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WE'RE HERE IF YOU NEED US



# We are LGBT Foundation

# We believe in a fair and equal society where all lesbian, gay, bisexual and trans people can achieve their full potential.

Our work started in 1975 and we've been changing the lives of LGBT people ever since. Over the last five decades, we've provided information, services and support for LGBT people who've had nowhere else to turn.

We've been at the forefront of the social and legal changes that mean LGBT people in the UK have more rights than ever before. Our work is as vital and urgent as ever. LGBT people still face persecution, discrimination and stark health inequalities.

Through our services we reduce isolation amongst our communities, help people feel more confident and in control of their lives, and enable people to flourish. Every year we serve 40,000 people - amplifying people's voices, providing support and offering hope.

We work in partnership with others to build strong, cohesive and influential LGBT communities and promote attitude change in society, reaching 600,000 people online each year.

Together, we can secure a safe, healthy and equal future for all LGBT people. **Until then, we're here if you need us.** 

# EQUALITY WINS

# TRANS + NON BINARY EXPERIENCES OF MATERNITY SERVICES

Survey findings, report and recommendations



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# **Executive Summary**

The Improving Trans Experiences of Maternity Services (ITEMS) project is a collaborative research project commissioned by the Health & Wellbeing Alliance, which is jointly managed by the Department of Health and Social Care (DHSC), Public Health England (PHE) and NHS England and NHS Improvement (NHSE&I). The project is supported by the National LGBT Partnership, the Trans Learning Partnership (TLP), and the Voluntary, Community and Social Enterprise Health and Wellbeing Alliance (VCSE HWA).

The experiences of trans and non-binary birthing people are often sensationalised, with reporting focusing solely on the supposed novelty of 'the pregnant man' as opposed to the specific health and care needs of this community. The UK has announced not one, but two 'first' pregnant men, in both 2012 and 2017, and such announcements fail to do justice to the lives of the many trans men and non-binary people who have given birth both before and after this.

This report aims to shine a light on the many and varied experiences, insights and needs of trans men and non-binary people who have accessed perinatal services. It should be especially useful for perinatal practitioners, service managers, commissioners and policymakers. However, anyone with an interest in trans healthcare or improving services for marginalised communities will find the contents of this report helpful.

We found numerous examples of poor experiences, poorer outcomes, and patients and their babies being put at risk. These inequalities were especially stark for multiply marginalised trans men and non-binary people, most notably those trans men and nonbinary respondents who were Black and people of colour.

We also found many examples of trans men and non-binary pregnant and birthing people coming together as a community to support one another. We found examples of innovation and best practice, where trans and non-binary people felt listened to, respected, and supported by the perinatal services they accessed. These were cases where their midwives and the services as a whole took a proactive approach to gender inclusion, from language use to providing care options that clearly centred the needs of individual patients.

We are proud to have worked with a diverse and active steering group comprised of trans and non-binary people who have given birth; midwives, obstetricians and other clinicians with experience of supporting trans birth parents through pregnancy; Dr Ruth Pearce; the Trans Learning Partnership; the NHSE&I LGBT Health Team; the NHS Maternity Transformation Programme; the Lived Experience Alliance; Disability Rights UK; Gender Inclusive Midwives; the Race Equality Foundation; and the National LGBT Partnership.

Thank you to everyone who has supported this project. Thanks especially to the trans and non-binary people who shared their honest, and sometimes very painful, experiences with us through the survey or interviews. We hope that this report does justice to your generosity, and prompts the change that is needed to ensure every trans or non-binary pregnant person is able to receive the care they deserve.

Toze, M. (2018). The risky womb and the unthinkability of the pregnant man: Addressing trans masculine hysterectomy. Feminism & Psychology 28, Issue 2, pp. 194-211.



I have three home-educated children, an aspiring author career, and overall, a busy life. Still, when I was invited to join the ITEMS project, I didn't hesitate, I was in. There's something special about this project.

My first two children were born in Israel. I was the first openly trans, post-transition person, to give birth there. It was quite a traumatic experience, in many ways, especially my eldest's birth: I felt invisible, I was addressed as a woman and a mother, and told that I was not who I said I was. I was made to feel ashamed of my body, which is different, and my parenting ability questioned, when a social worker was sent to my room after giving birth - only because I was trans. I was asked irrelevant and intrusive questions, but I wasn't listened to.

My third pregnancy, which sadly I lost, and my fourth, which ended in the birth of my third child, were here, in England. My experiences were a world different. The system here is very different, and we know for a fact that it is under-staffed and under-funded and does suffer from various other problems. However, almost all the people I came across in what turned out to be quite a complicated pregnancy were respectful and kind, and I felt that many of them wanted to learn and do better.

I was respected as the person who knows most about themselves, and I never was given the opposite impression - that someone knew what I needed better than I did. I see this project as doing just that, but on a wider scale.

I feel that the NHS as a whole, wants to get better at treating trans and queer people, and I appreciate that this included listening to trans people's real-life experiences, no less than to various other experts.

This project, which I am very proud to have taken a part in, is an excellent example of this sort of collaboration, between people from within the medical system and their clients. I truly believe that this is the future of trans health care, pregnancy care, and healthcare in general.

## Yuval Topper ITEMS Steering Group Member

# **Foreword from Paul Martin**

Despite the progress that has been made towards LGBTQ+ equality in the UK, it is undeniable that our communities still face significant barriers to leading the happy, healthy, and long lives that we deserve. LGBT Foundation's own research on LGBTQ+ health inequalities, published in the 2020 Hidden Figures report, demonstrated that LGBTQ+ people in the UK experience unjust and avoidable differences in physical and mental health compared with the general population. This can be attributed to a variety of causes, including the various ways that homophobia, biphobia and transphobia still manifest across our society. There has sadly been a rise in LGBTQ+ discrimination in the past few years, including a steep increase in hate crimes and harassment, a rise in misinformation about our communities, and challenges in the policy and legislative arenas that limit access to rights and dignity. This has been particularly difficult for transgender and non-binary people, as they tend to be disproportionately targeted.

The impact of transphobia is evident in how trans and non-binary birthing people's experiences have been sensationalised in society and the media. Trans men and non-binary parents are often pigeonholed into pre-existing cis-binary language, especially around concepts such as fatherhood and motherhood. This highly gendered spectacle has a direct influence on how care and support are offered through maternity services – with even the name of the service being gendered. Despite these challenges, there has been an outpouring of unconditional support within communities, including the offer of peer support and collective learning.

Health care services need to step up and provide the care service users actually need – and deserve – instead of them having to try and fill gaps themselves. The ITEMS project is the most comprehensive piece of research on this topic in the UK and it shows how much change is desperately needed to ensure trans and non-binary birthing people are appropriately supported through pregnancy and childbirth. One of the consistent and urgent findings was for service users to have a sense of dignity and agency throughout their journeys: for their identities to be respected and their experiences understood, to have options that suited their needs, and be provided with the fullest information to make informed choices about their own care. This is evident both in the examples of good experiences that were shared with us, and in the recommendations for personalised and trauma-informed care that have come out of the research.

The guiding principle of the ITEMS project has been about centring community voices and uplifting their needs through robust and ethical research. The work shines a light on people's diverse experiences, and it is informed by both detailed community participation and the guidance of a steering group. The steering group consisted of professionals involved in maternity services across the board as well as trans and non-binary people with lived experience of using these services. What the project firmly demonstrates is that the solution to healthcare inequalities lies in healthcare services and provisions actively listening to their users and committing the necessary will and resources to making change happen at every level of design and delivery. The end result of these combined efforts can be healthcare that is truly inclusive of the range of lived experiences of trans and non-binary people, and is able to support and celebrate every individual's unique journey through pregnancy.

Thank you to everyone who was involved in this unique and very important project.

## Paul Martin OBE

LGBT Foundation CEO

# **Key Findings**

This report includes data from the 'Improving Trans and Non-binary People's Experiences of Maternity Services (ITEMS)' survey, interviews, and recommendations. This survey of trans and non-binary birth parents, the largest of its kind in Europe, has been compared to the Care Quality Commission Maternity Services survey (MSS) to allow comparison of maternity\* care between trans and non-binary birth parents and cis women. Throughout the ITEMS survey, trans and non-binary birth parents reported poor experiences of care. When compared to women in the Care Quality Commission Maternity Services Survey sample, we can see significant inequality of experience, with trans and non-binary birth parents reporting poorer experiences in every question.

The survey found that there were notable inequalities when looking at 'freebirthing', defined in this report as giving birth without ever accessing perinatal care. By its very nature it is hard to know how many people have freebirthed, though figures from the Office for National Statistics showed that 2.4% of women who gave birth in 2020 did so at home (ONS, 2020). This of course includes women who accessed maternity care but chose to give birth at home, or those who gave birth before they could get to their birthing place. 30% of our ITEMS sample reported accessing no NHS or private support during their pregnancy or pregnancies. This percentage rose to 46% when looking at trans and non-binary birth parents of colour. This is an extremely high number considering the risks associated with freebirthing.

Further findings suggest that the motivation to freebirth was likely due to a desire to avoid maternity services rather than not wanting a midwife to be present, with over half (53%) of the respondents who freebirthed agreeing that it would have been helpful to have a midwife there to support them during their pregnancy. Additionally only 20% of those who freebirthed reporting being confident to access Maternity Services if they felt that they needed to. When they did access maternity care, trans and non-binary birth parents reported lower levels of respect and dignity in their care, nearly 3 in 10 trans and non-binary birthing parents said they were not treated with dignity and respect during labour and birth, compared to just 2% of theCare Quality Commission Maternity Services Survey respondents.

ITEMS survey respondents also reported a lack of information around their birthing process, feeding their baby/babies, and potential mental health changes after birth. Trans birth parents were twice as likely to say they did not receive support and encouragement about feeding in comparison to the sample and almost three times more likely to say they were not given the help they needed when contacting a midwifery or health visiting team. Results from the survey free text boxes and from the interviews also suggested that trans and non-binary birth parents often concealed their gender or trans status in order to more safely navigate their care and to avoid transphobia.

The fear of poor quality care was often compounded by other experiences of discrimination such as racism. For some in the sample a fear of poor experiences of care meant that they concealed parts of their identity, for others it was direct experiences of poor care that led to concealment. These ranged from misgendering, non-inclusive language, confusion around family make-up, and incorrect assumptions, to ignorance around the birth parent's medical history, lack of empathy, poor pain management, lack of information around how to feed their baby, and missed diagnoses of tongue tie.

\*The term 'maternity' is used in this report as this is how the NHS refers to services for people accessing perinatal care. This survey has demonstrated multiple areas where trans and non-binary birth parents are receiving inadequate care, before, during and after birth of their babies. Perhaps the most worrying finding is that this is leading to a high proportion of this community avoiding accessing any care altogether.

# **Key Findings Summary**

Reported outcomes for trans and non-binary birth parents in the ITEMS survey were consistently worse across the board when compared to comparable results from the Care Quality Commission (CQC) Maternity Services Survey 2019.

The Survey
of trans and non-binary respondents did not access any NHS or private support during their pregnancy or pregnancies.
of trans and non-binary respondents who freebirthed* would have found it helpful to have a midwife to support them during labour and giving birth
of trans and non-binary respondents who freebirthed were not confident to access maternity services if they needed to.
of trans and non-binary respondents felt they were spoken to in a way which respected their gender all the time during antenatal care.
of trans and non-binary respondents said they were not treated with dignity and respect during labour and birth compared to just 2% of the MSS sample.
Less than half of the trans and non-binary respondents felt that their decisions around feeding their baby were always respected by midwives, compared to 85% of the MSS sample.

#### The Interviews

- Racism and transphobia in perinatal care are experienced as a **lack of action**, **empathy or appropriate care**.
- All 4 of the interviewees had **experiences of concealing their gender** while accessing perinatal care. For each of them, it was not a choice they wanted to make, but one which they felt would improve their care, or would be necessary to get them through their perinatal care.

