Trans and Non-binary Experiences of Maternity Services: cautioning against acting without evidence.

# Abstract

Research into the experiences of trans and non-binary (TNB) users of maternity services in England was recently commissioned by the Health and Wellbeing Alliance. It was conducted by the LGBT Foundation, culminating in the *Improving Trans and Non-binary Experiences of Maternity Services (ITEMS)* report, which made a range of recommendations for the NHS. This article argues that there are substantial problems with the framing, data collection and interpretation of data in the ITEMS report, and that its findings and recommendations should therefore be viewed with substantial caution, and not be used as the basis of NHS policy. We further argue that caution should be taken before using the experiences of a very small minority of service-users, such as those who identify as TNB, to inform policy for all service-users, and instead suggest that personalised care may be the most suitable approach to meeting the specific needs of TNB maternity service-users.

# Key Words

Trans; Non-binary; Transgender; Evidence-based practice; Maternity; Personalised care

# Introduction

In 2022, research into the experiences of trans and non-binary (TNB) users of maternity services in England was commissioned by the Health and Wellbeing Alliance (jointly managed by the Department of Health and Social Care, Public Health England and NHS England and NHS Improvement (NHSE&I) (LGBT Foundation 2022). The research was conducted and published by the LGBT Foundation, and culminated in a report entitled *Improving Trans and Non-binary Experiences of Maternity Services (ITEMS)* (LGBT Foundation 2022). The ITEMS report argues that TNB maternity service-users have “poor experiences” and “poorer outcomes” compared to other maternity service users, and that TNB “patients and their babies [are] being put at risk” in the NHS (LGBT Foundation 2022: 5).

The report made a range of recommendations, which included changes in use of language, display of trans-inclusive communications in maternity settings, staff use of pronoun badges, provision of personalised care and trauma-informed care to TNB service-users, staff training, and changes to IT systems and demographic monitoring which would require staff to ask all service-users questions about their gender identity. NHS England announced plans to spend £100,000 on staff training based on the report’s recommendations (NHS England 2022). These plans were subsequently withdrawn following a petition by clinicians expressing concerns that the report’s conclusions and recommendations were unsupported by its data (With Woman 2023a; With Woman 2023b).

This article argues that there are substantial weaknesses with the framing, data collection and interpretation of findings in the ITEMS study. The claims and recommendations made in the report should therefore be viewed with caution. Furthermore, some of the recommendations include policy changes that would impact all maternity service-users (not only the very small minority who identify as TNB). We argue that caution should be taken, and wider impact assessed, before using the experiences of a very small minority to inform policy for all service-users. We recommend that the NHS should not make policy on the basis of the ITEMS report, that the NHSE&I review the ITEMS report and consider whether there is a need for more rigorous research into the experience of TNB maternity service-users, and that any consideration of policy change on the basis of such research should balance the needs and interests of different groups of service-users.

# Critique of the ITEMS study and report

In this section we present a critique of the ITEMS study, based on its report (LGBT Foundation 2022). We argue that the study framing lacks clarity and balance, that there is a lack of engagement with relevant literature, that the methodology is substantially flawed, leading to potentially invalid findings, and that some of the recommendations are not based on the findings of the study.

## One-sided, uncritical framing and lack of conceptual clarity

Concepts relating to gender and gender identity are unstable, controversial and lack universal consensus (Jones and MacKenzie 2020; Joel and Fine 2022; Sullivan 2023). With reference to maternity care, Gribble et al. (2022) has argued that sex-based (rather than gender identity based) language is important for communicating clearly. However, the ITEMS report uses gender-identity based language without acknowledgement that such language is contested. For example, the study sets out to “allow comparison of maternity care between trans and non-binary birth parents and cis women” (p.8), with ‘cis’ defined as “someone whose gender identity matches with their gender assigned at birth” (p.10). ‘Gender identity’ is a contested term, and not everybody agrees that it is universally experienced (Stock 2022; McGrath 2023). We suggest that a report into maternity service provision should be reflexive about language use and make an evidence-based case for the choice of concepts on which the study is based.

