaver Community	95%
The birth of the baby	Prison leaver Community	90%
Feeling safe	Prison leaver Community	95%
Parenting	Prison leaver Community	75% 95%
Domestic abuse	Prison leaver Community	5% 26%
Social services	Prison leaver Community	55% 92%

Many more worries are evident amongst prison leavers with regard to 'keeping yourself healthy', 'relationship with the baby's parent/family' and 'feeling safe'.

Conversely, amongst those on community orders, greater concerns arose in relation to 'parenting' and, quite significantly, 'domestic abuse' and 'social services'.



Importantly, we also asked prison-experienced women to share with us the issues around which they felt most nervous upon leaving prison. They reported:

- Home and housing 90%
- Finances 86%
- Mental health 86%

This was sobering as, despite all the pregnancy and parenting needs that exist, almost all respondents were worried about where they would live, how they would pay for essentials and how they would cope.

#### Learning about pregnancy and birth

Upon being asked where they had learnt about pregnancy and birth, the overwhelming answer in both the prison leaver and community order cohorts was friends and family, at 76% and 92%, respectively. This was followed by the television, GPs and midwives for prison leavers (at 57%, 43% and 43%, respectively), and personal experiences and TV for those on community orders (at 76% and 71%, respectively).

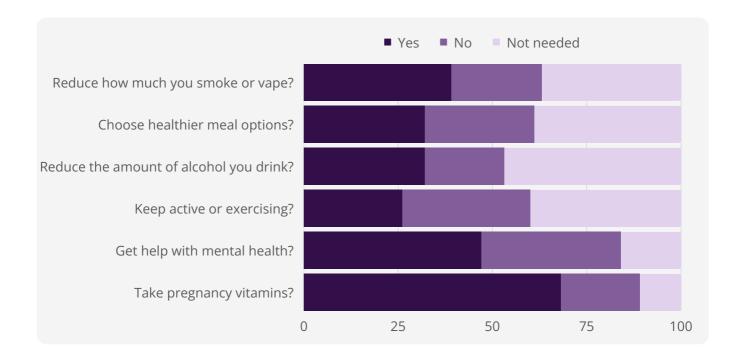
Women on community orders were found to be more likely to have learnt about pregnancy and birth from social media (58%) than from a medical professional such as a midwife (34%) or a GP (37%).

Importantly, for those currently in prison and living on an MBU, the most common source of learning was through the prison midwife, with friends and family being the second most common source.

#### Lifestyle changes

Women were asked whether they were making any changes to their lives while pregnant, and the following table presents the results for the community order sample.





- Pregnancy vitamins were widely taken, with 76% of those who needed them choosing to do so.
- 44% of those needing help with mental health support appear to not be seeking this help.
- 40% of those stating that they did drink alcohol did not state that they were reducing their intake during pregnancy.

Of the 27 participants who were pregnant at the time of the survey, six (approximately 22%) consistently answered that they were not attempting to address any of the health interventions suggested in the table above.

#### Early interaction with the CJS

Just four prison leavers (19%) and one current prisoner (14%) were aware of their pregnancy at the time of their arrest. A greater number (39%) of those on community orders knew they were pregnant at the time of their arrest. Thus, a large proportion of women are not aware of their pregnancy at the time of their arrest, representing a potential area for further consideration.

In terms of testing, low numbers of women recall being asked by the police about pregnancy, as follows:

- 8% of those on community orders
- 14% of prison leavers
- 14% of current prisoners

Also interesting is the high number of women who felt the need to conceal their pregnancy from the criminal justice authorities:

- 34% of those on probation orders
- 38% of prison experienced-women

While some women conceived at a later point (while on bail or on ROTL, for instance), a clear need exists for pregnancy testing to be offered at the point of arrest, to ensure that all pregnancies and their associated needs can be managed appropriately. Of concern is the 82% of women on probation who felt their pregnancy needs were not accommodated by the police. Indeed, just 3% of pregnant women reported receiving help while in police custody or by probation to see a GP, midwife or bereavement support.

Nineteen percent of prison leavers were offered a pregnancy test on entering prison, while 57% of those currently in prison were offered one, which is a promising step forward. Only one participant in prison answered 'no' to this question, while the others could not recall. All but one of the participants in prison accepted the test when offered; this number was lower in the community sample, with a smaller proportion accepting the test.

The predominant reasons given for concealing a pregnancy were fear and uncertainty.

"Scared what was going to happen or if I will be separated or punished harsher."

"The feeling of being different... Jealousy. People think you're different and that means you are treated better. People are hungry... all I get extra is stale bread and jam and powdered milk and put on biggest wing, but I don't want people to turn on me."

Other feelings concerned loss of control over the pregnancy, agency intervention and the perceived stigma of being on probation whilst pregnant.

"Didn't know how probation would be with me even though there [are] no issues around me being pregnant."

"Was scared they might judge or try [to] control pregnancy with social services etc."
"I'm scared to tell them as (the) Dad just got a sentence and I have community order."

Court processes were also mentioned – an aspect of the CJS not specifically covered in this consultation. Additionally, we were made aware of one woman who had given birth two days before her trial and was remanded in custody. Of particular note is that the court did not inform the receiving prison, and they were therefore unaware of the needs of this woman on reception.

"I was on bail for almost 2 years, during that time I had 3 trials. I found out I was pregnant whilst on trial, my barrister wasn't keen for me to share this information with the judge".

