City of Sanctuary
Maternity
Stream

Good practice guide for maternity research among women seeking sanctuary

With thanks to the following Experts by Experience:

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This document should be cited as:

Sharma E., Miller J., Pérez Arribas I. & Hili C. (2026) A good practice guide for maternity research among women seeking sanctuary. UK: City of Sanctuary Maternity Stream

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21st April 2026

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Introduction

This guide is for those who conduct maternity-related research among women who are seeking sanctuary, including refugees or asylum seekers. It is informed by literature on the participation of refugee and asylum-seeking people in research, lived experiences of those who have participated in the NCT and Yorkshire and Humber Maternity Stream of Sanctuary and the King's College London No Recourse to Public Funds (NRePF) study, and the joint experiences of the members of the City of Sanctuary Maternity Stream Research Network who have conducted research of this nature. Although this guide has a UK focus, many of the underpinning principles are applicable to research taking place in other contexts.

It has been developed in response to the increase in research that is being conducted among refugee and asylum-seeking women, recognising that guidance on how to conduct research of this nature is either disparate or incomplete. It aims to counter research practices that can be unwittingly deleterious to those being researched, reproducing harms to women in already highly precarious circumstances. Instead it provides recommendations grounded in ethical principles. It is therefore our aim, through developing this guidance, to consolidate research praxis to provide a centralised resource of good practice, encompassing both academic considerations as well as seldom-documented practicalities. It is not designed to be exhaustive but rather to spotlight good practice and signpost to further reading or information, all within one document. In addition to providing guidance for those undertaking research, including at the stage of applying for research ethics, this document will also be helpful for research ethics board members assessing applications for research in this field.

The guidance is structured according to the various stages of research, for ease of reference, followed by cross-cutting considerations. Whilst it is recognised that the extent to which this guidance can be implemented may be constrained by resources available to researchers, we nonetheless urge researchers to prioritise, as far as possible, good practice in the context of limited resources.

Study design and grant application

- From the early planning stages of the research proposal involving those with relevant lived experience can help to identify a meaningful research topic and question(s). Experts by experience provide insights into the research question to ensure that research is relevant, important, and of potential benefit to those being researched.
    - Collaborating with community groups, charities or other relevant organisations can provide important insights into study design and connections to Experts by Experience.
    - Consider opportunities for Experts by Experience to receive training so that they can fully participate in their role in the research project.
    - Ensure the time and expertise of experts by experience in the early stages of planning a study and developing a grant application is recompensed.

- Involving experts by experience in the selection of methods, data collection tools, data analysis, and dissemination (and later on, study materials eg. participant information sheet, consent form, leaflets, posters etc.), will establish a study design that is well-suited to those with whom research is being conducted and reduces the risk of causing unintended harm to participants.

Involving women with lived experience in study design planning: The MAMAH Study, Dr Kerrie Stevenson

The Migration and Maternal Health (MAMAH) Study aims to improve maternity care for underserved migrant women (asylum seekers, refugees, those with NRPF, and undocumented women) in the UK. We reflect on engaging these women in our grant proposal development. An expert by experience, a migrant woman who had given birth in the UK, joined the team early, aiding recruitment and planning. With NIHR Public Involvement Funding, we hosted two online workshops to learn what women wanted the study to address. Many felt disempowered by researchers focusing on negative experiences and preferred to discuss strengths-based solutions. This shifted our focus to co-designing improvements. Women said that having an expert by experience co-host workshops encouraged participation and reduced the power imbalance, so we embedded this approach throughout. Some women were uncomfortable in institutional settings, so we formed expert-by-experience subgroups with elected reps for multi-disciplinary meetings. Online engagement was preferred for its flexibility. The lead expert by experience co-developed the proposal with the principal investigator, and the wider group provided feedback. We budgeted for training in research methods for our lead expert by experience. Though not fully representative, this work shows the value of consulting underserved voices from the outset of planning a grant proposal. We offered women a shopping voucher to reimburse them for their time. It can be used at over 100 shops in the UK and offers women flexibility with where they want to spend it.

