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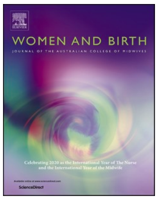

Diversity of representation in pregnancy research: A national mixed-methods survey of women's perceptions and experiences in the United Kingdom

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ABSTRACT

Aim: To explore the experiences and perceptions of women who may take part in antenatal research, including their perceived motivators, enablers, and barriers to participating in research with a sub-analysis of under-represented groups.
Methods: A mixed-methods parallel explanatory design was employed, and a national semi-structured online survey was circulated nationally using a start to end participatory framework. Likert scale responses and participant experience and demographic data were cross-tabulated to explore the differences between groups using descriptive and non-parametric statistics. A content analysis was used to explore open-ended questions and generate coding clusters. The qualitative and quantitative results were then merged using a using a pillar integration process.
Findings: There were 260 survey responses across the UK, from Oct to Nov 2021 as part of wider research. Three meta-themes were developed from the merged integration: 1. Participation being mediated by perceptions and experience of safety, convenience, and communication, 2. Lived experience and education may increase access to research participation, and 3. Sociocultural differences may lead to research hesitancy.
Conclusion: Clinical researchers and research delivery teams working in antenatal settings, have the potential to impact the inclusion of underserved communities through facilitative research designs, well considered communication strategies, and authentic relationships which support participant education about research.

Abbreviations: HCP, Healthcare professional; LGBTQ, Lesbian, Gay, Bisexual, Trans, & Queer; MRI, Magnetic resonance imaging; NHS, National Health Service; PPIE, Patient and Public Involvement and Engagement; SCAG, Stakeholder and Community Advisory Group; US, Ultrasound.

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Statement of Significance

Problem or Issue	*There is known inequity in relation to participation in clinical research and this is also true in relation to women's health studies.*
What is Already Known	*There is lower generalisability of some clinical research studies because clinical trial recruitment may not be representative of local populations. There is a lack of UK-based research exploring this issue.*
What This Paper Adds	*Lived experience and education impacts willingness to participate in research. There are clear mediating factors identified by women, including considering convenience, outreach and communication, as strategies which can utilised in study designs and recruitment activities to address barriers.*

1. Introduction

Women have been underrepresented in clinical research leading to stark examples of health inequalities [1–4], with hormonal variability, reproductive safety, and pregnancy cited as reasons for their exclusion [5]. Women from Black, Asian, mixed ethnicity, or belonging to other ethnic minority backgrounds are also underserved [6–8]; meaning these populations have not seen improvements in outcomes [9,10]. The dearth of ethnic diversity in clinical research is not only a scientific and medical concern, but also a moral issue intertwined with societal biases and also in maternity outcome data [11–13].

Clinical research directly related to pregnancy may have different bias profiles leading to lower generalisability when trying to extrapolate results to a given (diverse) intended population. The effects of health inequity are seen in relation to clinical outcomes [14]. In addition, as an indicator of the level of health burden, clinical negligence claims make up the largest proportion of all health-related medicolegal claims, and in the UK, claims related to obstetric care made up 41 % (£1.15 billion) of the total claim value in 2023/2024 alone, with sociocultural and economic variations in care seen across the health services [15].

Health equity is an important health policy goal. However, despite existing guidance on inclusive research, health disparities persist [16] compounded by under-representation of intersectionally diverse groups in pregnancy research [17–20]. Much of the literature exploring direct participant involvement in (or experience of) research is from a North American perspective and focuses on their specific diverse population groups (for example, African American, Hispanic, First Nations populations). In this study, the aim is to explore the first-hand perceptions and experiences of women who have recently experienced antenatal care in the United Kingdom and perform a sub analysis of defined under-represented groups. The core aim is to gain an understanding of their opinions related to participating in pregnancy-related research.

2. Participants, ethics, and methods

2.1. The present study

The aim of the study was to understand the perceptions of pregnancy-related research, and the barriers and facilitators to taking part in it for the abovementioned under-represented groups. Additionally, we aimed to explore which factors mediate willingness to take part in research (including demographic factors and previous lived experiences). We utilised an online mixed-methods survey and used a convergent (parallel) analysis within a participatory framework with oversight from a Stakeholder and Community Advisory Group (SCAG). The Checklist for Reporting Results of Internet E-Surveys) [21] and a mixed-methods reporting framework [22] was used to report the methods and results.

2.2. Ethical considerations

Ethical approval for the study was granted from the King's College London Health Faculties Research Ethics Subcommittee (ref:-HR/DP-20/21-21756).

2.3. Patient and Public Involvement and Engagement (PPIE): participatory framework

The 'start to end' SCAG (n = 12) was formed at the outset of the study. The group used co-production principles throughout the research cycle including values-based design [23]. Six, two-hour virtual meetings were held from March 2021 to March 2023 with interim communication (feedback and updates) taking place via e-mail, a study WhatsApp group and smaller working groups or one-on-one meetings related to specific survey-related tasks. Participants of the SCAG included members with either lived experience of antenatal care and/or pregnancy research in the UK (n = 6) and healthcare professionals and/or clinical researchers with experience in women's health (n = 6). Public members of the group included representatives from the NHS Maternity Voices Partnerships and Best Beginnings Charity, representing ethnically, racially, and socio-economically diverse service users in the UK. Topics discussed in the SCAG meetings included: PPIE and co-production training; input into public-facing research study documentation, the study website, and social media presence; a systematic review interim and final [24], inclusive survey design, advertising, and recruitment strategies; survey development and testing; and survey results and findings at interim and final stages. A tabular impact log was kept for each meeting detailing the contributions and outcomes of each meeting.

2.4. Philosophy and positionality

The study adopted a philosophically pragmatic approach [25]. This meant, ontologically we acknowledged the often-competing interpretations and worldviews people hold, and reason that no single viewpoint provides the whole picture, but rather canvassing wide option – in this case, via a survey – was best to capture these differing opinions [26]. Epistemologically, we accepted that peoples' held knowledge and lived realities are somewhat measurable within the world, but we must be cognisant of generational time and cultural shift [27].

The research team diligently addressed positionality and potential biases throughout the qualitative data collection, interpretation, and integration, as scrutinised by both the public SCAG and research team members of the SCAG. Notably, despite our reflexive judgement being 'ordered' (i.e. interpretive judgement according to extant social norms), all members brought a nuanced perspective to the study, having either direct, indirect, or professional connections to the research topic. This encompassed addressing our position within and in relation to the data as 'subjective spectators' evidenced through our active involvement in pregnancy research delivery, the conduct of pregnancy-related clinical research, and personal experiences with pregnancy, with some team members personally participating in pregnancy research.