"I was unsure of my sentence length when I discovered I was pregnant. The judge was told at sentencing and he told the courtroom he was "angry" to find this out. This made me even more frightened and once I was given my big sentence I knew I would have to separate from my new baby or not carry on with the pregnancy. I was made to discuss this in a busy visits hall with my husband and no support from prison or probation".

"[We need] support, understanding reasons behind why an offence was committed and understanding that babies change women."

# SUPPORT DURING THE MATERNITY PERIOD

#### **Key learning**

- Most women on probation report receiving no support to access services connected with pregnancy and birth. More support was offered around social services than other services.
- Prison experienced women tended to be open with their probation workers about their pregnancy, with 95% and 86% of prison leavers and current prisoners respectively, having discussions with a probation worker.
- 71% of individuals on probation felt they were offered no help by their probation officer in relation to pregnancy and birth.
- Prison leavers appeared to receive more help than those on probation.
- Those currently in prison reported receiving high levels of help and support.

- Prison leavers rated other women in prison and the Chaplaincy team as being the most supportive. This was not the case for women currently in prison, however, who rated the Pregnancy, Maternity and Baby Liaison Officers (PMBLOs), prison midwives and Mother and Baby Unit (MBU) staff as the most supportive.
- Support was lacking for those in prison and prison leavers in relation to loss and separation, and legal support, affecting up to 100% of those currently in prison.
- Although those currently living on the MBU were able to access goods and services relating to pregnancy and birth with relative ease, prison leavers found this much more difficult.
- That 100% of current prisoners were on the MBU might have affected this outcome. In the prison leaver sample, around half of those who would have benefited from a place on the MBU were allocated a place, while 24% of prison leavers did not know about MBUs.
- MBUs were valued and respected.
- The wait for MBU decisions could be long, but many women currently in prison received a decision within two weeks. The wait is said to induce extreme anxiety and discomfort.
- Nutrition was raised as a particular concern.
- Little support was available for women with older children, causing stress.

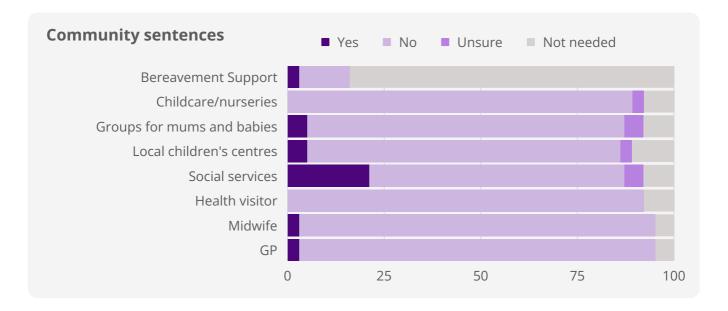
#### Access to support services and healthcare professionals

Overall, women on probation reported receiving only minimal help from the police and probation to access maternity-related services.

#### "Did it all myself as so close to birth."

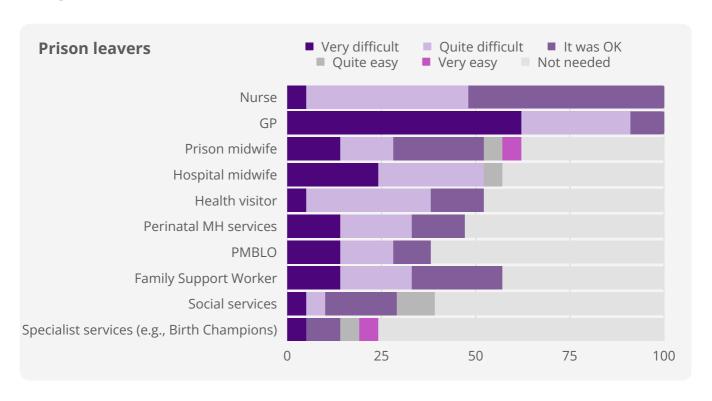
The following graph outlines the number who responded 'yes', 'no', 'unsure' or 'not needed' to receiving support from the police or probation to access each of the services.

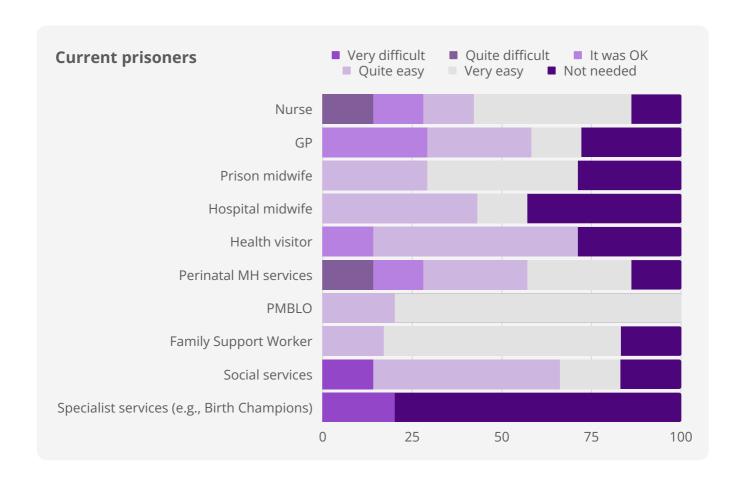
As can be seen, the greatest assistance related to accessing social services, followed by groups for new mums and local children's centres – albeit these numbers are small and the number who have not been helped is clearly significantly higher.