## \*Freebirthing

Giving birth without ever accessing perinatal care.

# Glossary

There are terms in this report which people may not be familiar with or have a clear understanding of. We are providing a glossary of terms to ensure that terminology used in this report is understood. We recognise that some of these terms may be understood differently by different people and so this glossary provides information on how they are used in this report. The terms used here are not exhaustive and language should always be led by the individual.

Breast/Chest/ Infant Feeding	Inclusive terminology referring to nursing a child. Traditional terminology may induce dysphoria or discomfort for trans and non-binary parents.
Cis	Someone whose gender identity matches with their gender assigned at birth.
Disabled People	Within the social model of disability, the focus is not on the impairment, disability or long-term condition, but instead on the way society excludes people who have impairments like mobility issues, mental health conditions or sensory impairments. As such, the social model says disabled people are disabled by society.
Dysphoria	A feeling of discomfort or distress from the incorrect perception of a trans or non-binary person's gender. This can vary in intensity, and in some instances can lead to significant distress. Someone can feel dysphoria from the way society or others around them treat them, or can experience dysphoria in relation to their own body. If someone is experiencing dysphoria, they may say they feel "dysphoric".
Freebirthing	Giving birth without ever accessing perinatal care.
Frontal/Lower/ Vaginal	Some trans men and non-binary people feel discomfort talking about having a vagina, and so instead opt to use terms like frontal birth instead of vaginal birth.

Intersex	Aa general term used to refer to individuals born with, or who develop naturally in puberty, biological sex characteristics which are not typically male or female. That is, a person with an intersex condition is born with sex chromosomes, external genitalia, or an internal reproductive system that is not considered typical for a male or female. Some of these people may use the term intersex to describe themselves, others may use terms such as Disorders of Sex Development, or Variations in Sex Characteristics. It is important to use the terminology that these people use for themselves when describing them.
Maternity Services	Maternity services are the providers of health services throughout an entire pregnancy, during labour and birth, and after birth for up to six weeks. These services can include monitoring the health and well-being of the parent and baby, health education, and assistance during labour and birth.
MMS Sample /Respondents	This refers to the people who completed the NHS England and Care Quality Commission's Maternity Services Survey 2019.
Misgender	Referring to someone using incorrect gendered terms, using incorrect pronouns or treating them as the incorrect gender.
Perinatal Care	Care provided during pregnancy, before, during and after birth. This also includes care for the baby during their first year.
People of Colour (PoC)	Black people, Asian people, Mixed people and other people who have experienced racialisation and racism.
QTIPOC	Queer, Trans and/or Intersex Person of Colour
Trans	Someone whose gender identity does not match, or does not sit comfortably, with, their gender assigned at birth. This can include non-binary people, though not every non-binary person considers themselves to be trans.
Trans Birthing Parent	A parent who carried a pregnancy and then gave birth, who is trans.

# **Literature Review**

In order to inform this research project, a literature review was carried out at the start of the project. This literature review was designed to identify current knowledge on the barriers to access, the outcomes and the experiences of trans and non-binary birthing parents. Several important themes emerged in this literature review.

For this review, we identified two relevant strands of literature. The first is that which is specific to trans and non-binary birthing parents. For this, we drew primarily on the preexisting Trans Reproduction Literature Database, a regularly-updated list of over 350 articles created jointly by trans reproduction scholars A.J. Lowik (University of British Columbia), Juno Obedin-Malliver (Stanford University) and Ruth Pearce (Trans Learning Partnership). The authors supplemented this with searches on Google Scholar, using the terms "trans", "transgender", and "non-binary" in conjunction with relevant keywords: "pregnancy", "birth", "maternity", "prenatal", "antenatal", "postnatal", "postpartum", "breastfeed", and "lactation".

Much of the literature we found was more experiential or social, looking at the ways in which trans and non-binary people experience pregnancy, and the way they are perceived by society. Additionally, there is a substantial amount of research looking at fertility treatment and fertility preservation, which falls outside the remit of this project.

A consistent theme in the literature was the way in which pregnant trans and non-binary people are often rendered either invisible or unintelligible by others (e.g. Hoffkling et al., 2017; Landau, 2012; Halberstam, 2010). There are several connected reasons for this, which have important consequences for trans and non-binary peoples' access to maternity services, and all aspects of perinatal care. This creates a challenging series of choices for trans and non-binary birth parents. In accessing services, some trans and non-binary birth parents pretend to be cis women (Hoffkling et al., 2017). This is often motivated by a fear of transphobic discrimination or violence if they present as a visibly pregnant person who is also male, and reflects how trans people often navigate healthcare services with caution (Linander et al., 2019). As a strategy, pretending to be cis carries its own stresses, with Hoffkling et al. (2017) identifying it resulted in additional experiences of dysphoria. It did, however, often allow participants to receive more acknowledgement and affirmation as a pregnant person.

A second strategy is 'going stealth' as a man, and concealing pregnancy from the wider world (Hoffkling et al., 2017). The scope of this can vary; some may choose to reveal to trusted healthcare professionals that they are pregnant, while others may choose not to tell any health professionals at all. Where cis women do this, it is often called freebirthing as it is seen as a choice to give birth free from pressures, trauma and hospitals, and instead in an environment in which they feel comfortable. In this way, it is a positive, empowering choice. Whilst it is possible this could be a motivation for some trans and non-binary birthing parents, it is also possible the stigma or perceived stigma of services plays a factor in this. This therefore determined that it was important for our research to look at the proportion of trans men and non-binary people who were freebirthing, and to include their experiences in our research so that we didn't exclude this group. The final possibility for trans and non-binary birth parents is to present as openly trans and/or non-binary and openly pregnant. This can place individuals at increased risk of transphobia from both healthcare practitioners (Falck et al., 2020; MacDonald et al., 2020) and the general public, as seen in instances where trans men with high visibility have become pregnant and given birth (Landau, 2012; Beatie et al., 2020). Where professionals are not prepared to provide appropriate support, this can have extreme consequences for trans and non-binary birth parents and their families. Examples from the literature include a birth parent being reported to child protection services by a midwife simply because he was trans person who experienced pregnancy (MacDonald et al., 2020), and the delivery of a stillborn baby in a US hospital after nurses initially refused to believe that the father was pregnant (Stroumsa et al., 2019). With this in mind it is understandable that some people may elect to conceal their pregnancy, their transness, or both in order to feel safe. Thus in our research, it was important to ask participants questions which related to use of appropriate language and respecting their gender, in order to determine if services could see them as pregnant and a man, or as pregnant and non-binary.

A second theme within the literature was that the language used within maternity services is almost entirely centred on the assumption that anyone accessing care will be a cis woman. In NHS literature there has been significant progress in recognising that not every pregnant person will have a male partner, to reflect the growing number of LGB women having children, or a partner at all, to reflect different family make-up. This shows that changes in the language used around birth and perinatal care are possible. However, the very possibility of trans and non-binary birthing parents is rarely recognised (Bower-Brown and Zadeh, 2020; Riddington, 2020) and is only seen in isolated webpages across the NHS website. This is perhaps a result of the invisibility of trans and non-binary people who become pregnant, and the way that trans and non-binary pregnancy is often sensationalised and seen as a 'one-off' occurrence.

A third important finding was a lack of literature on the service experiences of trans and nonbinary birthing parents. While some literature exists, it often is more focused on their experience of pregnancy and navigating society as a pregnant man or pregnant person. This could be because many research projects on trans and non-binary pregnancy have been international, and the UK is an exception within perinatal care, with an incredibly high rate of women and people who become pregnant accessing some form of care. Equally, there is a bias within the literature to focus on certain aspects of pregnancy, with many resources focusing on breast or chest feeding or fertility, rather than service usage. This could be because fertility and lactation are key sites of unintelligibility, and have therefore drawn more attention. It could also be that these issues have thus far been a priority to trans men and non-binary people, and so other projects have focused on these.

# Methodology

The ITEMS project is a co-produced research project that ran from September 2020 through to April 2021. This project was commissioned by the Health & Wellbeing Alliance (https://www.england.nhs.uk/hwalliance/) which is jointly managed by the Department of Health and Social Care (DHSC), Public Health England (PHE) and NHS England and NHS Improvement. The project was developed as a partnership between trans and non-binary birth parents, midwives, obstetricians and other clinicians with experience of supporting trans birth parents through pregnancy, Dr Ruth Pearce, the Trans Learning Partnership, NHS England's LGBT Health Team, the NHS Maternity Transformation Programme, the Lived Experience Alliance, Disability Rights UK, Gender Inclusive Midwives, the Race Equality Foundation and the National LGBT Partnership. As a co-produced project it was essential that all voices on the steering group were seen as equal, whilst centring the voices of those with lived experience.

The steering group met through the duration of the project in order to provide input into the design of the survey, the design of the focus groups, the suggested outputs, and ways to ensure the outputs continue to have meaning beyond the end of the project. The ITEMS project was a mixed methods study, which collected primarily quantitative data through a survey, and collected qualitative data through semi-structured interviews. Our survey ran from November 9th 2020 through to March 28th 2021, and in that time received 121 eligible responses. This makes it one of the largest studies on trans pregnancy globally, and the largest outside of the US (Moseson et al., 2021; Riggs et al, 2021; Light et al., 2014; Charter et al., 2018; MacDonald et al., 2021). This adds to the growing evidence that there are a number of trans and non-binary people who become pregnant, and that this number appears to be increasing. Since the NHS currently does not consistently record trans or non-binary status in maternity services, or anywhere in its services, this is a unique study of this community's experiences. It is also important to note that there is very little data collected on the number of trans and non-binary people in the UK as a whole. The Government Equalities Office estimate that there are between 200,000 and 500,000 trans people in the UK (GEO, 2018).

We initially began promoting our survey through social media platforms such as Twitter, Facebook and Instagram, and members of the steering group shared the survey within their social circles and professional networks where appropriate. In January 2021 it became evident that engagement with trans people of colour was significantly lower than it should be. Therefore, we incentivised survey responses for people of colour, created additional outreach materials, and took other measures to increase representation within the sample. Asian and Asian British respondents were still under-represented in the final sample. The MSS looks at the experiences of those receiving maternity services. Our ITEMS quantitative survey was largely based on the questions asked in the MSS to allow comparison between responses. This created fields that allowed some comparison, such as quality of care, with some questions edited to respect the varying language used by trans birth parents. Doing this allowed us to compare responses from the trans population answering our survey and the sample. Additionally, there were some questions added to capture the unique experiences of trans birth parents. Many of the original questions were removed to prevent the survey from becoming too long. The survey still only achieved a completion rate of 41%, though this is comparable to the MSS which had a completion rate of 36.5%.

From our initial scoping and group discussions, we decided two areas would benefit from further exploration through gualitative research. We wanted to explore the experiences of trans and non-binary birth parents where they have to either hide their pregnancy or their identity. Due to existing knowledge around the extreme inequalities which cis women of colour face in pregnancy and childbirth, we also wanted to address the effects of race on our participants through a focused study of trans and non-binary birthing parents of colour. We originally planned this research to take the form of focus groups, however nonattendance to these sessions led us to undertake semi-structured interviews. In order to increase responses from people of colour, further consultancy work with LGBT Foundation's Queer, Trans and/or Intersex Person of Colour (QTIPOC) Programme Coordinator was undertaken, and this led to actions to improve engagement. Two independent consultants provided expertise in doing research with people of colour. As queer people of colour themselves, these consultants helped further promote the survey to relevant communities and shape the direction of the interviews. Uptake for the interviews was successful, which may have been because participants felt safer to attend an interview format rather than a focus group.

All personal data has been destroyed, and all anonymised data will be securely stored in line with GDPR and best practice for information governance. Any questions on the storage of data should be directed to research@lgbt.foundation.