It is essential to recognise the diversity within the research team, with five out of ten researchers self-identifying as being from non-White British backgrounds. This diversity extended to professional backgrounds, encapsulating the expertise of the lead author and two co-authors with backgrounds in fetal sonography/radiography, two research midwives, a fetal medicine consultant, a professor of perinatal radiology, a senior psychologist and social scientist specialising in women's health and qualitative research, and a maternity advocate and peer researcher.

2.5. Study design: survey development and validation

The survey was developed using the on-line survey platform Qualtrics XM™ and the research survey was nested in a public engagement survey aimed at asking the public and healthcare professionals their opinions on research priorities specifically for pregnancy scanning (screening and diagnosis) research. Participants would only have been given the option to complete the research survey, about their opinions on pregnancy research, if they fulfilled the inclusion criteria. The backend survey settings were selected so that participants were prompted to answer all questions. However, they had the option to skip a question if desired. To help encourage survey completion, participants could always see their progress through the survey and they had the option to return to the survey at a later time to complete it. Since this was a public survey, a 'prevent ballot stuffing' option was selected on the survey platform to prevent repeated submissions and reduce the chance of 'spam' entries.

The survey was split into three sections: 1. Demographics and Background Information; 2. Likert Scale Questions; and 3. Open-ended Questions. The demographic and background questions included questions about age, ethnicity/race, recent experience of antenatal care or NHS research. For the Likert scale questions, the initial findings of the systematic review on factors affecting participation in research in minority ethnic women [24] served as a guide to ask questions which related to single or multiple themes elicited from the previous study. A 10-point Likert scale was used to collect responses about willingness to participate in research based on a scenario (see supplementary file – Box 1). Scores ranged from '1: unlikely' to '10: likely' to participate in the research. To reduce response bias questions were phrased in negative and positive forms. Three open-ended questions asked for additional information on: reasons which would make participation in research more likely; reasons which would make participation less likely; any other comments related to research participation during pregnancy.

The SCAG members reviewed the survey template and proposed minor amendments to the wording, suggested public access to a glossary of terms, piloted the unpublished version of the survey online, and approved amendments before the survey was re-piloted with 15 postgraduate healthcare professional students to check for any errors in the consenting process and logic design of the questions.

2.6. Participants: sampling, recruitment, and data collection

The survey was advertised with a Qualtrics XM website link via social media, with sharing from professional networks (e.g. Society and College of Radiographers, British Medical Ultrasound Society), charities (e.g. Antenatal Results and Choices, Best Beginnings), and relevant public and grassroots organisations (e.g. Mumsnet, FiveXMore, National Maternity Voices network), as well as shares from individuals via their social networks or WhatsApp. These were chosen due to established links the research group already had with the respective organisations.

Participants were directed to the survey if they fulfilled the inclusion criteria: 16 years of older; pregnant or having received antenatal care in the last three years in the UK. They were then directed to the information sheet, a video link to narrated information, and an online consent form.

The online survey format may have excluded certain groups who were in digital poverty or had low digital literacy, had a low reading age, or where English was a second language – therefore the offer to complete the survey via telephone was made via a contact form on the website (which included a translatable and captioned information video). Engagement and survey responses were monitored, and recruitment strategies amended where needed e.g. using opportunities at public conferences related to the research topic, and where SCAG members were present.

2.7. Data analyses

The threshold for inclusion in data analysis was 80 % completion of the survey as this would mean the Likert scale questions were completed.

Quantitative survey data were exported from Qualtrics to Microsoft Excel for cleaning and data visualisation. SPSS was used to analyse the survey Likert scale responses and to explore any significant differences between participant demographics and previous or perceived experiences of healthcare and research. The non-parametric Mann-Whitney *U* test was used to assess ordinal scale Likert responses and the differences between dichotomous groups e.g. healthcare professional = 'yes' or 'no'. However, 'unsure/sometimes' or 'prefer not to say' responses were excluded from the analysis. Where there was more than one categorical dependent variable, e.g. race or ethnic group, a Kushal Wallis test was performed, however very small subgroups ($n \leq 5$) were excluded due to the risk of strong individual responses giving a spurious result. An *a priori* power calculation for the Mann Whitney *U* test, using G*Power 3.1, determined a sample size of 220 (assuming balanced groups) was required to detect a moderate effect size ($d = 0.5$), for an alpha error (i.e. probability threshold, *p*) of 0.05 and a power of 0.95.

The content analysis of the open-ended questions was performed in NVivo and matrix cross-tabulation was subsequently used to compare responses with individual dichotomous attributes of interest that relate to underserved groups (e.g. race/ethnic background, experience of discrimination, English as a second language). The content analysis procedure included using a pre-defined set of codes with code definitions agreed by two researchers (HL, JM). The coding template was derived from a previously published systematic review on the same topic [24]. The coder was instructed to use top-level codes or sub-codes if more appropriate and there was flexibility to add codes throughout the coding process if new and important material did not fit the pre-existing coding structure and could have significant implications to the research question. The open-ended questions were coded for a specific concept, by a single researcher (HL). Different text or narrative forms could be coded under a single code if it had the same implicit meaning. The coding researcher left comments as memo's, using the NVivo platform, if any queries, analytical, or interpretive thoughts arose during the coding process. Irrelevant comments e.g. *'no comment'* or *'nothing else I can think of',* were left uncoded.

The aim of the content analysis was to quantify the frequency codes and the frequency of references to the codes, and to provide insight into general trends and patterns in the responses. The quantified codes were used to develop new top-level codes and then overarching clusters contained within the open-ended response data and they were subsequently reported with narrative descriptions and using the matrix cross-tabulation as a guide to find illustrative verbatim quotations. This was performed by a second researcher (JM) and the results agreed by consensus with the initial coding researcher for validity.

The results of the respective quantitative and qualitative data analyses were integrated (JM) and merged to expand and explain the evidence within the data with meta-themes or inferences, guided by the principles of the pillar integration process (PIP) [28]. The integration was presented visually using side-by-side joint data displays with the descriptive interpretation of the Likert scale responses and inferential statistical data representing the quantitative evidence and the content analysis of open-ended survey questions representing the qualitative aspects related to the phenomena presented by the quantitative data. The results of the integration were reviewed for accuracy with the coding researcher (JM) and the senior author (SAS), and the peer researcher (ZB).