We asked prison-experienced women how easy or difficult it was to access certain health professionals linked with pregnancy and birth while in prison. The tables below show the results for prison leavers and current prisoners separately, in percentages.

It is noteworthy that only the prison midwife was considered very easy to see by prison leavers, although we are aware some women will have only seen community midwives and not all prisons have a midwife on site. When compared with women currently in prison, the level of difficulty for prison leavers is striking. Women in prison now only find it difficult to access perinatal mental health services, specialist support and the nurse. Prison leavers found it difficult to see anybody, to varying degrees.





Further, it is clear from the above tables that no prison leavers (0%) felt it was easy or very easy to access a PMBLO whereas all (100%) of those currently in prison did. Sixty-two percent stated that they did not need a PMBLO. While we cannot explain with certainty the reason for this, we recognise the role of PMBLO was implemented and rolled out following the 'Review of operational policy on pregnancy, Mother and Baby Units and maternal separation' in 2020.

It is important to consider the very low number of current prisoners when analysing the given percentages.

#### Provision of good support

When asked an open question around which groups provided the best support, 'family' featured most prominently for community ordered participants.

It is notable that, when the 'family' and 'friends' responses are combined, an approximately equal number of responses to this question is achieved, compared to collating all other statutory services together.

The chart below shows the responses in full.

However, when asked specifically to rate the help provided by particular services, those on community orders stated the following:

- Eighty-nine percent rated the support of probation as 'ok', with the remaining 11% feeling it was 'really supportive'.
- Seventy percent found community maternity services to be 'really supportive' (although they did not list them when given the opportunity), with 29% feeling the support was 'ok'.
   Only one respondent answered with 'not supportive'.
- When we looked at RECONNECT and Peer Mentors, only two women reported any contact, both of whom reported a 'really supportive' experience.

BEST SUPPORT	NO. OF TIMES MENTIONED
Family	17
Nurse	10
GP/surgery	4
Social services	3
Friends	2
Midwife	2
Mental health worker	1

An issue was raised in relation to insufficient awareness of the support services on offer within communities, meaning that less information was forthcoming.

"Felt like a grey cloud hanging over me! But had to prod in conversation for answers and got some."

"I have to ask and badger for info."

"Had to find things out myself with very little input from probation officer."

This situation impacted on the mental health of some participants, who struggled to navigate new motherhood alongside a community sentence.

"I feel alone a lot of the time." [I] still had to attend appointments no matter how I was coping with baby."

Some women felt it would be beneficial to have at least one 'pregnancy champion' [1] per probation area who could direct support to women and help probation officers understand the services available locally.

[1] This was not the term used by the women, but we believe it represents their suggestion.

"It's nervous time so be good to have more advice available and information and [be] shown direction, and directed to services that can provide support."

"More should be shared about how you are supported. Maybe get allocated a mentor or support worker through the process."

"More forthcoming support needed. Feel isolated and have to work it out alone with probation looming over you too."

Turning to prison-experienced women, they were asked to rate the degree to which they felt supported by a range of providers in prison. A greater mix of responses was received within the prison leaver group than the current prisoner group, who were more likely to respond positively.

The highest rated support in the prison leaver group came from other prisoners and the Chaplaincy. Current prisoners felt the PMBLOs, MBU staff and specialist midwives to be universally 'really supportive'. The least supportive source of support came from peer mentors. The table below summarises the responses of prison leavers, but includes (in brackets) the percentage of current prisoners who feel that this support provider is 'really supportive'.

SUPPORT PROVIDER	NOT SUPPORTIVE (%)	IT WAS OK (%)	REALLY SUPPORTIVE (%)
Healthcare team	18	65	17 [50]
Peer mentor	8	75	17 [33]
Officers	22	67	11 [50]
PMBLO	0	100	0 [100]
MBU staff	22	78	0 [100]
Other women in prison	0	20	80 [50]
Family Support Worker	11	56	33 [50]

[##] = the percentage of current prisoners who feel that this support provider is 'really supportive'

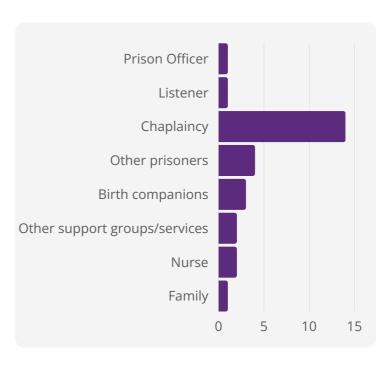
SUPPORT PROVIDER	NOT SUPPORTIVE (%)	IT WAS OK (%)	REALLY SUPPORTIVE (%)
Perinatal mental health team	14	86	0 [75]
In-prison maternity services (midwives, health visitors)	13.5	73	13.5 [100]
Specialist services	0	100	0 [100]
Chaplaincy	6	19	75 [75]

[##] = the percentage of current prisoners who feel that this support provider is 'really supportive'

The above table shows how the participants felt about the various providers of support. Percentages are shown only in cases where the provider of support had met with the participant and knew they were pregnant.

A dramatic difference emerged between the free text responses of prison leavers and those currently in prison, in terms of who they felt offered the best support in prison.

far the most common response to this question for prison leavers the was Chaplaincy; in line with the previous graph, half of the respondents cited this (50%). 'Other prisoners' and companions' were the next best perceived supportive group, with 14% and 11%, respectively, citing these. Relatively few mentioned any formally appointed prison staff, although one woman mentioned a prison officer and two nurses as providing support.