## Lack of thorough engagement with literature

The ITEMS report starts with a literature review that the authors state was the basis for elements of their methodology and some of their recommendations. However, there are substantial gaps in the cited literature. The authors did not engage with key literature that evidences the complexities and differences in individual preferences and strategies of TNB people navigating reproductive services (Hoffkling et al. 2017; Klein and Golub 2020; Klein and Golub 2020; Agénor et al. 2021). It also does not distinguish between international and UK research contexts, compromising transferability to the NHS.

## Lack of methodological rigour leading to unreliable, ungeneralisable findings

The ITEMS research design included a survey and individual qualitative interviews. We suggest that the design of the survey lacks rigour and transparency. This includes major weaknesses with sampling strategy, survey design, plus misrepresentative analysis and presentation of findings We believe that this means that the findings of the report may by unreliable and invalid.

### Sampling and eligibility

The ITEMS report makes direct comparisons between its findings and the findings of the National Maternity Survey (NMS) (Care Quality Commission 2020), and on this basis claims that TNB maternity service users have poorer experiences than the wider population of maternity service users. However, sampling and participant recruitment differ substantially between the two studies. The NMS 2019 used a self-selecting sample from their target population, which was all those who gave birth in any one of 121 NHS trusts during February 2019. Thirty-seven percent of this target population completed the survey (n=17,151). The ITEMS survey was publicised via personal and professional networks of the research group and also to the general public via social media. Responses were collected during a five-month period from November 2020 to March 2021. No specific eligibility criteria are recorded in the report. There is no indication that respondents were required to have given birth in England, or under NHS care. ITEMS respondents gave birth over a thirty-year period, with 45% giving birth before 2015, and in unknown countries. The report claims that the survey achieved a response rate of 41%, but as no target population is identified it is not clear what this claim is in relation to. There were 121 respondents in total, but none of these respondents completed the whole survey, and each question relating to experiences of maternity care were answered by only 52-62 respondents. As the authors identify, there is no data on numbers of TNB users of maternity services in England, so it is not possible to identify the response rate in relation to this unknown population. We suggest that these differences between the sampling strategies of the NMS and ITEMS mean that meaningful comparison cannot be made between the findings of the two studies. Of particular note is the substantial difference in the time period under investigation. NHS maternity services have changed substantially since some ITEMS participants gave birth in the early 1990s. For example, NMS survey results show improvements in women’s experience of maternity services between 2013 and 2019 (Care Quality Commission 2015; Care Quality Commission 2018; Care Quality Commission 2020), and a subsequent decline (Care Quality Commission 2023). The ITEMS report is therefore comparing experiences of (any) maternity service-users across an extended time span with those who used the NHS service in England during one month at its highest rate of maternal satisfaction in at least a decade. Furthermore, nearly half of the participants in the ITEMS study gave birth before the introduction of contemporary models of practice implemented after Better Births (NHS England 2017), and after the introduction of the NHS Long Term Plan aiming to increase personalised care ]

(Winfield and Booker 2021 Aug 2) and patient access to digital records (Kulakiewicz et al. 2023 Jun 14). The number of midwifery-led units has also increased substantially (McCourt et al. 2014). All of these changes may have impacted the experience of maternity service-users, which means that the ITEMS survey cannot be directly compared to the NMS 2019 without controlling for year of use of service. In addition, the ITEMS sample was demographically different from the NMS sample, with the ITEMS respondents substantially less likely to be white and more likely to be disabled than NMS respondents. ITEMS respondents were thus more likely to be in groups already known to have disproportionately negative experiences of maternity care (Malouf et al. 2017; Higginbottom et al. 2019; Peter and Wheeler 2022). These differences were not controlled for in the ITEMS analysis, and we suggest that attribution of disparities in experience to TNB identity may be invalid.