3. Results

There were 260 valid responses between September and November 2021. All participants identified as having been pregnant or experienced

Table 1
Baseline demographics.

Baseline Characteristic	n	%	**Baseline Characteristic**	n	%	**Participant experience**	n	%
HCP background?			**Disability status**			**Care in pandemic**		
Service user	208	80	No	230	88.46	Yes	211	81.15
Healthcare professional	52	20	Yes	19	7.31	No	49	18.85
Total	**260**	**100**	Prefer not to say	3	1.15	**Total**	**260**	**100**
Age			No response	8	3.08	**Experience of discrimination**		
16–19	1	0.38	**Total**	**260**	**100**	Yes	27	10.38
20–24	6	2.31	**English as a second language**			Unsure	16	6.15
25–30	59	22.69	No	233	89.62	No	217	83.46
30–35	109	41.92	Yes	17	6.54	**Total**	**260**	**100**
36–40	52	20.00	Prefer not to say	1	0.38	**Experience of NHS research**		
> 40	27	10.38	No response	9	3.46	Yes	59	22.69
No response	6	2.31	**Total**	**260**	**100**	Unsure	36	13.85
Total	**260**	**100**	**Translation needs**			No	165	63.46
Ethnicity			No	13	5.00	**Total**	**260**	**100**
Asian or Asian British	11	4.23	Yes	2	0.77	**Experience of pregnancy research**		
Black or Black British	10	3.85	No response	245	94.23	Yes	49	18.85
Mixed race or Ethnic Group	9	3.46	**Total**	**260**	**100**	Unsure	14	5.38
Other ethnic group	2	0.77	**Index multiple deprivation (decile)**			No	197	75.77
Prefer not to say	2	0.77	1	23	8.85	**Total**	**260**	**100**
White British	189	72.69	2	9	3.46	**Experience of MRI in pregnancy**		
White other	29	11.15	3	15	5.77	Yes	16	6.15
No response	8	3.08	4	24	9.23	Unsure	1	0.38
Total	**260**	**100**	5	23	8.85	No	243	93.46
Sexual orientation			6	31	11.92	**Total**	**260**	**100**
Heterosexual	235	90.38	7	29	11.15	**Openness to MRI scan in pregnancy**		
Bisexual	11	4.23	8	22	8.46	Yes	186	71.54
Gay man	2	0.77	9	30	11.54	Unsure	58	22.31
Lesbian/gay woman	1	0.38	No response	54	20.77	No	16	6.15
Let me tell you (optional)	1	0.38	**Total**	**260**	**100**	**Total**	**260**	**100**
Prefer not to say	4	1.54	**Region**					
No response	6	2.31	England, East	12	4.62			
Total	**260**	**100**	England, London, South and the South East	86	33.08			
Education Status			England, Midlands	14	5.38			
School leaver age 15 or less	1	0.38	England, North East	11	4.23			
GCSE or equivalent	16	6.15	England, North West	10	3.85			
A-Level or equivalent	49	18.85	England, South West	120	46.15			
Undergraduate degree	82	31.54	Scotland	5	1.92			
Masters degree or equivalent	66	25.38	Wales	2	0.77			
Other (please specify)	39	15.00	Northen Ireland	0	0.00			
Prefer not to say	1	0.38	**Total**	**260**	**100**			
No response	6	2.31						
Total	**260**	**100**						

NHS pregnancy services in the last three years. Full demographics are reported in Table 1.