In contrast, those currently in prison almost universally referred to staff in the MBU or PMBLOs, and also to officers, as the best providers of support. Nobody in this group mentioned the Chaplaincy.



#### Support with older children

Participants wrote about their experiences of being supported with older children. Generally, those currently in prison felt unsupported, with the location of women's prisons and the cost of telephone calls and travel being cited as barriers to maintaining family ties.

"I did not feel supported at all. We financially struggled and got into thousands of pounds of debt, also the massive emotional separation."

"The call costs to home are horrendously expensive [from prison]. There was no extra visits to accommodate children and mothers (this was weekly) which we did but this was adding financial pressure to my family."

"I felt over a barrel and helpless as I was pregnant and without my other young children and to see them and keep the regular contact was extremely expensive due to the distance of the prison to our city."

Those currently in prison spoke of the emotional toil of separation, as well as the burden on other members of the family.

"Dad & Nan have him, living with Mum. Baby was 6 weeks when I came to prison on this sentence. Have a lot of 'hangover' from that."

"Mum & Dad have them. Surely there's another way. Custodial sentence won't benefit my family."

#### Support on release

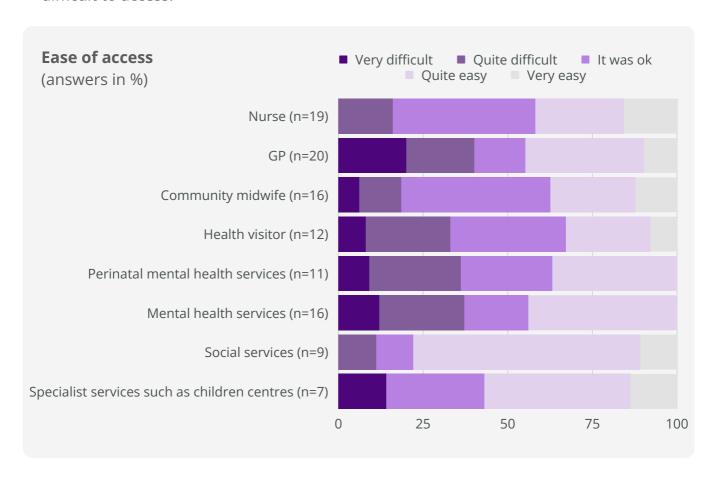
The results of our prison leaver survey revealed that many women face a significant number of needs on their release from prison, particularly in relation to health.

For example, 24% of prison leavers needed to access other healthcare services. In the prison sample, prisoners were most likely to say they either did not need support or did not know if they did. Further, only 10% of prison leavers were referred to a local midwife on release.

We heard how only 21% of prison leavers needing medication were given sufficient provisions to last until they could see a GP.



The table below highlights the number of women who felt that each of the various services were easy to access. This was based only on those requiring the services and this number is given in brackets. Social services (n=9) and specialist services (n=7) were considered the easiest to access, although fewer participants actually needed these services. GP and mental health services were reportedly the most difficult to access when required, with 40% and 50%, respectively, reporting these services as difficult to access.



Positively, a higher number of individuals requiring perinatal mental health services were able to access them than not.

Almost all women stated that they needed no help registering with a GP on release across both prison leaver and current prisoner groups. Only four prison leavers and one current prisoner needed this support.

Just 21% of participants who required it received sufficient medication to last until a GP could be accessed.

Twenty-four percent of prison leavers commented that they needed to access healthcare services, other than the GP, on leaving prison. A further 14% were unsure if they needed such access. Of those stating that they did require access to healthcare services, their answers included midwives, nursing teams, baby scans, and drug and alcohol services.

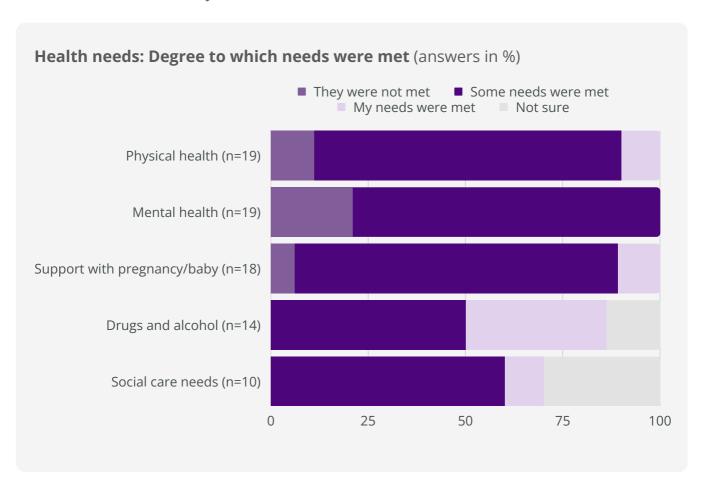
Ten percent of women were referred to a midwife or health visitor on release, and 28% were unsure whether they had been so referred. Those who were referred had generally positive experiences, but were receiving support from multiple agencies at that time.

It was striking that not a single person was referred to perinatal support services in our prison leaver sample (especially since 95% were concerned about their mental health in prison).

As mentioned previously, many individuals felt anxious about housing and finances on release. We found that 59% experienced difficulty in getting accommodation following release, although 82% found supported housing to be 'really supportive'.