In addition to this lack of comparability to the NMS 2019, it is not clear that all of the ITEMS participants were TNB, or what precisely the authors mean by TNB maternity service users. There was no requirement that respondents must have identified as TNB at the point of giving birth, nor when completing the survey. Two of four participants reported that they concealed their TNB identity from healthcare professionals, which perhaps makes it particularly uncertain that negative experiences were associated with TNB status. Only 70% of ITEMS survey respondents declared their gender identity, which means that there is no way to know the gender identities of 30% respondents (i.e. they may not have been TNB). Furthermore, while the report defines the terms “trans” and “non-binary” in its glossary, not all of those who gave a gender identity identified themselves by either of these terms (p.16). Respondents identified variously as Man, Woman, Non-binary, Agender, Gender queer, Genderfluid, Bigender, Transmasculine, Demi-boy, and ‘In another way’. Most of these terms are not defined in the report, and they all appear to be included in the analysis as representative of TNB experiences (including those identifying as ‘Woman’). None of the terms appear to relate to whether people have undergone physical procedures in relation to gender reassignment. The needs of medically transitioned maternity service users are likely to be different from other TNB service users but are mentioned only briefly in the ITEMS report (page 21). For example, elective double-mastectomy can impact the ability to produce breast milk (Gribble et al. 2023), and long-term testosterone can cause vaginal and uterine atrophy (Grynberg et al. 2010) which can impact on birth itself, as well as postnatal health (Indig et al. 2023). Hoffkling et al (2017) found that previous medical interventions made a difference to the needs of trans maternity service users, so failure to ask respondents about their history of physical transition may mask important information relevant to the needs of TNB maternity service users. Lack of clarity about who the target population of the study are means that there is no way to identify who precisely may require particular types of care.

### Lack of internal reliability

In addition to these problems with sampling and eligibility, the survey instrument for the ITEMS study appears to have asked imprecise questions, making the responses difficult to interpret and threatening internal reliability. The survey does not appear to be publicly available, but some of the questions are documented in the report. For example, respondents were asked *“Did you get support from NHS or private midwives during your pregnancy/pregnancies?”*. Thirty percent of respondents answered ‘No’ to this question. The ITEMS research team interpreted this as meaning that 30% of their respondents gave birth “without ever accessing perinatal care” (LGBT Foundation 2022: 8). However, the report states that, elsewhere in the survey, respondents were asked whether they received antenatal, labour and birth, and postnatal care, with 82%, 79% and 75% responding affirmatively, respectively. If the former question is intended to determine whether respondents received any perinatal care at all—as it is being interpreted by the report authors—this disparity between the answer to this question and answers to questions about receipt of care indicates a lack of internal reliability. It cannot be the case that 30% of respondents received no antenatal, birth and labour, or postnatal care, *and* that 82%, 79% and 75% respectively received this care. We suggest that there are at least five ways to interpret the question *“Did you get support from NHS or private midwives during your pregnancy/pregnancies?”* and at least four reasons for a respondent to answer “No” that do *not* mean the respondent received no perinatal care.

1. Respondents could have been supported by nurses or doctors during their pregnancy.
2. Respondents may have given birth before the arrival of a midwife or their arrival to hospital (Born Before Arrival (BBA)) (Birthrights 2023).
3. Respondents may have interpreted the term “supported” to mean whether they *felt* supported, rather than whether they were under clinical care
4. Respondents may have interpreted “during your pregnancy” to mean antenatal care only, not birth and labour or postnatal care.
5. Respondents received no perinatal care.

This lack of clarity, and questionable internal reliability, undermines the credibility of the ITEMS report headline claim that “30% of trans and non-binary respondents did not access NHS or private support during their pregnancy or pregnancies. This is sometimes called freebirthing” (LGBT Foundation 2022: 9).

### Misleading claims

On the basis of the questionable claim that 30% of their respondents answered No to *“Did you get support from NHS or private midwives during your pregnancy/pregnancies?”* , the ITEMS report authors claim that 30% free birthed. Free birthing is defined by the Royal College of Midwives (2021), maternity rights charity Birthrights (2023), and widely cited scholars Feeley and Thomson (2016) as choosing to give birth without the presence of a healthcare professional. Birthrights explicitly distinguishes between freebirthing as an active choice, and BBA.