# **Survey Findings**

## Demographics

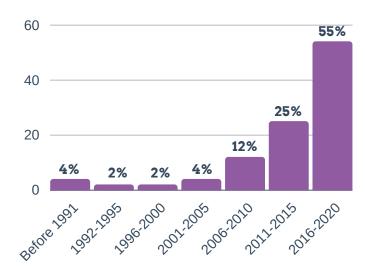
Demographic information was collected at the end of the survey and as a result of nonresponse, the figures reported here may be lower than the number of responses you see in future sections. The title of "n=…" on each chart tells you the total number of answers we had for each question.

## How would you describe your gender? (select all which apply) n=85



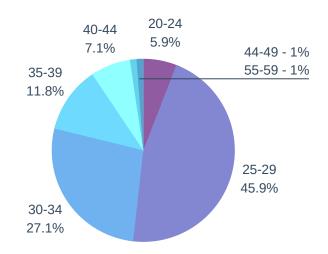
In our survey we wanted to recognise the ways in which individuals can perceive their own gender, and acknowledge that this can be in many ways and can also vary over time. We therefore allowed participants to select multiple options to recognise this. Whilst most participants identified as men or as non-binary, many additional options were also chosen. The majority (57%) of those who identified as non-binary also selected an additional option. Those who selected 'In another way' described their gender in varying ways, including "trans masc" and "I don't need a label".

As this research focuses on pregnancy, it is unsurprising that the sample was predominantly younger, with a mean age of 31. Most participants had given birth within the last 10 years, with the figure more than doubling every 5 years from 2006 onwards. Many participants had given birth more than once, which is why the total number here is higher than the total number of respondents. 3 participants were currently pregnant.

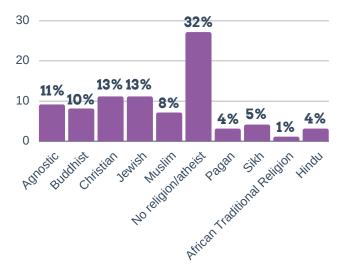


When did you give birth? n=124

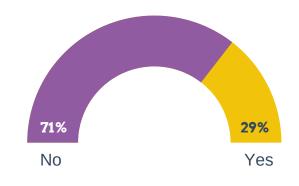
#### At what age did you give birth? n=85



# What is your religion or belief even if you aren't currently practicing? n=85



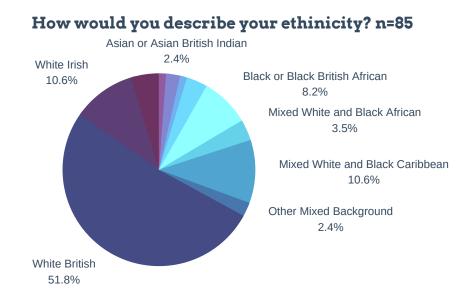
Do you consider yourself to be a disabled person? (This may include impairments, long term conditions, and mental health conditions) n=85



The majority of respondents had no religious belief or were atheist, with the next largest groups being those identifying as Jewish and those identifying as Christian. There was an option to record other beliefs under the category "other please specify", three of the respondents using this category had described themselves as "Pagan" and the fourth had described their belief as "African Traditional Religion", so these were recoded to better reflect their beliefs.

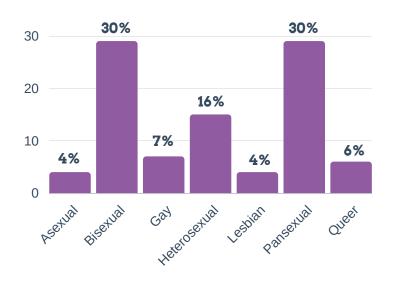
25 of the 85 respondents (29%) reported that they considered themselves to be a disabled person, this is higher than the estimated prevalence in the general population (22%) according to the ONS (2021). When asked an optional question where more detail could be provided, many mentioned mental health issues like depression, anxiety, PTSD and cPTSD (complex PTSD). Chronic pain and joint issues were also commonly reported. Some participants reported being autistic or having ADHD, and of these a few highlighted the complexity of not defining themselves as disabled where others may consider them to be. This highlights the particular issues around how disability is defined. In this project, we have used a social model of disability, where a person is disabled by society failing to meet their needs. White respondents were almost twice as likely to consider themselves disabled compared to people of colour in the survey.

52% of respondents identified as White British, with a total 68% identifying as White. After initial low response rates from people of colour (in January just 8% of the total sample), work was undertaken with the LGBT Foundation's QTIPOC Programme Coordinator and independent consultants who were people of colour. This allowed the work to be



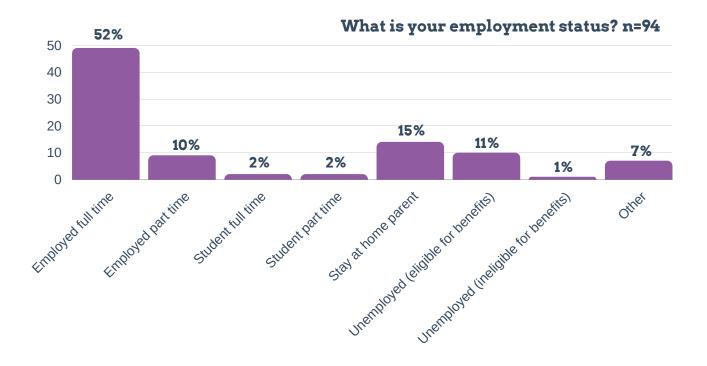
adapted to offer guided and incentivised survey responses for people of colour. This consultancy helped us to increase the response rate from people of colour, though there were still lower response rates from Asian and Asian British people, and no responses from Chinese people. We would recommend involvement of a trans person of colour to deliver this work in future similar projects.

# How would you describe your sexual orientation? (select all which apply) n=85



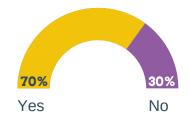
Participants used an array of terms to describe their sexual orientation and could select multiple if they wished. Queer was not listed as an option due to a design error, though 6 respondents wrote this in, and so their responses were recoded. All lesbians chose a gender other than woman. It is not surprising to see a high proportion of LGBQ identified respondents as this has been widely observed in other research on trans communities also (Scottish Trans Alliance, 2012).

Employment status varied across the sample, with most saying they were in full time employment. Based on feedback from the steering group we added an employment option for "stay at home parent", which proved to be a popular choice. It was often chosen in conjunction with other options, such as "employed part time". Some people who selected "stay at home parent" also added further information within the "other" option. Of those that chose other, the most common response was self-employed or freelance work.



## Accessing Care

30% of respondents did not access NHS or private support during their pregnancy or pregnancies. This is sometimes called free birthing. By its very nature it is hard to know how many people have free-birthed, though figures from the Office for National Statistics showed that 2.1% of women who gave birth did so at home (ONS, 2019). This of course includes women who accessed maternity care but chose to give birth at home, or those who gave birth before they could get to their birthing place. Even without these qualifiers, the occurrence of free birthing within our survey sample is 15 times higher than the proportion of cis women who free birth. The potential reasons behind such high proportions of free-birthing among trans men and non-binary people were explored through the survey and the findings reported later.



Did you get support from NHS or private midwives during your pregnancy/ pregnancies? n=117

The levels of risk in freebirthing are unknown, due to it happening outside of healthcare systems, though researchers have suggested that risks may be similar to Births Before Arrival - births that happen away from a hospital or birth centre setting, prior to the arrival of a midwife. The risks associated with BBAs are bloodloss for the birthing parent, and failure to maintain body temperature for the baby (Feeley & Thomson, 2016). BBAs are often unplanned as opposed to freebirths, which often are more thought out, so it is possible steps are taken to reduce risk in free-birthing situations. However, guidance from the World Health Organisation recommends that all pregnant people should receive skilled care during their pregnancy, childbirth and recovery.

Within this sample, we found that a higher proportion of people of colour reported freebirthing (46%, compared to 28% of white people). This is concerning given the 2020 MMBRACE report which found that Black women were over 4 times more likely, and Asian women twice as likely, to die in childbirth compared to white women (Knight et al., 2020). This finding largely relates to historic and contemporary medical racism (Jeraj, 2021) which will also affect trans and non-binary birthing parents of colour, and is something we touch upon in some of the stories the case studies section.

In the survey participants were also asked if they accessed the following forms of care: antenatal care, labour and birth care, and postnatal care. This showed that fewer people in our sample accessed post-natal care than antenatal care, and labour and birth care. The following sections discuss the overall experiences people had when accessing care.

What kind of care people accessed



LGBT Foundation 2022

## **Antenatal** Care

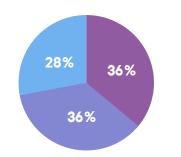
We asked five survey questions on antenatal care and also provided a free text box at the end of the section for any experiences or perceptions which participants felt were not captured by the survey. These questions covered interactions with midwives, appropriate language and care, and involvement in care.

"With most of the care I received, my identity wasn't questioned, but the way the midwives would interact with me was very awkward. It was as if they felt anxious talking about pregnancy and birth around me despite that fact that I was totally fine with it as long as they didn't misgender me".

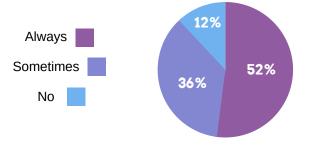
Agender person, Pansexual, White British

These questions were chosen based on the scoping literature review and the discussions within the steering group. Each of the survey questions taken or adapted from the MSS sample could be answered in the same way to create comparable data. This has allowed us to demonstrate that reported outcomes for trans and non-binary birth parents were consistently worse across the board when compared to the MSS sample.

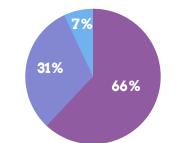
## A1. During your antenatal check-ups, of your medical history? n=70



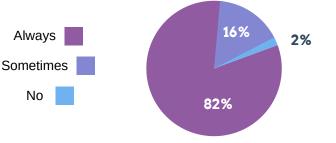
2019 Maternity Services Survey: B8 did your midwives appear to be aware During your antenatal check-ups, did your midwives appear to be aware of your medical history? n=16752



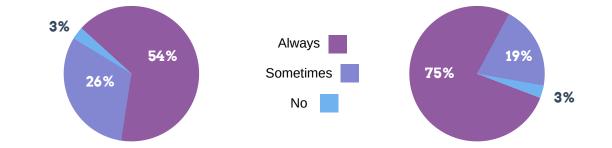
### A2. Thinking about your antenatal care, were you involved in decisions about your care? n=71



#### 2019 Maternity Services Survey: B17 Thinking about your antenatal care, were you involved in decisions about your care? n=16629

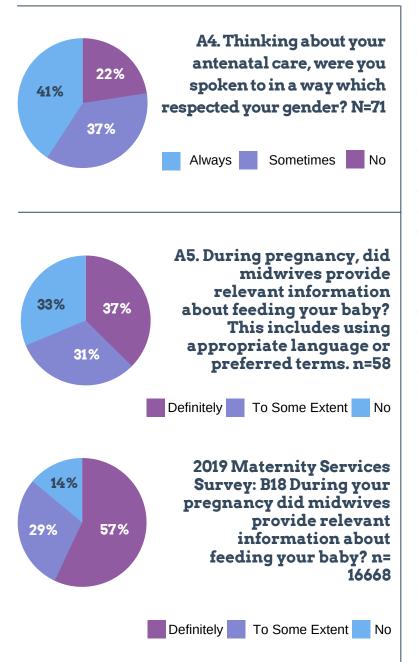


A3. During your pregnancy, if you contacted a midwifery team, were you given the help you needed? n=58 2019 Maternity Services Survey: B15 During your pregnancy, if you contacted a midwifery team, were you given the help you needed? n=14207



Looking at questions A2 and A3 together, we can see that although neither question explicitly explores instances or sites of direct transphobia, there is an inequality in experience. Where 88% of the MSS sample said their midwives were always or sometimes aware of their medical history, only 72% of trans and non-binary birth parents said the same. Trans and non-binary birth parents were also more likely to say midwives only knew their medical history sometimes (28% compared to 12% of the MSS sample), and were more than twice as likely to say their midwives were not aware of their medical history compared to the MSS sample. A lack of awareness of a birth parent's medical history can have serious and possibly life-threatening consequences for the birth parent and for the baby.