Notably, 62% found it 'hard to cope most of the time' during the initial weeks following release from prison. Mentors, buddies and having someone to talk to were by far the most noted ways in which to best help women cope after prison, with friends and family also being highly rated.

Women were asked to comment on whether their health needs were met on release from prison, looking at the first month specifically. 'Some needs were met' represented the most common response for every need type. Mental health was the most commonly cited unmet need, at 21%. In contrast, 36% felt their drug and alcohol needs were fully met.



Women shared with us their feelings surrounding release. Many were fearful and felt more support could be given in both the lead-up to release and post-release.

"I needed support with post-natal depression – I was a previous sufferer and made this very clear but still no support."

"Worried in case I got back on the drugs but happy to be back with the kids, but nowhere to live."

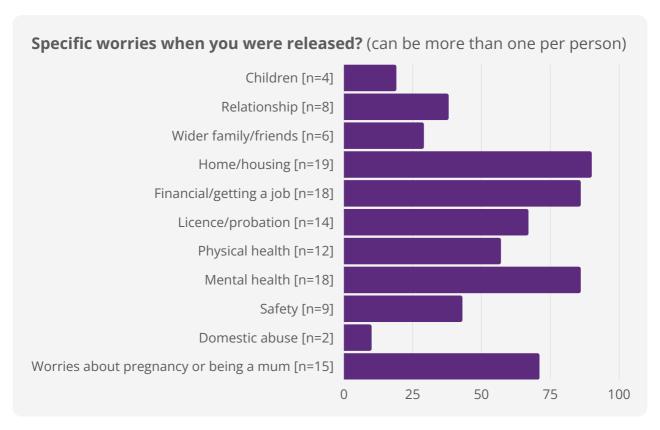
"On edge, I sat my tag board, but they said it takes weeks for a decision. During that time, I was attending hospital 3 times a week due to dehydration, my baby not growing and antibodies."

"I was moved to open prison so felt not too bad but I had a lot of panic attacks etc when released and really needed help with my mental health but was just thrown back out into the real world with a baby and no real support."

"A little overwhelmed and scared. But glad too as can have Baby without the stress [of] handcuffs/officers etc."

"Scared baby would arrive before release and I haven't got MBU place as didn't think I would need and prison didn't think either that [it was] necessary to apply."

Key worries upon release were housing, finances and sustaining an income. Also uppermost were worries surrounding mental health, the pregnancy and being a mum. Further details are outlined below.



# **MBUS AND PLMBOS**

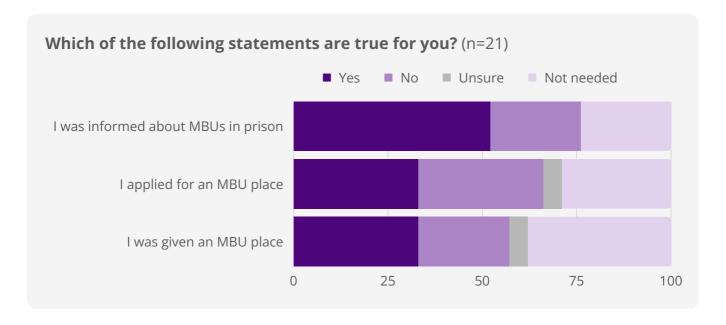
## **Key learning**

- Just over half (53%) of prison leavers needing a place on an MBU received one.
- Twenty-four percent of prison leavers were not made aware of MBUs.
- The wait for a place on an MBU was associated with immense anxiety.
- Forty-seven percent of prison leavers requiring support from a PMBLO were not informed about these officers.
- Current prisoners reflected very positively on the support received from PMBLOs

It is important to reflect on the experiences of prison-experienced women, specifically in relation to MBUs and PMBLOs.

#### **MBUs**

In terms of prison leavers, only 53% of participants who needed an MBU were allocated one. Pressure on places was identified by several participants as a reason for not being offered a place.



Twenty-four percent of prison leavers were not informed about MBUs, and it was felt by the women that it would be valuable if more information was freely shared, as most would otherwise have no knowledge of the unit. "Advice on what is available and when to apply for MBU and what you do if pregnant. What is available on release and support you can get or is out there."

Within the prison sample, all were already on an MBU at the time of the survey interview.

Of the seven successful applications for an MBU place in the prison leaver sample, the average wait for a decision was four months. This was described as an anxious wait.

"Took ages, didn't know until my 8th month."

"Felt like forever and only near due date did they tell me."

"Took forever, only found out in the last month of pregnancy."

"5 months – and this was eventually rushed as covid-19 came about and I had to be transferred to an MBU for the safety of my unborn child so an "emergency board" was sat for my place."

Within the current prisoner sample, the waiting period tended to be shorter, ranging from two weeks to five months. The five month wait was said to be due to waiting for social services to complete paperwork; once this paperwork was returned to the prison, the decision was made within two weeks.

All respondents – even those who received a decision quickly – described emotional and logistical barriers with the process, including:

"I wasn't able to sit the board. As I wasn't far enough in my pregnancy, despite informing the prison I have my children 4 weeks early. And it's been written in my pregnancy book and notes from the hospital."

"Very difficult and worrying as you want to know it's all sorted."