- Methods that enable reciprocity redress researcher-participant power imbalances that may otherwise reinforce vulnerability and powerlessness[1] should be considered.
    - Avoid "dip-in, dip-out"[2] methods that can be extractive, causing participants to feel that their stories are being 'stolen' but rather consider using participatory research methods that foster collaboration and contribute to enhancing people's lives and their futures[3].

- When engaging with women as experts by experience in-person, it is important to go to them, rather than expecting them to come to the researchers' location. Additionally, visiting women in spaces where they already feel safe (for example, a women's group run by a community group or charity) provides reassurance to women about researchers, enabling trust to be developed.

- Ensure there is sufficient budgetary allocation when putting together a grant application. For example, the time taken by charity or other organisational partners to support the study with recruitment or other resources, recompense for the involvement of experts by experience and those participating in the study (including childcare and travel costs), and costs of study materials that are accessible to all.

Making participatory approaches work: The ERicar study, Dr Mabel Lie

The ERicar zine was part of a community-based research project with Czech-Slovak Roma mothers. The project consisted of a series of workshops in which pregnancy stories were explored to inform an antenatal information resource. The zine – a handmade magazine – was used to bring together key messages and important information workshop participants wanted to share with other women in their community. At the start, workshops to hear from women about their migration stories provided an opportunity to break down barriers, build trust, and promote understanding of each other's circumstances. In the case of ERicar, the two workshops also included an opportunity for the women to create a memento from materials provided e.g., a handmade badge that they decorated representing what was most important for them in their journeying.

Recruitment and data collection

1. Building trust

- engaging with community groups and charities can often be critical in providing access to research participants and can also act as an important safety 'buffer' between participants and researchers.
    - Take time to develop a continuous good working relationship with key organisational partners, and subsequently with potential and recruited participants, prior to commencing data collection, in order to build trust and confidence in the researcher(s).
    - Be mindful that NGO / charitable sector organisations often operate under time and funding constraints. Furthermore these organisations may be fielding many requests by researchers to access those whom they support. One option to support the demands on such organisations is for researchers to take on a volunteering role.

- Where possible, organising a one-to-one or group introductory meeting with participants, with a partner NGO or organisation present where relevant (who can if necessary mediate between researchers and participants), can be helpful prior to commencing data collection. This enables rapport and trust to be built. It also acts as a means to provide information to participants, such as how to withdraw from participation, and allows for a discussion of questions or concerns about the research and participation.

- At the point of recruiting women, offer them the option to use a pseudonym to protect their identity, including use of a pseudonym when signing a consent form.

Building trust during interviews: Exploring asylum seeking and refugee women's experiences of perinatal social support, Dr Marie-Clare Balaam

I found that many women may have experienced hostility and prejudice and so be hesitant to trust people they perceive to have authority. I was careful to always keep the woman at the centre of the interview; their voices are the ones we need to hear. I considered participants' psychological and physical needs, and comfort, in terms of the location, timing and set up of the interview. For example, meeting in places that were already known to them, and that were easy for them to access, such as mother and baby groups. I built connections and relationships with them by arranging multiple meetings in their community locations which demonstrated my interest and commitment. Women who have migrated often have complicated lives and many calls on their time, so I was flexible and adapted my research practices to their needs and preferences, for example, by rescheduling interviews, working round infants' nap times or school pick up. I was ready to move away from ideals of how interviews are done. Many women who have migrated may have experienced trauma as part of their journey and/or in relation to perinatal experiences, so I used a trauma-informed approach to interviews and to the subjects we explored together. I also considered my positionality with regards to the participants with whom I worked and how aspects of my identity and social location may have impacted my relationships and the knowledge we produced together.