Unassisted birth is sometimes called ‘free birth’. It means deciding to give birth at home or somewhere else without the help of a healthcare professional such as a midwife. Unassisted birth does not mean giving birth at home before the midwife you planned had time to arrive. This is called ‘born before arrival’. (Birthrights 2023)

Based on this definition, a cohort study estimated that less than 0.05% women freebirth in the UK (Loughney et al. 2006). It is not clear that ITEMS participants were asked whether they free birthed, much less whether they were provided with a definition of the term. As we have seen, there are several other possible interpretations of the responses given. Despite this, the authors go on to make a range of claims about the specific experiences of respondents who allegedly free birthed, without explanation of the empirical basis of those claims. The report claims:

30% of those who free birthed 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 free birthed reporting being confident to access maternity services if they felt that they needed to. (p.30).

The report contains no detail of the basis of these assertions. For example, it is not clear that any respondent identified themselves as having free birthed, or that these respondents were asked particular sets of questions. Overall, the claim that 30% of participants free birthed (some 600 times more than the UK national freebirth rate) is not a valid interpretation of the data presented in the report, and any particular claims about the experiences of those who free birthed are also invalid.

Problems with sampling, instrument design and interpretation of data all raise concerns about the reliability and validity of the ITEMS report findings. In particular, the claims that ITEMS respondents had relatively poor experiences compared to NMS 2019 respondents, and the claim that 30% of ITEMS respondents free birthed, are used by the authors as evidence that TNB maternity service user and their babies “are being put at risk” (p.5). We suggest that the study’s data does not support this claim.

## Recommendations not supported by findings

In addition to making unsubstantiated claims, the ITEMS report includes recommendations that are not related to the claimed findings of the study. One recommendation is that the experiences of TNB maternity service users would be improved by the use of visible markers such as “posters, badges, including name badges with pronouns, and lanyards” to “communicate that they are welcome” (page 52). However, there is no justification for these recommendations on the basis of the research findings. The survey report does not mention any investigation of people’s experiences with interventions such as these, and one of the four interviewees reported that “a rainbow poster” was inadequate—they wanted personalised care (p. 48). This policy recommendation therefore appears to be unsupported by the findings of the study.

Overall, the ITEMS report contains some substantial flaws relating to its framing, methodology and recommendations. We therefore suggest that the NHS should exercise great caution before making use of these findings to inform policy.

# The importance of a balanced approach to policymaking

We have argued that some of the findings and recommendations of the ITEMS report are not well-founded due to fundamental flaws in the study and unsubstantiated recommendations. However, the authors do make some recommendations that are, to some extent, grounded in their reported findings. For example, the report recommends the use of “inclusive language for every service-user” (p. 51). The authors do not specify precisely what they mean by “inclusive language”, but they include an example of an interview participant who said that receiving a letter referring to “‘pregnant women’...made them worry that the maternity service would not be able to accommodate them.” (p.51). This appears, therefore, to be a recommendation for a move from sex-based to gender-based referents in maternity services, and it appears that at least one ITEMS participant would have found such a change beneficial. However, whether the NHS should change its approach overall, we suggest, should be considered by balancing the interests of this person (and any others with similar experiences) with impact assessments relating to the wider population of maternity service users.