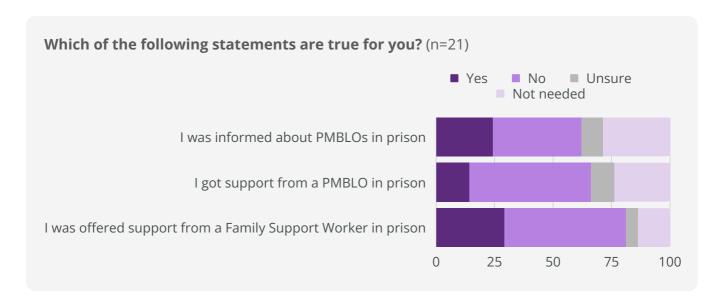
"Very long winded, unpredictable, stressful, no guarantee of place so fear of being moved or baby being taken away."

"Daunting as there was so many people in attendance."

"They make it very clear that you might not get a place but it's a long process. The thought of having to hand the baby back is too tough."

### Pregnancy, maternity and baby liaison officers (PMBLOs)

Forty-seven percent of prison leavers requiring support from a PMBLO were not informed about these officers. None of this group were offered support from a Family Support Worker either.



Current prisoners were all informed about PMBLOs and Family Support Workers.

Prison leavers were asked about their experiences of PMBLOs and a mixture of responses was received. Most prison leavers expressed concern at the insufficient resources and considerable waiting times.

"It was okay, someone to talk to but should have been a much more supportive role than it was."

"It was still scary as didn't always answer all the questions and sometimes left for a long time with no response when you already have so many worries and fears in your head. Some of the things said are not realistic."

"It was very limited and not as frequent. Had to wait if you had concerns for when they were free to see you."

However, all current prisoners were complimentary about the support received from the PMBLOs, without exception.

"She's an angel."



# MEETING THE NEEDS OF WOMEN DURING THE MATERNITY PERIOD

#### **Key learning**

- 60% of women on community orders needed, but did not receive, support to receive maternity pads. Eighty-four percent of prison leavers felt these were difficult to access, while 84% also struggled to access breast pads in prison.
- 40% of women on community orders asked for support with their finances but were unable to access this.
- Significant concerns emerged among prison leavers in terms of accessing goods and services.
- The need for improved nutrition was raised by many prison-experienced women.
- 81% of prison leavers experienced difficulty accessing scans while in prison, while 93% struggled to access urgent hospital treatment.
- Almost a third of prison leavers found it difficult to access a single cell while in prison.
- It was clear that prison leavers found it easier to access goods and services once released.
- Current prisoners reported much easier access to almost all goods and services than former prisoners.
- For example, 80% of current prisoners experienced no difficulty accessing urgent hospital treatment and all of this group felt that accessing scans was either 'ok' or 'very easy'. Everybody could easily access maternity pads.
- However, 100% of prison leavers and current prisoners found it very difficult to access support for loss or separation, indicating a significant gap in services.
- Prison leavers spoke about the stigma of being in prison and following release, and addressing this emerges as a clear 'need' for women in custody during the maternity period.
- Women who had been released felt that access to a mentor would be beneficial, to help them navigate maternity and other services during the difficult post-release phase.

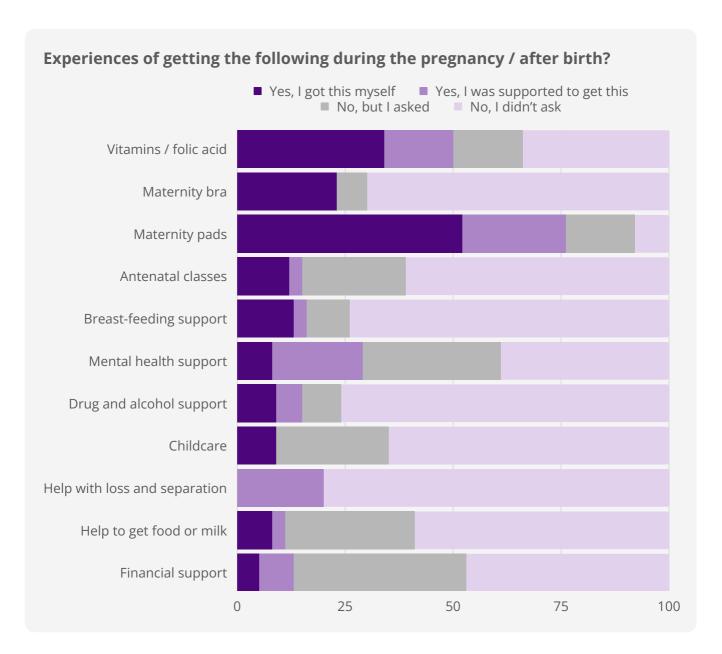


We explored whether women had access to the items and services required throughout the maternity period and the below chart details the ease (or otherwise) of accessing each item for each cohort (i.e. community order, prison leaver and current prisoner).

As the table shows, for those on community orders, some of the clearest gaps related to very basic provisions. Around a third, 30% asked for support with food and milk but were not supported to access this; and 16% needed but did not receive to maternity pads

32% were looking for support with mental health during pregnancy or beyond but received no such support. A further 21% were actively supported with their mental health during this time.

### **Community orders**



Turning to the prison-experienced women, notable differences are evident between the prison leaver group and those in prison now, with many more women in prison currently benefitting from easier access to provisions and services.