Trans and non-binary birth parents were less likely to feel involved in decisions about their care when compared to the MSS sample, suggesting that their care may be less individualised. This is especially important considering number of people who reported being disabled or living with a long-term condition within this sample, as their healthcare needs may be less likely to be met if they are not involved in decisions about their care.



Only 41% of trans and non-binary birth parents felt they were spoken to in a way which respected their gender all the time. This means that over half of the sample experienced misgendering or lack of respect for their gender during their antenatal care. Those who identified exclusively as non-binary were much less likely to say that they were always spoken to in a way which respected their gender (28%).

Trans and non-binary birth parents were twice as likely to answer no when asked whether they had received relevant information on feeding their baby (32% compared to 14%). Only 37% said they definitely received relevant information on feeding their baby compared to 57% of the Maternity Services Sample. Non-binary people were more likely to say they did not receive relevant information, with 43% saying no, and 36% saying yes to some extent. This means only about one fifth of non-binary birth parents are definitely provided with relevant information on feeding their baby.

"I felt there was no framework of language that was inclusive of people who do not identify within the gender binary so it was consistently a triggering experience"

non-binary/no gender, queer, Black or Black British African, disabled. In questions A4 and A5, the use of language is important, and the results show that high numbers of trans and non-binary birth parents report being spoken to in a way that does not respect their gender or their bodies. Many in this group also report that midwives failed to provide relevant information about feeding their babies, this could potentially be attributed to a lack of relevant resources and content, as well as a need for more appropriate language. This is concerning as it suggests potential harm for the birthing parent through disrespectful interaction, and to the baby where there are unresolved questions about feeding. This will be touched on in the postnatal care section, as respondents also reported misinformation around feeding on demand, unrecognised tongue ties, and a lack of advice on latching and preventing pain to the nipples during feeding.

The lack of appropriate and respectful language used about trans and non-binary birthing parents may contribute to their experiences of dysphoria. It is also important to consider that some trans people going through pregnancy may have had to pause, delay, reverse, or hide aspects of their transition. This can make experiencing dysphoria even more challenging. Dysphoria can be greatly distressing and can lead to periods of depression, anxiety, self-neglect and low self-esteem. The impact of this is particularly relevant because evidence shows that depression, anxiety, and stress during pregnancy can result in miscarriage, low baby birth weight, and consequences for infant development (Schetter and Tanner, 2012). The baby's future development can also be affected, with findings showing that the infant of a depressed parent is at risk for developing insecure attachment, negative affect and dysregulated attention and arousal amongst other issues (Schetter, 2012).

## Labour & Birth Care

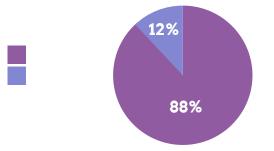
While the responses to question L1 are similar across the two samples, fewer trans birth parents reported being given appropriate advice when contacting a midwife or hospital at the start of their labour (85% compared to 88% of the sample). Notably, this disparity increased further when looking at the experiences of disabled people or people living with a long-term condition, where only 81% said they were given appropriate advice. People of colour also reported lower levels of appropriate advice at 82%.

Yes No

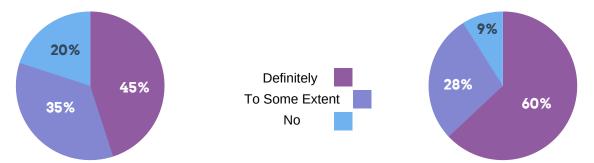
L1. At the start of your labour, did you feel that you were given appropriate advice and support when you contacted a midwife or the hospital? N=62

> 15% 85%

2019 Maternity Services Survey: C1 At the start of your labour, did you feel that you were given appropriate advice and support when you contacted a midwife or the hospital? N=12131



L2. During your labour, did staff help to create a more comfortable atmosphere for you in a way you wanted? This includes the type of ward you were on, the imagery inside hospitals and whether they reflected you or not. N=60 2019 Maternity Services Survey: C2 During your labour, did staff help to create a more comfortable atmosphere for you in a way you wanted? N=14130



Trans birth parents were over twice as likely to feel there was not an effort to create a comfortable atmosphere for their birth environment compared to the MSS sample (20% compared to 9%), and less likely to feel like their birth environment was definitely improved in a way they wanted (45% compared to 63%). After this question, there was a space for further comments relating to this, and some indicative examples follow below. Some participants described negative experiences of care (or the absence of care), and other participants shared positive stories describing how staff helped to create a more comfortable atmosphere.

These quotes illustrate instances where midwives, doctors and medical staff made significant efforts to address individual needs. However, notably only men mentioned being given a private room, while some non-binary respondents discussed how they were still placed in a room with women, which in some created dysphoria or discomfort.

An important lesson from this data is that some trans and non-binary birthing parents benefit greatly from being offered a private space, although each birth parent will have different preferences. Some may not wish to be singled out, or to be at risk of being identified as trans by others. As such there should be no requirement for trans and non-binary birth parents to be treated differently, and instead there should be a focus on choice and individualised care. I didn't have to go to a ward full of women after giving birth, I was actually provided with a private room for me and baby which was very helpful and accommodating for me and my gender identity"

#### Man, gay, White British

"Felt like I was often being judged and it was an overall very awkward situation, in an already uncomfortable experience. Some staff even treated me as if I wasn't there to experience actual childbirth, and instead were just waiting for the child to arrive. It didn't feel like an inclusive situation - it was all about the child, rather than my experiences/how I was feeling."

Non-binary, Black or Black British African, disabled.

#### Non-binary, White British, disabled.

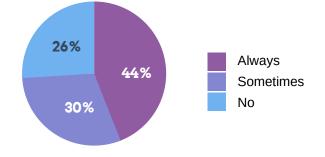
"I had to be induced after losing my waters at home. We brought all of the things we would have had at the home birth to hospital which made the delivery room much better for me as I have PTSD around hospital environments."

"I was on an all-female maternity triage ward, on a bay with four other parents. I didn't feel that this experience particularly reflected me as a parent and I was uncomfortable with having to stay in a gendered space like that during labour until I was able to be moved to a delivery suite."

#### Non-binary trans-masculine, White British

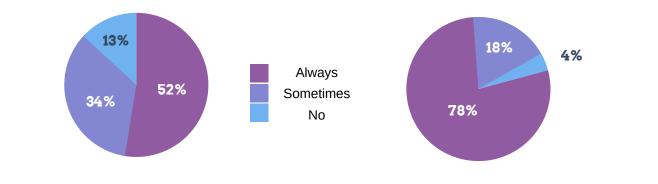
An additional question around respecting gender was added to the ITEMS survey since this has significant impact on the atmosphere during labour for trans birth parents. Over 1 on 4 trans birth parents said that during labour and birth they were not spoken to in a way which respected their gender and a further 30% said they were only spoken to with respect only sometimes.

L4. Thinking about your care during labour and birth, were you spoken to in a way which respected your gender? N=61



L5. Thinking about your care during labour and birth, were you involved in Thinking about your care during decisions about your care? N=61

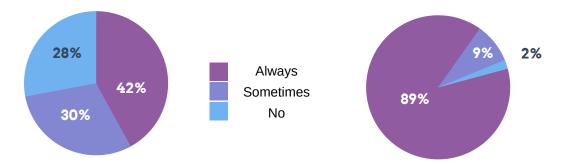
2019 Maternity Services Survey: C19 labour and birth, were you involved in decisions about your care? n=16496



In the MSS sample 4% less people reported being involved in decisions during labour and birth compared to during antenatal care. Among the sample of trans and non-binary parents this reduction was larger, with 13% less people reporting involvement in decisions during labour and birth compared to during antenatal care.

L6. Thinking about your care during labour and birth, were you treated with respect and dignity? This includes using the language you use for your body, referring to your gender correctly and using the right pronouns. N=61

2019 Maternity Services Survey: C20 Thinking about your care during labour and birth, were you treated with respect and dignity? n=16930



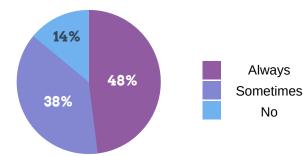
This question has the greatest difference between the ITEMS sample and the MSS sample, with only 43% of trans and non-binary birth parents saying they were always treated with dignity and respect in comparison to 89% of the MSS sample. 28% of trans and non-binary birthing parents said they were not treated with dignity and respect during labour and birth compared to just 2% of the MSS respondents.

The NHS Long Term Plan and the accompanying guidance, Universal Personalised Care, made commitments to delivering choice and personalisation in maternity services. (NHS, 2021) This guidance compliments the recommendations in the national maternity review, Better Births. The findings from the ITEMS survey suggest these commitments are not being met for trans and non-binary birth parents.

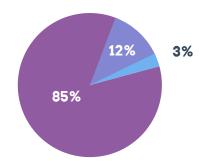
## **Postnatal Care**

Less than half of trans birth parents in the sample felt their decisions around feeding their baby were always respected by midwives, compared to 85% of the MSS sample. Care should always be non-judgmental and individualised, and this question shows that many did not receive this standard of care.

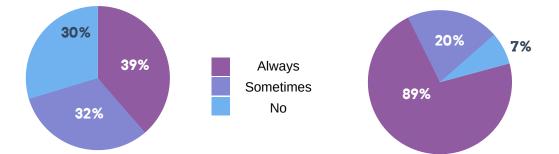
P1. Were your decisions about how you wanted to feed your baby respected by midwives? This includes using appropriate language or preferred terms. n=58



2019 Maternity Services Survey: E2 Were your decisions about how you wanted to feed your baby respected by midwives? n=16972

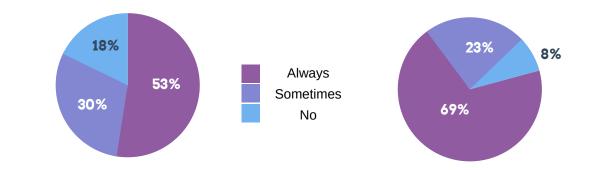


P2. Did you feel that midwives and other health professionals took your personal circumstances into account when giving advice about feeding your baby? N=57 2019 Maternity Services Survey: E3 Did you feel that midwives and other health professionals took your personal circumstances into account when giving advice about feeding your baby? n=15610



30% of trans and non-binary birth parents said 'no' when asked if their personal circumstances were taken into account when health professionals provided information about feeding their baby, this was over 4 times more than the proportion of those in the MSS sample answering 'no' to this question. Additionally, only 39% of the trans and non-binary birth parents answered 'yes, always' to this question, compared to 72% of the MSS sample.

P3. Did you feel that midwives and other health professionals gave you active support and encouragement about feeding your baby? n=57 2019 Maternity Services Survey: E4 Did you feel that midwives gave you active support and encouragement about feeding your baby? n=16199



An assumption about chest feeding can lead to a lack of appropriate support and encouragement. Trans and nonbinary birth parents were twice as likely to say they did not receive support and encouragement about feeding in comparison to the MSS sample (17% compared to 8%).

"I wanted to use an SNS [supplemental nursing system] but struggled and had to give up. Also my baby's tongue tie was not treated early because it was assumed I wouldn't chest feed at all, when in fact I could have"

Man, Gay, White British.