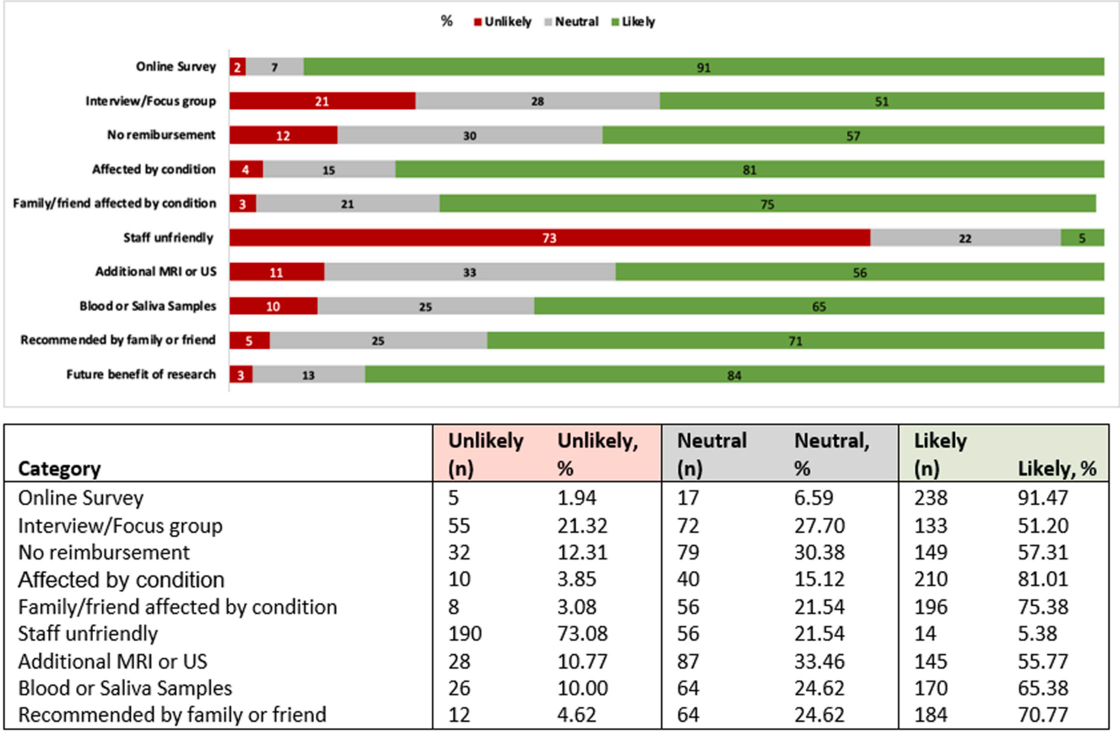
3.1. Quantitative results

The scenario question requiring ten Likert scale responses was completed by all 260 participants, and categorised into unlikely to participate (scores 0–3), neutral (scores 4–6), and, likely to participate (scores 7–10), see Fig. 1. The questions covered themes of altruism, study design, convenience, perceived benefit or harm, family or cultural influence, health data concerns, invasiveness, and incentives. The majority of questions (9/10) reported “likely to participate” responses of more than 50 %. The exception was, when asked: *"How likely are you to participate if the researcher approaching was not particularly friendly?”*, where there was a high unlikely to participate response of (n = 190, 73.1 %). The next two highest ‘unlikely to participate’ responses were if the research was an interview or focus group only study (n = 55, 21.3 %) and if there was no reimbursement (n = 33, 12.3 %). The highest scoring ‘likely to participate’ questions related to if the research involved an online survey only (n = 238, 91.5 %) and if the respondent was personally affected by the condition under investigation (n = 210/ 81.0 %). When asked: *"How likely are you to participate if the study was unlikely to benefit you, but might help others in the future?"*, there was a high likely response of (n = 219, 84.2 %).

To understand the differences in responses, the Likert scale scores were cross-tabulated with background and personal experience information. A statistical analysis was performed using the Mann-Whitney *U* test (where there were two categorical yes/no response groupings, excluding unsure or prefer not to say responses) or the Kruskal-Wallis H test (where there were more than two groups e.g. ethnicity). Due to small samples some sub-groups were excluded from the Kruskal-Wallis H analysis (education: school leaver at age 15 or less, n = 1; race/ ethnicity: other ethnic group, n = 2; sexual orientation: gay man, n = 2, lesbian/gay woman, n = 1; region: Scotland, n = 5, Wales, n = 2). Statistically significant findings are presented and explored with the rank sum outputs to explain the differences in magnitude and direction (see supplementary file Table 1 & 2).

HCPs were statistically significantly more likely to be willing to participate in research compared to non-healthcare professionals if the study included an additional pregnancy scan or included blood or saliva samples (mean rank HCP: yes = 158.00, no = 123.29, $p = 0.002$; yes = 150.79, no = 125.18, $p = 0.024$, respectively).

If the participants positively considered having a fetal MRI scan, they were statistically significantly more likely to be willing to take part in a study design which involved an online survey only, or if they had been personally affected by the condition under investigation (mean rank sum consider MRI: yes = 103.75, no = 75.34, $p = 0.034$ and mean rank sum consider MRI: yes = 104.37, no = 68.16, $p = 0.012$, respectively), and also more likely to take part if the study involved an extra ultrasound or MRI scan (mean rank sum MRI: yes = 105.24, no = 58.00, $p = 0.002$).



Category	Unlikely (n)	Unlikely, %	Neutral (n)	Neutral, %	Likely (n)	Likely, %
Online Survey	5	1.94	17	6.59	238	91.47
Interview/Focus group	55	21.32	72	27.70	133	51.20
No reimbursement	32	12.31	79	30.38	149	57.31
Affected by condition	10	3.85	40	15.12	210	81.01
Family/friend affected by condition	8	3.08	56	21.54	196	75.38
Staff unfriendly	190	73.08	56	21.54	14	5.38
Additional MRI or US	28	10.77	87	33.46	145	55.77
Blood or Saliva Samples	26	10.00	64	24.62	170	65.38
Recommended by family or friend	12	4.62	64	24.62	184	70.77

Fig. 1. Chart and data table of Likert Scale responses.

If participants had previous experience of NHS research they were still statistically significantly more likely to be willing to take part in a study even if the research staff were unfriendly compared to if they had not previously taken part in research (mean rank sum NHS research: yes = 128.14, no = 108.38, $p = 0.027$), and more likely to take part if the study involved an extra ultrasound or MRI scan or additional blood/saliva samples (mean rank sum NHS research: yes = 137.25, no = 104.65, $p = 0.001$ and mean rank sum MRI: yes = 133.44, no = 105.01, $p = 0.003$, respectively).

Statistically significant differences in Likert scale responses were seen between racial/ethnic groups relating to if a family member or a friend was affected by the studied condition or if the research staff were unfriendly (mean rank sum race/ethnicity: Asian/Asian British = 82.55, Black/Black British = 98.60, Mixed race/ethnic group = 101.72, White British = 124.66, White other= 155.38 p = 0.018, and, mean rank sum race/ethnicity: Asian/Asian British = 76.09, Black/Black British = 117.15, Mixed race/ethnic group = 80.83, White British = 128.65, White other = 131.88 p = 0.044, respectively). The mean rank sum suggested there were lower rank scores for willingness to participate even if a family or friend member were affected for those from Asian, Black, and mixed race/ethnic groups compared to White British and White other groups with White Other groups tending to score higher in this scenario. The results for researcher incivility just reached significance and lower scores were seen particularly in Asian and Mixed race/ethnic groups.

No statistically significant differences were found in this dataset for respondents living with a disability, members of the LGBTQ community, respondents for whom English was a second language, age, education

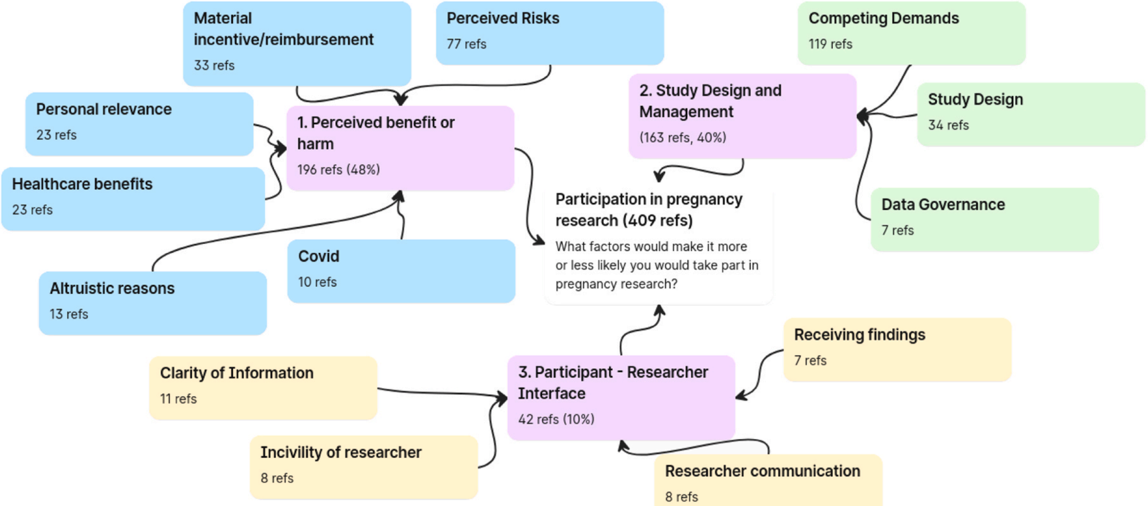


Fig. 2. Content analysis, coding clusters, and reference count for top-level codes.

status, location, index of multiple depravation, or any other background information collected as part of the survey.