For example, only one person in need of urgent hospital treatment in the prison leaver group found it easy to access help, with the remaining 12 experiencing some level of difficulty in doing so. With the current prisoner sample, all those who needed urgent hospital care found it either 'ok', 'quite easy' or 'very easy' to access.

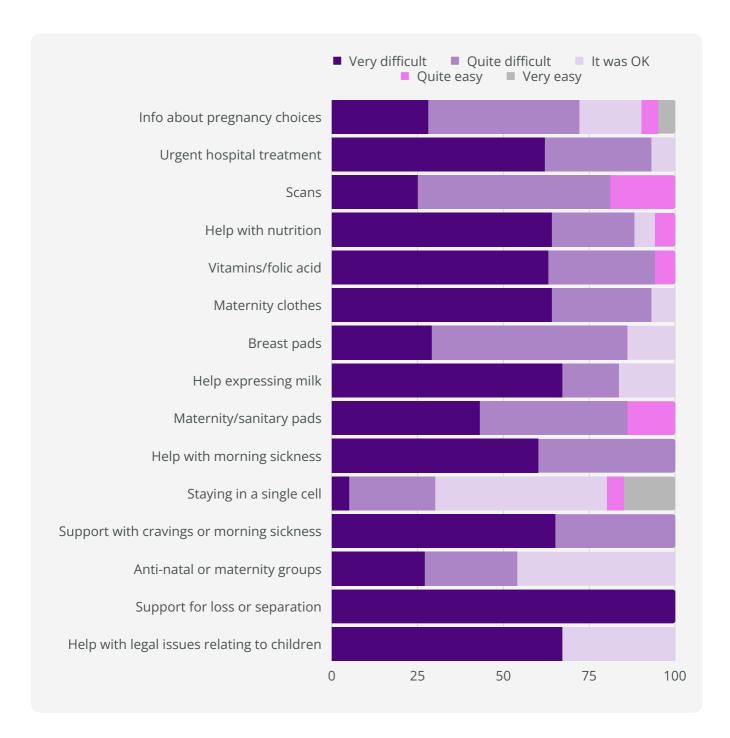
Within the prison leaver sample, the majority of choices were said to be difficult or very difficult to access, with almost every participant agreeing on this in many cases. A few stand-out examples include the following:

- 86% encountered difficulty accessing maternity pads, and the same number struggled to access breast pads.
- 86% found it difficult to access support with nutrition and only slightly fewer struggled to access help with expressing milk.
- 81% felt it was difficult to access scans.
- All participants stated that it was difficult to access any help regarding morning sickness.
- Almost a third, 30%, found it difficult to access a single cell.
- 54% found antenatal groups difficult to access

"Needs to be more understanding about what you are going through and easing the worries [as] early on as possible. Better access to healthcare and not put pressure to share a cell or threaten you with IEP (Incentive and Earned Privileges) if you don't agree or lock you in your cell for not sharing."

"Mother and child led weaning/ feeding/ choices – I was not in prison for being a "bad mam" but was made to feel that way when you have to ask or beg for simple items for your child and it is dependent on the individual officer as to whether your child can eat a certain food or have Calpol etc."

#### **Prison leavers**

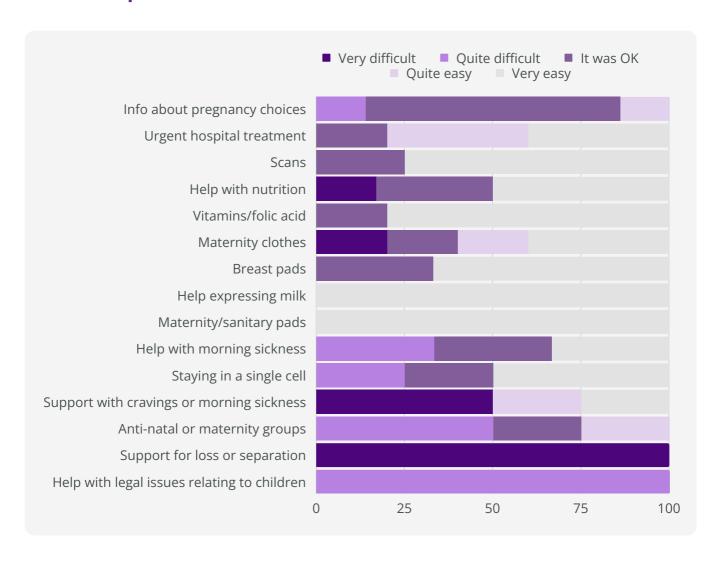


The situation is very different for current prisoners. Far fewer women pointed to difficulties, although access to maternity clothes, antenatal groups, and support with morning sickness were raised as issues by some women.

In contrast to prison leavers, it was very positive to see women easily access breast and maternity pads. All participants felt it was 'ok' or 'very easy' to access scans.



#### **Current prisoners**



It is important to reflect on the findings around support with separation and loss.

All of the women who needed support in the community sample (20%) were offered it, while none of those in prison (either prison leavers or current prisoners) were offered this support.

Additionally, two thirds of the prison leavers sample found it difficult to access legal support relating to children, whereas all current prisoners were able to access this.

The chart below looks at how prison leavers found accessing goods and services on their release, in comparison to while in prison. Across all options, a clear and highly significant difference is apparent in accessing the various options, between women in prison and women post-release.

While this clearly indicates a lack of access to pregnancy requirements in custody in comparison with in the community, the current prisoners tell a different story which has not been followed into the community.