## P4. If you contacted a midwifery or the help you needed? n=52

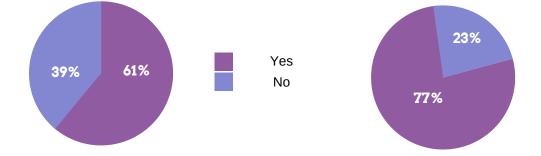
2019 Maternity Services Survey: F3 If you health visiting team were you given contacted a midwifery or health visiting team were you given the help you needed? n=11696



Trans and non-binary birth parents were almost three times more likely to say they were not given the help they needed when contacting a midwifery or health visiting team, and were over twice as likely to say that they only got the help they needed some of the time.

P5. Did the midwife or midwifery team that you saw appear to be aware of the medical history of you (i.e. being on testosterone, top surgery, lower surgery) and your baby? n=57

2019 Maternity Services Survey: F7 Did the midwife or midwifery team that you saw appear to be aware of the medical history of you and your baby? n=15504



Almost 40% of trans and non-binary birth parents said their midwives or midwifery team were not aware of their medical history or the medical history of their baby. Many of the comments that participants left in the survey's free text box for postnatal care related to dysphoria.

"It was traumatic and very dismissive of my experiences of dysphoria as well as mental health struggles"

> Non-binary/no gender, queer, Black or Black British African, disabled.

"When I suffered from some depression after having my baby a midwife suggested it was because 'deep down I knew I didn't want to transition anymore' this was deeply unhelpful and made me feel even worse".

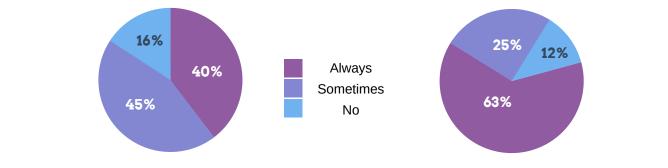
#### Man, Gay, White British

Additionally, there were multiple reports of situations where tongue-ties were missed, which can make breast or chest feeding more challenging and painful (NHS England, 2020b). It is not uncommon for health issues to be wrongly attributed to someone's status as a trans person, a phenomenon referred to as "trans broken arm syndrome". This has been named for experiences in which trans people with health concerns like a broken arm, something

unrelated to their status as a trans person, are asked by medical professionals if it relates to their dysphoria (Payton, 2015; Pearce, 2018). In this instance, it is possible that tongue-ties are under-diagnosed due to issues with breast or chest feeding being attributed to the parent's dysphoria or trans status, rather than the baby's tongue-tie. Further work should be done to determine if tongue-ties are more likely to be missed amongst trans birth parents, and midwives and health visitors must make efforts to approach situations with comprehensive knowledge and without bias.

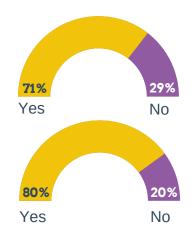
## P6. Were you given information about any changes you might experience to your mental health after having your baby? n=58

### 2019 Maternity Services Survey: F13 Were you given information about any changes you might experience to your mental health after having your baby? n=16362



P7. Were you told who you could contact if you needed advice about any changes you might experience to your mental health after the birth? n=58

2019 Maternity Services Survey: F14 Were you told who you could contact if you needed advice about any changes you might experience to your mental health after the birth? n=14829



P6 and P7 both demonstrate that trans and non-binary birth parents experience unequal support in post-natal mental health. We can see that trans and non-binary parents were less likely to have been given information about potential mental health changes after giving birth than the MSS sample. They were also less likely to be told who to contact for advice about any mental health changes after birth when compared to the sample. The inequality between the groups was further seen in comments left in the survey's free text boxes.

"I can't praise my mental health midwife enough (despite the fact that she frequently misgendered me), but the rest of the team didn't really acknowledge or take into account my transgender medical history."

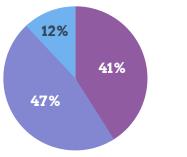
"Overall good but didn't fully support me with my mental health. Lack of follow up and information given"

Non-binary trans-masculine, White British.

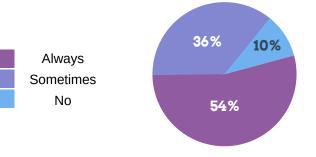
Non-binary, Asian or Asian British Indian, disabled. The first quote demonstrates that trans and non-binary birth parents often have to deal with misgendering when accessing services. Misgendering when accessing healthcare is often seen as an inevitability by trans and non-binary people, though its potential impact should not be downplayed, especially given importance of gender affirmation in relation to mental health (Vega & Temkin, 2018). The second quote further demonstrates the ways in which mental health support offered to trans and non-binary birth parents can be seen as good, but still insufficient. As previously discussed, mental health issues can impact not only the parent, but also the health and development of the baby.

These quotes also suggest that trans people may have come to expect a lower standard of care from health services, potentially due to historic poor experiences. An expectation of substandard care may be contributing to the high number of trans birthing parents avoiding accessing maternity services.

#### P8. Were you given information about your own physical recovery after the birth? n=58



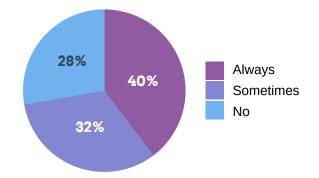
## 2019 Maternity Services Survey: F15 Were you given information about your own physical recovery after the birth? n=16343



Only 41% trans and non-binary birth parents were confident that they had received sufficient information about their own physical recovery, compared to 54% of the sample.

When comparing the questions which looked at whether people were spoken to in a way which respected their gender at different stages in the pregnancy process, proportions were similarly low across the different areas of care. The proportion of respondents saying they were not spoken to in a way that respected their gender was highest during postnatal care (27%), compared to antenatal care (22%) and labour and birth care (26%). Only 40% of trans and non-binary birth parents felt that their gender was always respected during postnatal care.

#### P9. Thinking about your postnatal care, were you spoken to in a way which respected your gender? n=58

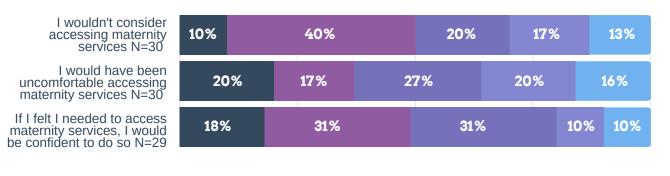


## Freebirthing

On the whole, we can see that desire to freebirth was quite high for participants who ended up doing so, with almost 65% answering agree to some degree. However fewer people agreed that free-birthing gave them the experience they wanted (52%), with only 43% agreeing that they would freebirth again. 30% of those who freebirthed agreed that they wouldn't consider accessing Maternity Services, almost 40% said they would have been uncomfortable accessing Maternity Services, and only 20% of those who freebirthed reporting being confident to access maternity services if they felt that they needed to.

This is important as it suggests a large motivator for freebirthing was discomfort in accessing Maternity Services. As previously discussed, the levels of risk in freebirthing are unknown, due to it happening outside of healthcare systems, though suggestions that risks may be similar to Births Before Arrival mean that associated risks may include bloodloss for the birthing parent, and failure to maintain body temperature for the baby (Feeley & Thomson, 2016). It is quite a stark finding that 80% of trans and non-binary birth parents who freebirthed were not confident to access maternity services if they needed to.

# On a scale of 1 to 5, where 1 is strongly disagree and 5 is strongly agree, how much do you agree with the following statements?



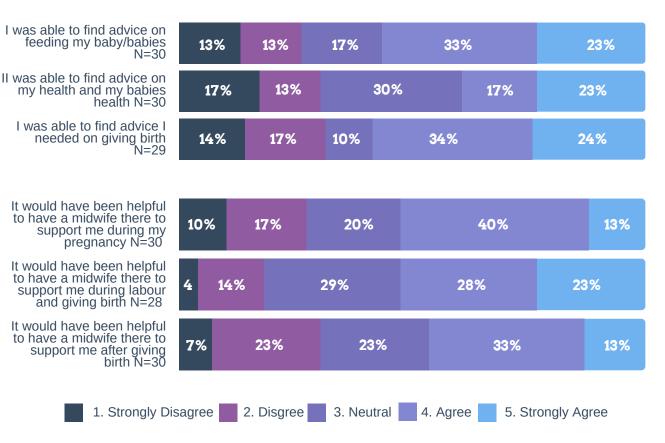
1. Strongly Disagree 2. Disgree 3. Neutral 4. Agree 5. Strongly Agree

Only 40% of freebirthing respondents agreed that they were able to find advice on their health and their babies health. Large proportions of trans and non-binary birth parents who freebirthed felt they could have had more information around their health and their baby/babies' health (60%), around feeding their baby/babies (43%), and on giving birth (32%).

Roughly half of the respondents who freebirthed agreed that it would have been helpful to have a midwife there to support them during their pregnancy (53%), their labour and birth (53%), and in aftercare (47%. Additionally, only 20% of people in the ITEMS sample reported feeling comfortable accessing maternity services. These findings suggest that freebirthing in this population may be largely motivated by a desire to avoid maternity services, rather than not wanting a midwife present. Numbers in fact suggested more than half of trans and non-binary birth parents felt they would have benefited from the presence of a midwife during labour and afterwards.



# On a scale of 1 to 5, where 1 is strongly disagree and 5 is strongly agree, how much do you agree with the following statements?



Further research could focus on whether reluctance to access the support of a midwife is associated with discomfort around maternity services, or more specifically the hospitalbased environment. There may be a lack of understanding around the services available to trans birth parents, such as the opportunity for a home birth. There is clearly significant outreach work to be done to promote Maternity Services among trans communities. However, making these services safe for trans people first is paramount.

Lastly, it is important to consider that some populations were more likely to freebirth. People of colour were more likely to freebirth (46%) than the general sample (30%), and the rate of freebirthing in the total sample is much higher than expected when comparing to general samples within the UK (2.1%) (ONS, 2020). This highlights that improving interactions with trans people of colour is particularly important for Maternity Services, and that efforts made to address transphobia must be intersectional.

# **Case Study Findings**

Initially there were plans to hold focus groups and one-to-one interviews as part of the research project. However, one-to-one interviews had better uptake with participants recruited through the survey. Interviews were focused around two themes that emerged from the survey findings; the first being racism and transphobia in perinatal care, and the second being concealing one's pregnancy or gender.

The research team brought in two queer people of colour as independent research consultants to help design interview questions and embed anti-racist principles into the interview process.

There are some discussions in this section that readers may find challenging, and in particular we wanted to include content warnings for racism, transphobia, discussion of injury, and minimising of pain and harm by medical professionals.

We used the following question guide before diverging into theme specific questions. We took a semi-structured approach, meaning these questions acted more as a guide for the facilitators.

How would you describe your experiences of talking to healthcare workers about pregnancy?

• How do you think it should have been?

Were there any trans-affirming interactions with a healthcare worker(s)?

- Why?
- What could other providers do to learn from them?

# Were there any challenging/frustrating/bad interactions with a healthcare worker(s) in relation to your gender?

- Why?
- What do you think caused this to happen? Could this have been avoided?
- If so, how?
- Was this resolved? If not, could it have been?

continues on next page

#### In an ideal world, how would trans men and non-binary people who are pregnant access support they need in:

- Pregnancy & antenatal care
- Labour and birth
- Postnatal care?

# Is there any additional support which trans men and non-binary birth parents may find helpful in navigating pregnancy, labour, birth and postnatal care?

- Social support groups to connect trans and non-binary birth parents
- More resources (i.e. on babies health if you cannot chest-feed)
- Support for dysphoria

#### If you could snap your fingers and make one change to maternity services right now to improve the experience of trans birth parents, what would that be?

#### Theme 1: Racism and transphobia in perinatal settings. We've spoken a bit about possible experiences of transphobia, so now I'd like to move on to look at possible experiences of racism and how they interacted during your pregnancy.

Theme 2: Under the radar. We've spoken a lot about services more abstractly, so now I'd like to explore a bit more about the way you all accessed services. In the survey each of you mentioned that you chose not to come out during your pregnancy. I'd like to explore why that was, and what impact you think it made for you and your baby.