3.2. Qualitative results

Content analysis of open-ended questions: For the open-ended questions, participants were asked if there were any reasons which would make it more or less likely that they would participate in research and any other comment they would like to make on the topic, with 241 participants providing open-ended responses and 47 unique codes were applied to a total of 409 unique references. References for a code are single instances where a phase, sentence, or word related to an *a priori* code and no new codes were added to the template. 28 top-level codes (which included 13 original/unique codes which did not fit neatly into the existing top-level codes) were used to summarise the initial coding. Three distinct coding clusters were identified and one labelled as 'Other'. Fig. 2 summarises the clusters as well as the top-level codes, which briefly included:

1. *Perceived benefit or harm* (n = 196, or 48 % of all references), where perception of risk (n = 77, 33 %), and material reimbursement or incentives (n = 33, 17 %) had the highest number of references within the group;
2. *Study design and management* (n = 163, 40 %), where the highest number of references in this cluster were for top-level codes which included competing demands (n = 119, 73 %), and study design (n = 34, 21 %); and,
3. *Participant-researcher interface* (n = 42, 10 %), where the highest number of references for a code included clarity of information (n = 11, 26 %), researcher communication and researcher incivility (both n = 8, 19 % each).

There were relatively few, but nonetheless important references assigned to the 'Other' cluster (n = 8, 2 % of all references), and this included six unique codes (family influence, medication, prioritising research, research availability, feeling relaxed about pregnancy, and research addressing inequalities).

3.3. Narrative review of content analysis

To understand the content analysis in the context of inclusive group status, a matrix table was constructed to cross-tabulate the coded clusters to dichotomous groupings of firstly, experience of discrimination (yes/no) to account for groups with protected characteristics which may have had negative healthcare experiences, secondly, self-reported race/ethnicity (White British/non-White British), to isolate race/ethnicity as an underserved group, and, lastly, respondents who reported English as a second language (yes/no), this group was primarily from a White Other background. The percentage of data coded to a cluster within these groups are presented in supplementary file table 3 where deeper orange/red colours represent a higher percentage of text data coded within the dichotomous groupings. The dominant clusters and significant coding spread (>10 %) are narratively described below, and includes representative quotations selected from relevant coding references (with a Cross-Tabulation Matrix presented in the supplementary file – Table 3).

3.4. Narrative description of coding clusters

Perceived Benefit or Harm to Participants:

For this cluster, the respondents discussed how research participation may be affected by the perception of risk generally in pregnancy. Their previous experiences of a difficult pregnancy may affect participation positively or negatively especially if related to a current ongoing pregnancy. The value of the research, in a greater context, was highlighted as important, as well as personal relevance and the potential of better healthcare (compared to standard care) if taking part. Material incentives or reimbursements were discussed as important, as were more altruistic reasons for participating in research often related to a personal difficult pregnancy experience. There were no strong differences in percentage coding spread identified on the matrix table for the codes in this cluster, however the risk of harm had the largest percentage of coding spread in all groups (between 8.03 % and 10.81 %, see supplementary file Table 3). Representative quotations are shown in Box1 below.

Box 1
Perceived Benefit or harm to participants.

Factors making it more less likely to participate. Code: Potential for risk or harm / research communication

"Scans are such a scary business as it is - I had a horrendous twin pregnancy and scary scans and referrals to fetal medicine - so I would feel very anxious. For this reason, I think the researchers would need to be very well versed in reassuring women and putting them at ease." *Pt 18, Race/ethnicity: White British, Age: 35–40.*

"Basically I found pregnancy really hard work and I was very anxious throughout that I wouldn't be "allowed" the birth of my choice so every time I had a scan or blood test or urine test I was scared of what would be found so I think any additional stuff like this would make me too scared. I think sometimes you can be hypervigilant which can also cause problems" *Pt 49, Race/ethnicity: White British, Age: 25–30*

Factors making it more likely to participate. Code: Better care

"If it involved finding out if the baby had any issues, we had a son who had [a rare]* Syndrome which meant he sadly passed at 17 months old and we had no idea anything was wrong until he was born" *Pt 104 Race/ethnicity: White British, Age: 25–30 *detail omitted for anonymity*

Factors making it more likely to participate. Code: Personal relevance and altruism

"Due to losing our much wanted daughter, I would be willing to participate in research that helps any woman in my situation" – *Pt 33 Race/ethnicity: Mixed Race, Age: 30–35*

"Because I have had very up and down experiences with 3 successful pregnancies and 6 miscarriages. If I can help other by doing this research then that is a really motivation for me." *Pt 121, Race/ethnicity: White British, Age: 25–30*

Factors making it more likely to participate. Code: **Material incentives/reimbursement**

"I would be more interested in taking part in research if you got a few things for the baby like nappies, wipes or vouchers to spend on the new baby" *Pt 152 Race/ethnicity: White British, Age 25–30*

3.5. Study design and management

In this cluster, the respondents discussed how competing demands could make participation inconvenient. The impact of research on available time, additional travel if the research was not local, childcare issues, and having to take time off work were seen as significant barriers to research. A greater percentage spread of coded data related to the inconvenience of research was seen for people who had not previously experienced discrimination in clinical care, for White British respondents, and when English was a first language (18.6/8.7 %, 17.9/6.7 %, and 18.2/6.4 %, respectively). This was also framed in the positive form as 'convenience' of the research, being a factor that facilitates research participation. A greater proportion of 'convinence' text coding was seen in groups who had not experienced discrimination in care, equally across ethnic groups and more for whom English was a second language (7.7, 0 %; 6.4, 6.3 %; 14.2, 5.9 %, respectively).

A smaller percentage of coded references were seen relating to other study design factors (e.g. the timing of approach), and were framed as enabling or creating a barrier to participation in research, as alluded to in Box 2. This was reflected by participants suggesting on-line or virtual participation would be preferable if it was possible. Data governance was also raised as a barrier with concerns about anonymity, data leakage, and trustworthiness of information being given about data security.