	DIFFICULT TO ACCESS		IT WAS OK		EASY TO ACCESS	
NEEDS	IN PRISON	POST PRISON	IN PRISON	POST PRISON	IN PRISON	POST PRISON
Information about pregnancy choices	72%	7%	18%	27%	10%	26%
Urgent hospital	93%	9%	7%	18%	0%	73%
Scans	81%	0%	0%	21%	19%	79%
Help with nutrition	88%	12%	6%	18%	6%	70%
Vitamins/folic acid	94%	6%	0%	25%	6%	69%
Maternity clothes	93%	27%	7%	7%	0%	66%
Breast pads	86%	11%	14%	22%	0%	67%
Help expressing milk	83.5%	12.5%	16.5%	12.5%	0%	75%
Maternity/sanitary pads	86%	11%	0%	11%	14%	72%
Support with cravings or morning sickness	100%	25%	0%	25%	0%	50%
Anti-natal or maternity groups	54%	16%	46%	17%	0%	77%
Support for loss or separation	100%	100%	0%	0%	0%	0%
Help with legal proceedings relating to children	67%	50%	33%	50%	0%	0%

When given the opportunity to comment freely, a wide range of issues arose in relation to understanding pregnant women in prison and their needs.

In line with comments received from 88% of the prison leavers cohort, a clear theme emerged relating to the need for improved access to support with nutrition in custody. These comments often emerged embedded within a wider response, as below:



"They need healthy food and people to listen to them."

"Women need a better diet, more food, breast pads etc. The quality of food is disgusting. My skin was horrible. Also they need to get outside in the sun light. I had a horrible roof garden and I felt like I never saw the sun until I moved out to open conditions."

"It is very different and challenging being pregnant in prison. Food is a big issue as in there is not enough or of decent quality/ nutritional [value]. A "pregnancy pack" consists of a sandwich."

"Need better nutrition packs. More information and access to advice as it's already scary being pregnant and being my first."

"I was diagnosed with gestational diabetes, and needed a specialist diet. This took weeks to be approved, and the baby was here by the time it was approved. Now I need a normal diet as I am breastfeeding and I can't get it reversed quickly."

Some women described the operational complexity of prison and how this can impact on the health needs of women, for example in relation to spending most of their time inside (as above), or as outlined in the quotes below.

"Need more advice in how baby stays with you and how long. What help is provided in prison and on release. Help to register for the services."

"Didn't know about MBU, OMU didn't tell me, other women told me. Took me a while to get back in their good books as I didn't always play by rules."

"You are not told when your scans are (for security reasons) which is difficult to process in your mind."

Further issues raised within the survey indicate additional needs of pregnant women in custody that have not yet been encompassed within this report. These issues are raised here for completeness in relation to understanding and meeting women's needs.

An interesting point was raised by a woman who was in prison at the time of the survey, and explained family days were mandatory for all those living on an MBU. She explained how, when the baby is out in the community, either with the father or for another reason, the mother was still required to attend family days as this was a prison rule. She felt this was stressful and it heightened her sense of tension at being a prisoner during the maternity period.

"Family days – have to go to family days even if don't have baby. Head fuck. Got negative for not going to family day cos wanted to settle baby after a stay with dad in community."

Relatedly, women spoke about feeling judged for being pregnant, or a new mum, in custody. This impacts on mental health and is therefore something to consider when examining the needs of women during this period.

"Already stressful time, some understanding from the officers and more explained of what help is allowed without being penalised for feeling ill/sick during pregnancy."

"Better care plan and access made easier to see professionals. The need to not have to share a cell or be forced to due to the impact of being pregnant and dealing with pregnancy as well as worry of existing family ties and children."

"Not having to feel unsafe to say you are pregnant. More open support if pregnant and guidance of accessing services that might be needed."

"[There is] Lots of tension in the MBU. Girls fighting with each other."

Women used a free text box to share thoughts relating to help for pregnant women or new mums being released from prison. The most prevalent type of response centred around the availability of help to navigate the stresses involved with being a mother after prison. Having someone to talk to, who can also advise on services available, was seen as important.

"Guidance on accessing services in local area."

"Need someone to ask how you're coping and help you get things in place with housing and benefits and support with your mental health. Someone you can talk to and feel safe."

"A mentor. More communication and services put in place before release. Guidance to what Support [is] out there and who to go to etc, having a mentor or support team you can speak to if needed."

"Having an advice hub or contact to approach when stressed or need help."

"Having a "go to" person to contact for advice or help and have follow up chats to make sure able to put everything in place."



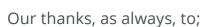
Women also referred to wider issues of leaving prison, such as housing and mental health, in addition to pregnancy or maternity needs specifically. Stigma and stress associated with prison life were mentioned by some.

"ROTL (Release On Temporary License) and help adjusting to outside life with their child, someone I could talk to. As no one knew I'd been in prison and [I] had to hide it and I needed to adjust to the outside world again. I was very panicky, paranoid people knew and worried."

"Help to retain home, better support network for maintaining family ties and the impact to the children's care and mental health."

"Having a contact and support team to get essential things sorted such as housing etc."

# **ACKNOWLEDGEMENTS**



Every person who took part in this consultation.

Our peer researchers who engaged with communities to support this work.

PMBLOs, MBU and prison staff.

All the community organisations who were involved.

NHS England who continually create space for people to be heard.