As we talk about the case studies we will first do a small introduction, though there will be details removed to protect confidentiality.

## Amrit's Story

Amrit (they/them or he/him) is an Indian British, non-binary person, who gave birth a few years ago. They weren't comfortable being out as non-binary during their pregnancy, and so often concealed this in order to access services without fear of discrimination. This often meant that he had to find information online. Below they outline some of their frustrations and the ways in which he often struggled to find relevant information.

"I found a lot of my support online, from other groups and stuff. So there being things online that talk about chest feeding, and your options with feeding in a way which isn't hyper-feminine... Or hyper masculine either, I don't want it to go the other way where we end up with breast feeding for women and its all soft and pink, and chest feeding for men where it is then all like blue and tough. I don't think any trans people want that to be honest... Like, I just want information on feeding my baby, in a way which doesn't assume my role based on my gender, right? Because there are so many different kinds of families now too, there are trans and non-binary birth parents like me, then you can have two cis women go through IVF, you can have a couple who use a surrogate, you can have a single cis man who lost his partner in childbirth... Like all of these people will need information on how to feed their baby, and some of it will overlap as well, but still assuming that there will always be one mum and one dad raising that baby holds us back."

Amrit's story demonstrates that the experiences of trans people often overlap with other communities who may receive inadequate care, and that trans-inclusive care can improve the experiences of these other communities too. Much of Amrit's experience here reflects frustrations that people in the survey reported, in particular their concern that information created for trans men and non-binary people may replicate binary stereotypes. They point out that there are more and more different kinds of families, and therefore binary gender roles in pregnancy and childcare don't just exclude trans birth parents, but also same-sex couples, single parents, parents who use surrogates and others.

Amrit goes on to explain how their own journey to starting a family was complex, and the ways in which expectations placed upon him by his family interacted with his queerness.

"It took me about a year of thinking about it before I knew [getting pregnant] was something I could do. I always wanted a family... and I think there was an expectation in my family that I would marry a good Indian man and have lots of kids... which I tried to fight for so long as a queer person that it then took me some time to come around to the fact that I actually wanted to have a baby with my partner. And so it's just a lot of effort that others don't have to go through, and then I have to risk invasive questions or bad care because they've never seen someone like me before?"

Ultimately, Amrit focussed on what they wanted, which was a family. Though the complications associated with this experience, such as difficulty with being accepted by family, remain. South Asian trans people often report higher levels of rejection and prejudice from their families, and can also face specific barriers unique to being trans and South Asian (Khatun, 2018). Additionally, there was a specific incident of racism and transphobia that Amrit experienced during labour that demonstrates how different forms of discrimination overlap and interact.

"One of the midwives who saw me said that she was surprised I didn't have any family with me. I only had my partner just because my family aren't all there yet with me being trans, and I thought this would confuse them more, especially with me not being out at the hospital too. When I said I only really wanted my partner, she said something like "oh… you know normally I see all the women in the family around when someone is giving birth, and usually you'll have your mum with you…". She then went on to tell me about one time she was looking after an Indian lady who also had a home birth and how she'd never seen so many women there during a birth, and it was just really awkward. Like even when she said the first bit, it just felt like it was a really loaded term about expecting all my family to be there because I'm Indian, and then her immediately telling that story afterwards just was like the nail in the coffin."

Amrit's experience in this moment demonstrates how racism and micoraggressions can occur during care. They explained that it was probably just the midwife trying to make small talk, but that the midwife's assumptions made them feel really uncomfortable. Amrit had also wondered if he would have experienced that racism if he had been out as trans. They suggested that perhaps the midwife would then have been preoccupied with them being trans and not focussed on them being Indian. As Amrit had concealed his gender to avoid transphobia, he wasn't able to address the inappropriate comments about who attended the birth. In this scenario, Amrit went to great efforts to avoid discrimination in one way, only to experience it in another.

## T's Story

T (they/them) is a Black African person who does not have a gender identity. In their interview they described experiencing severe medical racism, and a level of hostility and irritation whenever they would correct people on their pronouns, to the extent where they felt their care was compromised. Their concerns around the poorer quality of care they receive as a person of colour and a gender non-conforming person were so extreme that during birth they chose not to have any form of painkillers in order to be more cognisant and be able to advocate for themself.

"I chose to do that because I just wanted to be as present as possible because I didn't trust that if I was kind of not sober in any way that I'd be able to advocate for myself and I really didn't feel very safe in most of these experiences. So I just thought you know if I'm in labour I'd rather experience the pain and know that I'm fully present for it than have pain killers and be disoriented and not able to advocate for myself. I think if I didn't have to think about those things then I might have considered taking painkillers but because I did, I didn't want any painkillers.

I really didn't feel very safe and I just thought I didn't want any other excuse for my safety to be compromised. So I would rather deal with the pain of not having any painkillers or anything that could potentially like affect my ability to be cognisant than to be not experiencing pain. But then I also needed to remember or really understand or see the ways in which my safety might be compromised. It was a very anxiety inducing position for me but I think it was the only decision I could make at the time that would have felt safe for me because based on all the experiences I was having prior to my birth I just didn't feel like I was gonna be held in the way I needed to be."

They described a severe post-partum haemorrhage where they lost a significant amount of blood as the most serious failing in their care. The whole experience was, in their own words, violent and harmful and only made worse by them being misgendered throughout the process.

"I ended up having a post-partum haemorrhage. I lost like almost 12 litres of blood and had to have transfusions. I was passing out from losing so much blood because they had essentially left a little bit of the placenta in my uterus somewhere and when it dislodged it just you know created a hole for it to bleed. But that whole experience was very violent and very harmful, and quite traumatizing because uhh first of all it was all gend.... There is no consideration for any gender identity outside of woman because it was somebody that gave birth, it was quite stressful and I was in quite a lot of pain and was just trying to get a bit more empathy and support than what I was being offered..."

Something T outlines is the way in which many of their experiences relate to medical racism. In particular they felt that their experience of pain during and after their haemorrhage was minimised by others due to them being black. The quote below outlines this.

"I had two doctors who were just telling me to not be so vocal about my pain actually. Like literally telling me like why am I making noise and those kinds of things are so problematic. Like so damaging and I was shocked to be having those experiences but it does happen and I'm kind of sure that my race played a big part in that reality."

During their initial recovery they wanted support from their postnatal team, but ultimately were not able to get the care they needed. They even tried minimising their own identity by not correcting birth workers on their gender and pronouns for a time in order to see if this improved their care, but still ultimately felt they did not get the level of care they needed.

"I think first of all I remember there was already a correction about pronouns I use and about how I don't identify as a woman and I just think it makes people switch off. Like they are not really interested in engaging with you so much, so I noticed that happened every time I would do that. So I stopped really saying it because though I just thought maybe that will help yeah like with my situation or maybe they'd be more interested in offering me some sort of support as opposed to try and rush me out of the door and saying "oh the baby is ok you don't need to be here"."

Outside of T's experience with birthing and postnatal care, they often tried to keep their healthcare interaction to a minimum. They explain in the quote below that this was often to avoid a disorienting experience of being misgendered and having assumptions made about them.

"I didn't really go to any classes or yeah I didn't really attend any antenatal anything like that, it was just too... It was just too disorienting. I don't think I really had language for it at the time but it was... yeah. If I reflect back on the experience I think I would have realised I was avoiding most of them as I Just didn't want to have deal with the misgendering and the assumptions people were making based on my presentation"

T's experience describes the ways in which racism can endanger the lives of black people and people of colour. For T, the racism and transphobia they experienced created an environment which felt hostile, uncaring and violent and meant their needs were not met. Similarly to Amrit, they tried to conceal their gender at one point in order to receive better care, however they still experienced barriers and discrimination.

#### **Alex's Story**

Alex (they/them) is a queer, non-binary White British person who gave birth around 3 years ago. Their partner is a cis woman, and when Alex became pregnant, it was through accessing a fertility clinic. They are currently accessing fertility treatment, with their partner being the one who will become pregnant this time. Their GP and the fertility clinic did not know they were non-binary.

"We went through a fertility clinic. We're actually in the process of trying to do the same again but with my partner carrying for us. Its long, it's a long process. I mean we don't seem to be getting anywhere fast, and it's all in all a bit stressful. So I guess our first access to kind of the healthcare system around fertility and birth was through umm going to my GP, asking what are options were. I have never informed my GP of being trans."

They described some discomfort with the process of accessing the fertility clinic. The whole process was cisnormative and heteronormative; their partner, who is a cis woman, was repeatedly asked about her sperm levels and invited for genetic screening tests, despite not providing eggs or sperm for the pregnancy. Alex described some other difficulties below.

We used donor sperm from a sperm bank because we didn't know anyone at the time, that was all a bit of like a headfuck because... we kind of didn't want to, it all felt slightly eugenic like choosing sperm based on certain characteristics. Anyway we got through that and I was lucky because we conceived first time through IUI [intrauterine insemination ]."

Alex intentionally accessed the fewest possible services, as they were uncomfortable with the highly gendered nature of perinatal care. They felt that their queerness and sexuality were not recognised or taken into account. They did attend one half-day antenatal class, and found the experience to be highly gendered. Couples were split into mums and dads, something which didn't fit with their family. Below they describe a moment where gender norms were reinforced with another attendee in the room.

"There's also this moment where, I don't know what they call it, supplemental feeding tubes that like... little tubes that people like attach to their chest and uhhh I guess like put milk through them. So I think it's used to either try and stimulate breast or chest feeding or just give people the experience of doing that if they want with a baby, and this bloke in the room asked about "so can I use that?". And the two, I think it was two midwives, it might have been a midwife and a healthcare worker, they just found this hilarious that this man would maybe want to do that. They were like there "Oh no! That's really funny! They're for adoptive mothers, that's used by adoptive mothers" so there wasn't even space for like any kind of I guess like different sorts of masculinity in that room! Umm... and so that's what I mean when there's no space, it's like everything is so rigid in terms of gender structures and sexuality structures so there's no space for any movement within them, let alone one which fucks with the gender binary."

This experience reinforced Alex's perception that perinatal care is not a safe place to challenge gendered expectations, whether this is through sexuality, gender non-conformity, or through being trans. This can cause trans people to feel as though they have to conceal their gender when accessing care. As discussed in Amrit's story, there are many instances where trans affirming care actually stands to benefit all people, and the man in this example is one person who could perhaps have had a better experience, and a closer connection with his child, had he been able to receive better care.

Alex gave birth at home, with this being done intentionally to avoid accessing care from a hospital. This was not entirely linked to them being trans, but it was a factor in their decision. This shows that decisions that may be easy for many people, like whether to access healthcare, can be challenging for trans people.

"I gave birth at home, that was deliberate decision so which I guess was partly related to being trans, partly just related to not liking hospitals but those two things definitely intersect. [...] I think I was so kind of out of it with all of what was going on that I mean I was lucky in that things kind of came together and it was an easy birth as far as births go, [child's name] was born at home, I was in hospital after that because I lost quite a lot of blood. " Their most recent interaction with perinatal care was a phone call from a health visitor when their child was 2. This health visitor seemed to have no prior knowledge of their family, asking if the father was there. This was incredibly infuriating for Alex, who then did not have the energy to engage. Below they outline how the conversation went.

"The health visitor I remember as most fresh in my head is actually the one where [child] was 2, which was still quite a long time ago, but that was a phone appointment because of COVID and uhh the first question was like 'is [child's] dad there?' Like they must have notes right? They must have notes or records!! And I was like 'oh no she doesn't have a dad and they asked are you mum and I said no I'm her parent, her mum is also here'. And maybe it was mean of me because I just couldn't be arsed explaining it, I was just cross. You can't even... you can't get any level of trying to understand our family, right? And you're a health visitor and you must see so many different families. And that's your job is to like be family centred. So I didn't explain anything to her I just kept saying "I'm her parent, her mum is also here" "I'm her parent..."