3.6. Participant-researcher interface

In this cluster, respondents primarily discussed incivility, clarity of information, receiving findings, and researcher communication skills. The main differences between groups were seen for the incivility code, which could be described researcher behaviours making it less likely that the respondent would take part in the research. There was a greater percentage coding spread for 'incivility' as a factor, if the respondent had experience of discrimination in healthcare, if they did not describe themselves as White British, or, if English was a second language (18.55 % vs 0.00 %; 7.55 % vs 0.25 %; 2.59 % vs 0.00 %, respectively), see Box 3 for example quotations. Other topics with relatively minor coding references included the language used or lack of inclusive language, mistrust or trust and reputation or credibility of researcher or research group.

4. Quantitative and qualitative integration

The key themes from firstly the quantitative assessment and then the merging of qualitative evidence with illustrative quotations is presented in Table 2 below. Three meta-themes were developed from the integration:

1. **Participation being mediated by perceptions and experience of safety, convenience, and communication.**
   In this meta-theme, safety was defined in terms of physical, psychological, and data governance. Whilst the quantitative results suggested from the Likert scale data which participants were generally positive about taking part in research, the qualitative evidence suggested a more nuanced thought process with several caveats which would impact the decision to participate. Most of the discussion in the open-ended questions of the survey contradicted the finding of 'generally likely to take part in research' and centred on the convenience or inconvenience of the study in terms of the time needed to participate or any interference with standard care pathways. In addition, a substantial proportion of the open-ended responses was related to perceptions of 'risk or harm' which could relate to unexpected findings from tests, the use of data, undue risks to the baby, or increased anxiety at an already difficult time as a potential barrier to research. The role of research/researcher communication style in the quantitative Likert scale data is supported in the qualitative data by the lower willingness to take part in research if there was any incivility or lack of warmth perceived by participants.
2. **Lived experience and education may increase access to research participation.**
   Key quantitative results in this theme were related to the knowledge, interest, or experience of the respondents and the interplay of their subsequent willingness to take part in the research. Statistically significant differences were seen between HCPs and non-HCPs; those who would consider a more burdensome fetal MRI (whether they had experienced one previously or not); and those who had personally been involved in NHS research or not. Due to the nature of these groups, they were more likely to have had more exposure (through professional or personal knowledge and/or experience) to clinical research, clinical tests, or higher risk care pathways.

   The qualitative findings provided a nuanced perspective, both reinforcing and challenging the previously identified patterns in the quantitative results. Respondents discussed the heightened anxiety stemming from additional tests, driven by concerns over unexpected findings and potential psychological distress triggered by revisiting challenging experiences from past pregnancies. Interestingly, this juxtaposed with another sentiment expressed by some participants

Box 2
Study Design and management.

Factors making it less likely to participate in research. Code: Inconvenience:

"Time and location, e.g. An extra blood test when already at the hospital is fine but having to attend on a different day or having to travel separately for a focus group would put me off as I only started maternity leave a week before my due date so time was quite precious while still working." *Pt19. Ethnicity: White British, Age: 30–35*

Factors making it more likely to participate in research. Code: Convenience

"…sensible timing/ease of participation (e.g. no separate travel but folded in with ordinary antenatal care). *Pt241. Race/ethnicity; White Other, Age: 40 +*

Factors making it less likely to participate in research. Code: Concerns about data

'I was asked to have additional testing of my blood, …, I refused as it was supposedly anonymous but then said if something was picked up they could let you know' Pt227, Race/ethnicity: undisclosed, Age: 35–40

Factors making it more likely to participate in research. Code: Study design.

'There's a difference btw interview and focus group. Interview easier as don't have to fit in with others.' Pt82, Race/ethnicity: White Other, Age: 35–40

Box 3
Participant-Researcher Interface.

Factors making it less likely to participate. Code: Clarity of information.

"…not fully understanding of the overall research agenda and how my answers might be 'analysed'…" *Pt86 Race/ethnicity: White Other, Age; 40 +*

Factors making it less likely to participate. Code: Incivility

"If those conducting or involved with the research were in any way insensitive, condescending or showed signs of a lack of empathy I would find dispassion a bit off putting too though I understand the nuances of professionalism. The "bedside manner" of those involved. If the images and language used was discriminatory, not inclusive, unclear or too verbose I would also be less likely to participate as I would if questions seemed dumbed down or too surface level." *Pt 09, Race/ethnicity: Other, Age: over 40*

"…my traumatic experiences from last year with my pregnancy loss also led me to experiencing unpleasant and judgmental doctor appointments at time (others were supportive) and so the person leading the research on such a sensitive topic to me would need to be personable and kind as if they weren't I would avoid it…" *Pt 163 Race/ethnicity: White Other, Age: 30–35*

Table 2
Pillar integration display table.

Quantitative			Qualitative	
Data	**Description**	**Pillar Building Theme Iteratively developed meta themes**	**Description**	**Illustrative verbatim quotation**
Likert scale responses positive for research participation (9/10), other than for researcher incivility	General positivity about research	**Participation being mediated by perceptions and experience of safety (physical, psychological, and governance), convenience and communication**	Study design and management/researcher participant interface - data governance, researcher communication	"I was asked to have additional testing of my blood, …, I refused as it was supposedly anonymous but then said if something was picked up they could let you know" Pt 227
HCPs more willing to take part in research if additional tests are included (p>0.05)	Higher clinical or research knowledge lowering barrier to entry to research	**Lived experience and education may increase access to research participation**	Perceived benefit to research may lower bar to research - better care	"*[I'd be more likely to participate…]* If it *[the research]* involved finding out if the baby had any issues, we had a son who had [a rare]* Syndrome which meant he sadly passed at 17 months old and we had no idea anything was wrong until he was born" Pt104
Receptiveness to advanced imaging increases receptiveness to research (surveys), if previously affected or if additional imaging tests are included (p>0.05)	Preferences for more in depth research if there is an underlying interest in advanced assessments		Perceived risk of harm or benefit to research - difficulties in previous pregnancy	"Scans are such a scary business as it is - I had a horrendous twin pregnancy and scary scans and referrals to fetal medicine - so I would feel very anxious. For this reason, I think the researchers would need to be very well versed in reassuring women and putting them at ease." Pt 18,
Research experience (NHS research and HCPs) increases receptiveness and interest in additional tests despite researcher communication (p>0.05)	Enhanced perceptions of research benefit in terms of additional clinical tests, making other factors less of an influence		Perceived risk of harm or benefit to research - Altruism	"Because I have had very up and down experiences with 3 successful pregnancies and 6 miscarriages. If I can help other by doing this research, then that is a real motivation for me." Pt 121
Differences seen between race/ethnic group related to how social factors impact participation (p>0.05)	Sociocultural differences in facilitators to research participation related to altruism and researcher rapport	**Sociocultural differences may lead to research hesitancy**	Perceived risk of harm or benefit to research and researcher participant interface - researcher communication and rapport	"If those conducting or involved with the research were in any way insensitive, condescending or showed signs of a lack of empathy I would find dispassion a bit off putting too though I understand the nuances of professionalism. The "bedside manner" of those involved. If the images and language used was discriminatory, not inclusive, unclear or too verbose I would also be less likely to participate as I would if questions seemed dumbed down or too surface level." Pt 09