Gribble et al. (2022) have argued that failure to use sex-based language can have substantial negative impacts on women using maternity services—a position supported by the recent *Women’s Health Strategy* (Department of Health and Social Care, 2022). Responses to the 2021 Census suggest that only 0.5% of England’s population self-identity as TNB (although the validity of this data has been called into question and the true figure could be lower (Biggs 2023)). A population-level move from sex-based to gender-based referents may have a detrimental effect on clear communication, diminish accessibility of health communications and increase health inequalities for women with English as a second language, those with a learning disability, and those with low health literacy. If this were the case it may contravene the ‘clear information principle’ of health communications (Department of Health and Social Care 2022 Aug 30; NHS Digital 2023 Apr), increasing the potential for unintended adverse health consequences, and excluding some groups of service users. Furthermore, ‘inclusive’ language can inadvertently include those it should *not* include. For example, referring to ‘parents’ or ‘families’ instead of ‘mothers’ opens up the possibility that partners and family members be included as stakeholders in a pregnancy, because the centring of the pregnant woman becomes less clear (Munzer 2021; Gribble et al. 2022). In summary, what the ITEMS authors understand as ‘inclusive’ language for TNB maternity service users may, in fact, be detrimental to many other maternity service users. This means that, before making any policy changes that affect services across the board, the NHS must consider a broad range of evidence, perspectives, and potential impacts. The ITEMs report also recommends staff training run by LGBT advocacy groups, but such groups may hold views that do not take into account to the needs of other groups of maternity service users. We suggest that the NHS should be cautious about commissioning training run by organisations that represent only one very small group, and about making changes that effect the service *overall*, without an evidence-based assessment of impacts to the diverse and varied cohorts of maternity service users.

A recommendation on which we agree with the ITEMS authors is on the need for personalised care. There is broad evidence that this is in the interests of all maternity service-users (NHS England 2016; Sandall et al. 2016) and this recommendation is supported by other research into TNB maternity service users (Hoffkling et al. 2017). Were the NHS to assess the needs of TNB maternity service users in relation to the needs of service-users overall, they might consider interventions known to increase personalised care, such as investing in staffing and continuity of care (Sandall et al. 2016; Sandall 2017). Such an approach could help to meet the specific needs of TNB maternity service users without compromising the service’s ability to meet need overall.

# Conclusion

The *Improving Trans and Non-binary Experiences of Maternity Services (ITEMS)* study was commissioned to generate knowledge about the needs of TNB maternity service users. We have argued that the framing of the study is one-sided and lacks conceptual clarity. The report fails to engage with relevant literature, particularly literature that takes a different perspective from that of the authors. The survey study is methodologically flawed, with clear issues with sampling strategy and internal reliability. Claimed findings are not always consistent with the data, and recommendations are made which are not supported by the study’s own findings.

We are concerned that, despite these issues, the report was used as the basis for a planned intervention in the NHS, at significant cost. This was only stopped as a result of concerns raised by clinicians. This highlights why carefully considered, evidence-based policy planning is important.

We suggest that the Health and Wellbeing Alliance and NHSE&I should review the ITEMS report and its data, and consider whether further research is needed in order to inform provision of evidence-based care for TNB maternity service users and their babies. We suggest that any research into TNB maternity service users should consider whether the needs of this group might be consistent with the wider need for personalised continuity of care. If research into TNB maternity service users is to inform NHS policy, it would be appropriate for it to be peer reviewed. Any recommendations should be considered in relation to the needs of maternity services users overall, and should be impact-assessed before implementation.

# Key Points

* The *Trans and Non-binary Experiences of Maternity Services (ITEMS)* report, commissioned by the Health and Wellbeing Alliance and produced by LGBT Foundation, contains substantial conceptual and methodological errors, which make the findings unreliable and potentially invalid.
* The ITEMS report makes misleading claims that do not appear to be grounded in the data presented, such as an unsubstantiated claim that 30% of respondents free birthed, and makes recommendations that are not based on the reported findings, such as the introduction of pronoun badges for NHS staff.
* The ITEMS report makes recommendations for changes to practice relating to *all* service-users, such as changes to language use, despite the fact that TNB people make up a very small minority of service-users.
* Despite these problems, the NHS announced £100,000 expenditure on the basis of the ITEMS reports’ recommendations, without having conducted an assessment on how this would impact other service users.
* Evidence suggests that personalised care is beneficial to TNB maternity service users (as it is to all maternity service users), so it may be the case that improving personalised care overall could improve experiences for TNB service users.

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