They did also indicate some regret and said they felt as though they had been unduly harsh, as they acknowledged that the healthcare visitor was likely not trying to cause offense, and has not been trained for this situation. However, the expectation that minorities should constantly educate others about their experiences is a microaggression. Alex said they felt very upset in this moment, re-explaining their identity when they expected this to be recorded in their notes would have been very costly. Not only can this sort of educating be emotionally costly for trans people, but it can also put these people in danger when there is a lack of understanding or transphobia in response.

This notion of not fitting within the system, not having space to be who they are, is a consistent theme through Alex's experience. They chose to conceal their gender to avoid transphobia, and to attempt to move through a system, which they felt would resist against non-conformity. Their partner is currently struggling to get pregnant and if her current round of treatment doesn't work, they will then try with Alex. They have a lot of anxiety and many concerns around having to go through this system again, and how that will affect them. They don't think they could conceal their gender this time, but are also unsure how it would affect their care if they are identified as trans.

### Frankie's Story

Frankie (they/them) is a non-binary white person and is autistic. They have given birth twice in the last 5 years. They didn't feel there was ever space made for them to come out during their pregnancies. Making 'space' for such conversations means creating an actively welcoming environment without assumptions where people can talk openly.

#### "Because I had no chance to disclose it[their gender] I was constantly being misgendered. I don't know, it's not just the words that people use it was the way they saw me and the way they talked about my body and the way they sort of perceived me in relation to the other people in my life."

This concept of space is important for discussions around providing person-centred care in every aspect, but also in regards to trans and non-binary people who are accessing perinatal care. Trans and non-binary people are often expected to be experts in their own care, and to always be able to advocate for their own care. The expectations of a cisheteronormative environment, and the importance of navigating that environment safely, can limit the ability of trans and non-binary people to genuinely explore the kinds of care they would like, and the kinds of language they would like to use. Frankie talks about how actually they are comfortable with the term breastfeeding, but then as they spoke they discussed how perhaps that is the term they used because of familiarity, and perhaps they may have used the term chestfeeding had this been offered.

"I was never asked at any point what term I would like to use, but I was ok with breast-feeding. I was ok with that word but I feel like if they had asked me it still would've made me a lot more comfortable with the advice and that interaction. I would feel like I'd had a choice over what word was used, and I'd had the chance to say like how I like perceive that part of my body. You know what I mean? I'd have felt a lot more comfortable because it's quite an intimate interaction when you've got a midwife manhandling a part of your body like [laughs]."

#### "And I think maybe I mean maybe if there had been an option I would've been like... I guess I'm used to saying breastfeeding now but... Yeah its interesting to think about like if I'd had the option would I have chosen differently like I do... talk about my chest uhh when I talk about my own body. That would've maybe been a better fit if it had been more widespread..."

During their pregnancies, Frankie did report that pregnancy affected their dysphoria, but they also found it challenging to detangle their feelings, as they were uncertain of the extent to which it affected them. This again highlights the need for safe spaces to be created for exploration of such things, including services specific to trans and non-binary birthing parents. This is something they themselves recognise in the quote below.

"I could have really done with help dealing with how pregnancy affects dysphoria for example, and it's like services specifically for non-binary or trans people... there was more that I needed but I wasn't even getting like the basic level of that kind of thing you know?"

#### • Q. how would you say that it did affect your experience of dysphoria?

"It was difficult to separate out what was gender related. I guess there was a lot of stuff out there about how women would struggle with the changes to their body during pregnancy and like self-image and stuff like that. Some of that spoke to me and some of it didn't. And I did feel like there was this other element of it, but it was hard to draw a clear line between what was gender related for me and my experience and what wasn't."

They felt incredibly uncomfortable with the process, and felt that there was a lack of consent around this. Their discomfort with the process wasn't addressed, and they had no space to express this. In a way, the uncertainty around what is a typical level of discomfort and what is their dysphoria creates a situation which further disempowers them, and means aspects of their care feel invasive in a way which they struggle with. The quote below demonstrates them contextualising this experience. "The interaction I remember the most was when the midwife came to check my stitches on like day 5 probably, they weighed the baby, checked my stitches... that just felt really horrendously invasive. I don't know if that was made worse by the gender stuff, I feel like that would be felt pretty invasive anyway but it definitely didn't help.

If I had known that this was a trans-friendly midwife that was aware of my identity and was aware of my feelings about my body in that situation would it have been more comfortable for me? Would that have been less traumatizing for me? And the answer is definitely yes so then obviously gender does come into it."

Ultimately, Frankie's experience demonstrates why having a trans affirming space is important in pregnancy and perinatal care. Through their experiences with the services they accessed, there was never space to be out as non-binary. This was emotionally challenging, and made their pregnancy more stressful, as they were misgendered constantly. They also experienced an increased level of dysphoria, due to changes that happen during pregnancy, which they received no support for.



# Subtheme: Racism and transphobia in perinatal care

To summarise the points from Amrit's and T's accounts, racism and transphobia in perinatal care are complex, and are not always experienced as explicit or overt acts of discrimination. Often racism and transphobia in perinatal care are experienced as a lack of action, empathy or appropriate care. The link between racial bias and beliefs around experience of pain is well documented in research and shows that racial-ethnic disparities have effects on pain relief administration, often resulting in people of colour being provided with lower or less frequent doses of pain relief medication (Hoffman et al, 2016).

T's story described the way in which their pain was not recognised, and a failure to respond with empathy to this. Such failures can be life threatening, as T described. It is important to locate this account within the wider context of medical racism, and the context of medical racism in perinatal care where black people are 5 times more likely to die in Childbirth (Knight et al., 2020). Navigating these situations can cause challenging interactions with healthcare providers, which range from awkward to hostile, from dismissive to unknowing.

Below we have some quotes that give us more insight into T's and Amrit's perceptions on race, gender and trans status.

"When you are existing at the intersections of both like race and gender where people don't have that much access to language, that being able to hold space for all of who you are and what you need. It's just automatically going to happen that your care is going to be quite insufficient for what you need, and I think that's what I was experiencing every time "

- T

"If I experienced racism from someone, I'm not going to trust them to be trans inclusive, and vice versa. I guess it happens more that I experience racism because I'm often read as cis, but I'm always read as Indian or Asian."

- Amrit

"I don't know what could or can be done about that like, just some sensitivity training or just humanizing black people and people of colour more to medical professionals. Because at the moment I just don't really believe in any of my experience and in any of the experiences that I've studied or you know any of the ways that I've been like within the NHS that that's a priority or even a consideration."

- T

The experiences of Amrit and T, highlight the stark ways in which transphobia and racism can interact. As T points out, a lack of language is often a barrier to healthcare providers, and it means that they are fundamentally unable to provide appropriate care. This also emerged in Amrit's experiences of attempting to find resources that used the language he used.

Amrit and T tried at one point or another to conceal their transness to gain better healthcare, despite the stress and dysphoria this may bring. In both instances, they felt their care was still inadequate due to racism. In Amrit's accounts, racism and transphobia are often discussed closely together, with it being important that someone is trans-inclusive and anti-racist in order to be trustworthy. This connects to T's point about needing to feel like there is space being held for all of who they are. Any work to improve health care for trans and non-binary birthing parents must be enacted through an intersectional lens, taking into account other sites of oppression for these individuals.

## Subtheme: Concealing Gender

All 4 of the interviewees had experiences of concealing their gender while accessing perinatal care. For each of them, it was not a choice they wanted to make, but one which they felt would improve their care, or would be necessary to get them through their perinatal care. It is extremely concerning that these birth parents felt it was necessary to conceal parts of their identity in order to access health care. Some interviewees, like T and Alex, had moments where they would challenge healthcare workers and correct their assumptions about gender, but both experienced resistance in doing so. Quotes below from Alex, T and Amrit demonstrate different aspects of concealing gender.

"I have friends who like have got like histories of mental health problems who have been kept in that system for longer and its never said that its because of A, B or C, but it feels like it is and that's so... I feel like the less they know about me the less attention they pay to me. And that's what I want, just for them to go away".

- Alex

"I remember there was already a correction about pronouns I use and about how I don't identify as a woman and I just think it makes people switch off. Like they are not really interested in engaging with you so much, so I noticed that happened every time I would do that. So I stopped really saying it".

- T

## Subtheme: Concealing Gender

#### What needs to happen for it [being open about gender] to feel safe?

"Well, I think there needs to be clear evidence that the space is transinclusive. Not just like a rainbow poster or something, but like a statement that they've done training and that they are committed to trans inclusion. Then I think they need to be confident in talking about it with everyone, like asking people what pronouns they use or what terms they use for their body. And I guess services need to know that it takes time. They aren't going to build trust in a day. Like I talked about my weird experiences to my friends, so they are all going to have similar concerns, so conversely now they have to rely on people talking about their good experiences. So they have to just keep doing this knowing it will work eventually".

- Amrit

Alex and T both demonstrate different motives for concealing gender. For Alex it was about trying to navigate services with as little fuss as possible.

Due to the stigma and medicalisation of being trans, they were worried that this would draw undue attention to them and their family, when all they want is peace. They were concerned that disclosing their trans status may have affected the care they received and slowed down their discharge. Their experience also highlights the way in which poor experiences of care are communicated within the community. Re-building trust with trans and non-binary people will take time.

While Alex's reason for concealing their gender was based on a fear of inadequate care, T's concealing of their gender was in response to feeling that their disclose was actively affecting their care. Whenever they corrected healthcare workers about their pronouns they were met with hostility and frustration, but after their post-partum haemorrhage, they needed more support. They wondered whether the assertion of their gender was resulting in a reduced standard of care and therefore hid their gender to try to receive the care they needed.

Amrit's quote talked about the steps that would be needed to make a service feel safe for trans and non-binary people to share their gender identity. Amrit believes there need to be genuine efforts which are visible to trans and non-binary birthing parents. They say that a rainbow poster is not enough, and that he would need to see evidence of a clear commitment to trans inclusion, including training. All participants said that being asked for their pronouns would be beneficial. Frankie and T added that it needs to be asked in a way which does not assume the pronouns someone might use.

## **Key Recommendations**

#### How can this report be used?

**If you are a commissioner** this report is a good starting point for thinking about whether the services you commission are designed to meet the needs of trans and non-binary people.

**If you are a health care professional** this report provides key insight into the experiences of pregnant trans and non-binary service users that can help you inform and improve your practice.

**If you are a policymaker** this report can help you understand how to improve policy and drive best practice to be inclusive of the needs and experiences of pregnant and birthing trans and non-binary people.

The recommendations below have emerged from the findings presented in this report, in discussion with the project steering group. They aim to outline how different parts of the healthcare system can take coordinated action to improve experiences and outcomes for trans and non-binary birthing parents. The recommendations are listed in full on pages 48-55. Each recommendation has its own page with more detailed information. Throughout these pages the 'Putting it into practice' boxes follow a hypothetical patient's journey through an inclusive maternity service, demonstrating how these recommendations can be put into practice and the positive impact their implementation would have on a service user's experience.

#### **Putting It Into Practice**

Cam (they/them) is a Black Caribbean non-binary transmasculine person going through their second pregnancy. They hid their gender during their first pregnancy five years ago, as previous experiences of medical racism and transphobia meant they were afraid that asserting their identity could lead to being seen as 'difficult' and further compromise their care.

However, this was a very distressing experience and they don't want to conceal their gender again, so they are reluctant to access care during their pregnancy this time.



## **Recommendation 1: Targeted Information**

We recommend that NHS England & NHS Improvement produce targeted information and support for trans and non-binary pregnant and birthing parents. This should be available in a range of formats, including via the NHS.UK website.