who contended that navigating difficult experiences serves as a motivational factor in research. Despite the acknowledgment that personal benefits might not accrue, these participants emphasised the potential impact on future mothers in similar circumstances as a driving force behind their engagement.

Furthermore, certain participants expressed enthusiasm for the prospect of additional tests, such as 3D ultrasound scans. Their perspective was shaped by the comparison with practices in their native countries, where a broader range or more frequent tests are typically offered during pregnancy. Additionally, these participants were cognisant of the fact that not all conditions can be identified in the early stages of pregnancy as thus saw the research as an opportunity for enhanced antenatal care.

3. **Sociocultural differences may lead to research hesitancy.**

While the quantitative findings highlighted distinctions among racial/ethnic groups, related to participating in research when a family member or friend had experienced the studied condition, the qualitative responses did not corroborate the findings or provide an explanation for stronger or weaker altruistic motivations, which could be multifactorial. In the qualitative data, supportive quotations were identified for the code related to researcher incivility and appeared more densely discussed in groups who may be at higher risk of health inequalities (experience of discrimination, English as a second language and identifying as non-White British).

5. Discussion

This study gained first-person insight individuals' recent experiences of pregnancy or NHS maternity services and investigated the multifaceted factors influencing attitudes toward research participation. The diverse sample included participants from various UK regions, age groups, racial/ethnic backgrounds, sexual orientations, educational levels, and disabilities. Quantitative findings indicated a general willingness among participants to engage in research, with certain scenarios affecting their inclinations.

Within the qualitative data, nuanced perspectives emerged, reflecting the complex interplay of various factors. The convenience of research, concerns about risks or harm, and the quality of communication were highlighted as crucial elements shaping participants' attitudes. Noteworthy findings indicated that healthcare professionals and individuals with prior research exposure were more inclined to participate, suggesting the importance of early contact with researchers and outreach. Moreover, socio-cultural factors, such as race/ethnicity, played a role in influencing responses, with certain groups expressing hesitancy linked to past experiences of discrimination and concerns about researcher incivility.

In integrating quantitative and qualitative insights, the study illuminated the intricate dynamics influencing research participation and uncovered three overarching meta-themes:

1) Participation being mediated by perceptions and experiences of safety, convenience, and communication style,
2) Lived experience and higher education potentially lowering the bar for research participation; and,
3) Sociocultural differences possibly leading to research hesitancy.

Researchers should emphasise: The significance of convenience, education about the research process and any perceived risks, material reimbursement, and benefits to clinical care (without increased anxiety as trade-off). Established research group profiles and high-quality researcher communication skills may affect perceptions of trust and credibility, and trust in the management of data governance and ethics, bolstering feelings of altruism related to research participation The quality of the first recruitment is a critical window of opportunity which should not be underestimated.

Some of these findings are echoed in the published literature, which assess barriers to research participation amongst ethnic minority patient groups, [17]; but extend beyond research participation in minority racial or ethnic groups, promoting therefore a balanced view across service users [29].

5.1. Key strengths, limitations, and future directions

This is the first study which has focused specifically on research engagement of UK antenatal service users with a sub-analysis of ethnic minority groups; for which we had a collaborative community advisory group, including stakeholders from diverse racial/ethnic/sociocultural backgrounds. The narrative interpretations were in keeping with the quantitative and qualitative findings, however, to understand the antenatal care experiences (including research participation) of women from diverse backgrounds, focus group or interview studies with the population of interest will very likely offer richer insights.

The systematic approach to data collection and analyses offers invitation for similar replications in other healthcare services. The survey was built within this SCAG collaboration and piloted prior to being rendered online. The mixed-method design meant participants' views could be visited and analysed as broad perspectives towards research participation while being complemented by an analysis of the themes and details from the qualitative data which invited further insight. Although the sampling was skewed toward the south of the UK, sample sizes were sufficient for a meaningful sub-group analysis.

Our survey was nested within a wider research priority partnership public engagement survey, which may have biased our sample to those already willing to participate in research. Furthermore, the inclusion of healthcare professionals could be interpreted as skewing the data by speaking about their perceived experiences of women, although we do not believe this to have been the case as they remain a relatively small proportion of the participants and many of whom would have experienced maternity care themselves. We appreciate also our data collection approach may have excluded those experiencing digital poverty and our analytic decisions to exclude on the basis of survey responses may appear counter to the promotion of under-represented groups' voices, but believe our representation was still in-line with national levels of diversity and therefore not something to be problematised within the bounds of this study. Future research should attempt to engage those who may usually decline research in the antenatal period.

6. Conclusions

The findings in this work underscore the importance of safety, convenience, effective communication, and sociocultural considerations in shaping individuals' attitudes and decisions regarding involvement in research activities. Clinical researchers and research delivery teams working in antenatal settings, have the potential to impact the inclusion of underserved communities through facilitative research designs, well considered communication strategies, and authentic relationships that support participant education about research.

CRediT authorship contribution statement

Conceptualization (JM, SAS); Data curation (JM, HL); Formal analysis (JM, HL); Funding acquisition (JM, SAS, ES, LS, MR); Investigation (JM, ZB, HL, SAS); Methodology (JM, SAS); Project administration (JM, ES); Resources (MR, LS); Software (MR,LS); Supervision (MR, LS, SAS); Validation (SAS, HL); Visualization (JM); Roles/Writing - original draft (JM, SAS, JNS); and Writing - review & editing (all).

Author Agreement

This article is the authors' original work, and the article has not received prior publication and is not under consideration for publication elsewhere. All authors have seen and approved the manuscript being submitted and the authors abide by the copyright terms and conditions of Elsevier and the Australian College of Midwives.

Ethics Statement

Ethical approval for the study was granted from the King's College London Health Faculties Research Ethics Subcommittee (HR/DP-20/21–21756).

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Conflict of interest

The authors declare no conflicts of interest.

Appendix A. Supporting information

Supplementary data associated with this article can be found in the online version at doi:10.1016/j.wombi.2025.101942.

Data availability

The datasets generated and/or analysed during this study are not publicly available, but a de-identified dataset may be available from the corresponding author upon reasonable request.

References

[1] O. Esan, N. Adjel, S. Saberlan, , Mapping existing policy interventions to tackle ethnic health inequalities in maternal and neonatal health in England: A systematic scoping review with stakeholder engagement London, 2022.

[2] T. Awe, C. Abe, M.W.R. Peter, The Black maternity experiences survey: a nationwide study of black women's experiences of maternity services in the United Kingdom London, 2022.

[3] Birthrights. Birthrights. Systemic racism, not broken bodies. An inquiry into racial injustice and human rights in UK maternity care: executive summary. Coventry, 2022.

[4] S. Gohir, Maternity experiences of Muslim women from racialised minority communities Birmingham, 2022.

[5] University of Birmingham, Healthy Mum, Healthy Baby, Healthy Future. The Case for UK Leadership in the Development of Safe, Effective and Accessible Medicines for Use in Pregnancy. Birmingham, 2022.

[6] C.R. McCarthy, Historical background of clinical trials involving women and minorities, Acad. Med. 69 (1994) 695–698.

[7] A. Smart, E. Harrison, The under-representation of minority ethnic groups in UK medical research, Ethn. Health 22 (2017) 65–82.

[8] S.S. Rathore, H.M. Krumholz, Race, ethnic group, and clinical research, Br. Med. J. 327 (2003) 763–764.

[9] E.P. Havranek, M.S. Mujahid, D.A. Barr, et al., Social determinants of risk and outcomes for cardiovascular disease, Circulation 132 (2015) 873–898.

[10] G.A. Mensah, A.H. Mokdad, E.S. Ford, , et al. State of disparities in cardiovascular health in the United States. In: Circulation. Circulation, pp. 1233–1241..

[11] L. Wright, A. Steptoe, D. Fancourt, Are we all in this together? Longitudinal assessment of cumulative adversities by socioeconomic position in the first 3 weeks of lockdown in the UK, J. Epidemiol. Community Health (1978) 74 (2020) 683–688.

[12] UK Parliament. Written evidence submitted by Institute of Health Visiting, 2020. ⟨https://committees.parliament.uk/writtenevidence/4597/html/⟩ (Accessed 11 September 2020).

[13] NHS England. NHS England » NHS boosts support for pregnant black and ethnic minority women, 2020. ⟨https://www.england.nhs.uk/2020/06/nhs-boosts-support-for-pregnant-black-and-ethnic-minority-women/⟩ (Accessed 11 September 2020).

[14] A. Felker, R. Patel, R. Kotnis, , Saving Lives, Improving Mothers' Care Compiled Report - Lessons learned to inform maternity care from the UK and Ireland Confidential Enquiries into Maternal Deaths and Morbidity 2020-22 Oxford, 2024.

[15] NHS Resolutions. Annual report and accounts 2023/24, ⟨https://resolution.nhs.uk/wp-content/uploads/2024/07/NHS-Resolution-Annual-report-and-accounts_23-24_Access-1.pdf⟩ (2024).

[16] National Institute of Health Research. Improving inclusion of under-served groups in clinical research: Guidance from INCLUDE project. 2020.

[17] L.T. Clark, L. Watkins, I.L. Piña, et al., Increasing diversity in clinical trials: overcoming critical barriers, Curr. Probl. Cardiol. 44 (2019) 148–172.

[18] S. Dawson, S.M. Campbell, S.J. Giles, et al., Black and minority ethnic group involvement in health and social care research: a systematic review, Health Expect. 21 (2018) 3–22.

[19] Anekwe L. Ethnic disparities in maternal care. The BMJ; 368. Epub ahead of print 12 February 2020. DOI: 10.1136/bmj.m442.

[20] Psarros A. Mothers' voices: Exploring experiences of maternity and health in low income women and children from diverse ethnic backgrounds, 2018. ⟨www.maternityaction.org.uk⟩ (Accessed 11 September 2020).

[21] G. Eysenbach, Improving the quality of web surveys: the checklist for reporting results of internet E-surveys (CHERRIES), J. Med. Internet Res. 6 (2004) e34.

[22] A. O'Cathain, E. Murphy, J. Nicholl, The quality of mixed methods studies in health services research, J. Health Serv. Res. Policy 13 (2017) 92–98, https://doi.org/101258/jhsrp2007007074.

[23] Ahmed E., Newburn M., Moltedo V., et al. *I*nvolving diverse communities in maternity and perinatal mental health research: Insights and learning from a co-production training event. London, 2021.

[24] H. Lovell, S.A. Silverio, L. Story, E. Skelton, J. Matthew, Factors which influence ethnic minority women's participation in maternity research: A systematic review of quantitative and qualitative studies, PLoS One 18 (2) (2023) 1–19, https://doi.org/10.1371/journal.pone.0282088.

[25] D.L. Morgan, Pragmatism as a Paradigm for Social Research, Qual. Inq. 20 (2014) 1045–1053.

[26] J.C. Woodring, S.M. Foley, G. Santoro Rado, et al., Focus groups and methodological reflections, J. Disabil. Policy Stud. 16 (2006) 248–258.

[27] D. Ruwhiu, M. Cone, Advancing a pragmatist epistemology in organisational research, Qual. Res. Organ. Manag. Int. J. 5 (2010) 108–126.

[28] R.E. Johnson, A.L. Grove, A. Clarke, Pillar integration process: a joint display technique to integrate data in mixed methods research, J. Mix Methods Res 13 (2019) 301–320.

[29] F. Conforti, L. Pala, V. Bagnardi, et al., Cancer immunotherapy efficacy and patients' sex: a systematic review and meta-analysis, Lancet Oncol. 19 (2018) 737–746.