The findings of this research should inform this targeted information. We found that 30% of the trans and non-binary people in our study did not engage with perinatal services at all throughout their pregnancy and birth and that those who did were less likely than the general population to receive relevant information and advice. Therefore, targeted information should include (but not be limited to):

- Support with planning place of birth including the options of homebirth and standalone Midwifery-led Units, especially where there is a history of hospital based-trauma
- The availability of continuity of carer and the benefits of this to individuals
- Choices around feeding
- Support with mental health during and after pregnancy

#### **Putting It Into Practice**

While looking for information, Cam visits the NHS.UK pregnancy page and notices that support for trans and non-binary pregnant people is prominently signposted. This was not the case five years before, and makes them optimistic about what else might have changed.

They are anxious about the hospital environment but see that there are other options. This targeted information means that they reconsider their decision to avoid accessing care and decide to look into NHS services further.



### **Recommendation 2: Inclusive Language**

Another key element of providing individualised care includes prioritising the use of inclusive language for every service user.

While many service users are cis women, and there is already language in place that they may be comfortable with, there are also many ways to use language that is more inclusive to trans and non-binary pregnant people. For example, some trans and non-binary people use the terms chestfeeding or bodyfeeding, rather than breastfeeding. Others are completely comfortable with the term breastfeeding.

It is not possible to guess the language that someone might use to describe themselves based on how they look or sound, or who they are in a relationship with. Always ask people directly about the language that is appropriate to describe them, their bodies, and their experiences. A more comprehensive explanation of inclusive language in perinatal services (Green & Riddington, 2020a), as well as a template for recording service users' language preferences (Green & Riddington, 2020b), has been produced by Gender Inclusion Midwives at BSUH NHS Trust.

NHS England and NHS Improvement should provide best practice guidance about inclusive language across perinatal services at a national level, to support implementation and ensure consistency for trans and non-binary pregnant people.

#### **Putting It Into Practice**

In their previous pregnancy Cam received a letter that was addressed to 'pregnant women'. This made them worry that the maternity service would not be able to accommodate them.

Cam visits their local maternity service's website, which now uses inclusive language, and when they navigate to the service's online booking form they see that there are options to indicate their gender and what pronouns they use. They immediately feel more comfortable with the prospect of accessing perinatal care as an 'out' non-binary transmasculine person.



## **Recommendation 3: Pro-Active Inclusion**

Access to maternity, neonatal and perinatal services can be improved for trans and nonbinary people by proactively identifying and removing barriers faced by this community, and in communicating these improvements.

Research shows that trans and non-binary birthing parents report avoiding accessing care altogether, due to previous negative experiences of health services, or because of fear of negative services (Hoffkling et al). This was a significant finding in our research too. While it is important to improve the care actually available to trans and non-binary service users, it is also vital that services take proactive steps to demonstrate and communicate that they are welcome.

This may include:

- Visible markers of inclusion such as posters, badges, including name badges with pronouns, and lanyards
- Using social media and communications channels to mark significant dates such as Trans Parent Day (first Sunday in November) and Trans Day of Visibility (31st March)
- Signposting to tailored information targeted towards trans and non-binary pregnant people
- Using inclusive language in public-facing communications and across information and resources about your service
- Providing opportunities for trans and non-binary service users to feed back about how you can best support them and enable their care, and ensuring your Maternity Voices Partnership is welcoming for trans and non-binary voices
- Consulting and co-producing your services with local trans and non-binary communities, organisations and support groups

At a national level, we encourage the Royal College of Obstetricians and Gynaecologists (RCOG) and the Royal College of Midwives (RCM) to take explicit stances in support of providing safe and inclusive services to trans and non-binary birthing parents.

#### **Putting It Into Practice**

After filling in the form, Cam is referred to a midwife who has been trained in gender inclusive care, and they are invited to a booking appointment at a local Children's Centre. They are greeted by a receptionist who wears a name badge with pronouns, and in the waiting area there is a poster about gender inclusive perinatal care.

They pick up a leaflet about the specialist support available to trans and non-binary pregnant people, which they read while waiting. Seeing these markers of inclusivity throughout the physical space, not only online, helps them to relax and feel less worried about how their appointment might go.

## **Recommendation 4: Personalised Care**

Trans and non-binary people should receive holistic and personalised care, which recognises and is tailored to address their specific health and wellbeing needs. They should have a personalised care support plan (PCSP) that meets the five technical criteria outlined in the universal personalised care model:

- 1. People are central in developing and agreeing their PCSP, including deciding who is involved in the process.
- 2. People have proactive personalised conversations that focus on what matters to them, paying attention to their needs and wider health and wellbeing.
- 3. People agree the health and wellbeing outcomes they want to achieve in partnerships with the relevant professionals.
- 4. Each person has a sharable PCSP that records what matters to them, their outcomes and how they will be achieved.
- 5. People are able to formally and informally review their PCSP.

The principle that maternity care should be personalised and safe is central to the Better Births vision, and midwives already seek to deliver personalised care for service users who have been recognised as having enhanced needs. There is existing guidance for how the PCSP model can be incorporated into maternity care (NHS England, 2021) – though unfortunately its language is not inclusive of trans and non-binary birthing parents.

Our findings show that not being afforded the appropriate agency, dignity, and respect are particular barriers to trans and non-binary birthing parents feeling safe and comfortable accessing services. Prioritising the personalised PCSP model for trans and non-binary service users can address these barriers and ensure they receive the support they need.

The PCSP model is an opportunity to celebrate the person's identity and unique experiences, including and beyond their gender identity. It is also an opportunity to consider integrated anti-discrimination strategies to address the specific ways that historic and current discrimination may impact trans and non-binary pregnant people. This is especially important for those who are multiply marginalised, such as trans people of colour and disabled trans people.



#### **Putting It Into Practice**

Cam's appointment lasts an hour. The midwife asks Cam sensitive questions about their identity and their partner, making no assumptions and recording the information digitally. The midwife helps Cam start their personalised care support plan which includes the details about how they identify and how they should be referred to. Cam feels supported and included in decisions around their care. They start to trust the services and speak to some of their trans and non-binary friends about the positive experiences so far. This encourages one of their friends to access care.





## **Recommendation 5: Trauma-Informed Care**

Trans and non-binary people are more likely to have experienced trauma, compared to cisgender people (Barr et al, 2021). Discrimination in medical settings is common (Government Equalities Office, 2018) and can contribute to this.

While the principles of a trauma-informed approach are part of the PCSP model, it is important to highlight the particular needs trans and non-binary service users may have in relation to medical and other forms of trauma.

We recommend that services proactively discuss taking a trauma-informed approach with trans and non-binary service users, and explain the support that is available. Trans and non-binary service users should be supported to communicate their needs and boundaries, for example around being touched, and these should be recorded as part of their PCSP and consistently recognised when that person is using the service. Good practice guidance on trauma-informed perinatal care is available (e.g. Law et al., 2021), though it similarly is gendered towards cisgender women and there for should be adapted for use with trans and non-binary people. Further work is needed in this area.

One of the core principles of trauma-informed care is consistency and continuity. Within maternity services, continuity of carer means that the pregnant person should have continuity of the person looking after them during their maternity journey, before, during and after the birth (NHSE, 2017). It enables the co-ordination of care by a named individual who takes responsibility for ensuring that all the service user's needs are met; and it enables the service user to develop a relationship with the clinician responsible for their care.

Existing research demonstrates the benefits of continuity of carer (Sandall et al. 2016), and its value for women and babies in socially disadvantaged and BAME groups, including those with complex pregnancies and perceived risk factors (Homer at al. 2017, Hadebe et al. 2021, Raymont-Jones et al. 2021). Continuity of carer was found to result in both increased satisfaction with care and improved outcomes for pregnant women of colour and those living in areas of high socio-economic disadvantage (Homer at al. 2017).

Since this research shows the benefits of continuity of carer for marginalised women, and interviews during our ITEMS projects showed the importance of continuity of carer for trans and non-binary people, this is a positive way to respond to the complexities and increased risk experienced by trans and non-binary birthing parents.

#### **Putting It Into Practice**

Before doing any physical examinations or discussing the pregnancy in detail, the midwife asks Cam whether and how they would like to be touched, and what terminology they would prefer to use. Feeling unexpectedly listened to and respected, Cam opens up about the difficulties they faced during their first pregnancy, as well as previous traumatic experiences of health care, and the impact this has had on their trust in perinatal services. The midwife is empathetic, affirming their experience and informing Cam about the options available to address their concerns, including specialist support.

Cam leaves the appointment feeling comfortable, confident, and in control of their own care for the first time. Because Cam is identified as having enhanced needs, they are ensured continuity of carer, meaning that the midwife with whom they have begun to establish a trusting relationship will be responsible for coordinating the whole of their care. Cam is relieved that there will be a consistent individual they can speak to about their concerns, and that they will not have to repeatedly assert their identity or discuss distressing experiences in new care settings. Instead of minimising interaction with perinatal services out of fear for their wellbeing, they are able to make positive decisions about their pregnancy based on accurate and relevant information, and trust that they will be respected by the services they engage with.

## **Recommendation 6: Training**

While this report and the signposted resources provide a starting point for improving the inclusivity of maternity services, our goal is for every midwife and other clinicians involved in perinatal care to be supported to deliver gender-inclusive care. This means investing in training as a priority, designed and delivered by trans and non-binary led organisations, or individuals.

We recommend that service managers, commissioners, and policymakers also receive training on the specific needs of trans and non-binary people accessing maternity, neonatal and perinatal services, and how they can work to address these needs within their professional capacities.



#### **Putting It Into Practice**

Cam chooses to give birth at a midwifery unit, attended by the midwife they have gotten to know during their pregnancy. Two weeks later, their midwife coordinates the handover of their care to a health visitor, who is also trained in gender inclusion. The handover goes smoothly, and due to gender inclusion training, the health visitor is able to provide useful advice to support them with chestfeeding and recognises when Cam's baby has a tongue-tie.

Cam struggles with dysphoria in the weeks following their baby's birth. The health visitor picks up the importance of this and is able to help Cam access additional mental health support.



## **Recommendation 7: Upgrade IT Systems**

We recommend that IT systems for perinatal services are designed to collect data about service users' gender identity and whether they are trans and/or non-binary. We further recommend that IT systems should prompt health care professionals to proactively ask service users about their gender using standardised questions and healthcare professionals should be supported to feel able to ask about someone's gender.

Digital maternity care records are particularly important for trans and non-binary pregnant people to enable key information to be shared between people and health care professionals. This allows anyone involved in care to address and treat these individuals appropriately and to avoid misgendering these individuals. It would also prevent clinical errors which have been reported such as failure to complete a pregnancy test or ultrasound for someone with a male gender marker.

#### **Putting It Into Practice**

When Cam accesses mental health support their digital records are passed on. Since these include their preferences around language and information about their identity and their partner, the mental health service is informed when they meet Cam.

Cam therefore feels that they have been listened to and that they don't have to push to advocate for themselves when they are struggling.



## **Recommendation 8: Demographic Monitoring**

In addition to inclusive design of IT systems for perinatal services, NHS data collection more broadly should include demographic questions about trans status and inclusive questions about gender as standard. This data should be used to benchmark and monitor the perinatal experiences and health outcomes of trans and non-binary people compared to the general population.

We recommend the addition of an inclusive gender question and a trans status question to the CQC National Maternity Services Survey to make visible the specific experiences of trans and non-binary people accessing perinatal care. Trans and non-binary people should also be captured in other experience, outcomes, and safety measures such as the MMBRACE UK reports.

#### **Putting It Into Practice**

Cam's experience of the services they accessed is recorded in national statistics. Data over time shows how maternity services have improved their care provision for this community. Cam's information is also recorded in the mental health services data and when this is analysed it demonstrates that trans and non-binary people need additional support in certain areas. This allows the services to be proactive at helping this group.

Cam feels included and supported throughout their time accessing NHS perinatal care. They share about how excellent the care they received was in their community groups. Many trans and non-binary people who were afraid to access services decide to reach out to services.

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