2. Research team

- All those involved in data collection with direct contact with participants must take a trauma-informed approach. Training on trauma-informed research is available from a number of providers, such as the Social Research Association.

- If peer researchers are involved, it is helpful to be aware that their involvement can be potentially beneficial or a barrier during the data collection phase:
    - Peer researchers with lived experience of precarious migration can challenge traditional research hierarchies, power imbalances, and a 'them and us' relationship between researchers and those being researched.
    - While they can bridge language and cultural barriers and act as an advocate for participants, within some cultures, anxiety about sharing personal information with others from the same community can exist. It is important to seek advice from experts by experience on the appropriateness of peer researchers.

- It may be necessary to brief the wider research team and collaborators to educate them on the value of lived experience and avoiding hierarchies in their titles and introductions in meetings.

3. Data collection

- Some participants living in precarious circumstances may regularly change their phone number - consider scheduling a time for participation soon after recruitment.

- Offer women a choice of participation modes, for example, either focus group discussion or one-to-one interview, either in-person or remote participation, to enable women participating on their terms. This is particularly important when involving women who have or are experiencing violence, abuse or harm related to their migration or have been trafficked. Be aware that these women may not wish to disclose experiences of harm to researchers.

- Ensure that flexibility of timing of participation is provided so that women can participate at a time that is convenient for them, for example, avoiding school pick-up times, or coordinating with their baby's nap times.

- Ensure interview questions are not overly lengthy or complicated (see also the section on 'Interpreting and translation' for details on translating interview questions).

- For remote interviews, providing participants a choice of platform to use (eg phone call, WhatsApp video call) enables them to use a platform with which they feel comfortable. Ensure that any costs incurred in conducting remote interviews are covered (such as compensating for the cost of mobile data or providing remote phone credit top-ups).

- For in-person interviews, ensure the location prioritises participant comfort. For example, where possible, hold in-person interviews or focus group discussions at a location that is physically accessible to women, provide childcare (such as an on-site creche) so that women with pre-school age children can attend and participate fully, and reimburse transportation costs.

- When conducting focus group discussions, bear in mind that women vary as to how comfortable they feel speaking in a group with women from the same home country or ethnicity. Some women benefit from the social connections that focus group discussions offer, but other women prefer not to deliberately interact with others from their home country for fear of information they share during group discussions being shared with others in their community without their permission. Preliminary discussion with experts by experience can provide important insights into how best to conduct focus group discussions.

- It is important to recognise that participation has the potential to re-traumatise women.
    - It is vital that if sensitive topics will be raised that women are informed about this in advance so that they are aware of the nature of the discussion.
    - Participants becoming upset during interviewing is not a reason alone to terminate an interview - some women find participation in research therapeutic whilst also upsetting
    - Developing a 'distress protocol' can be a helpful tool in preparation for conducting qualitative research[4].

- All women should be offered the opportunity to debrief after participation, to provide an opportunity to discuss any aspects of taking part in the research that triggered negative emotions. Consider collaborating with another organisation (such as NGO or healthcare organisation) who can provide debriefing services if necessary. Signposting or referring women for further support may be necessary - researchers should draw up a list of relevant organisations to which participants can be directed.

- Member checking of transcripts can in some situations be useful for data validation (for example, to clarify meanings where interpreters or translators have assisted with interviews) but consider this on a case-by-case basis: this additional involvement may create an undue burden on participants.

Remote interviewing: A study to address inequalities in perinatal mental health assessment and support for asylum seeking and refugee women, Dr Amanda Firth

When completing online research interviews during the Covid pandemic I had to be mindful of women's physical surroundings. Many women were living in shared or crowded accommodation where it was difficult to secure privacy. Using headphones was helpful, as well as reminding women that they could pause the interview or decline to answer questions if others entered the room. Not everyone had access to wifi and data for video calls is expensive. I ensured that data costs were covered before the interview took place and was fortunate that sim cards with data were provided by a charity. During the pandemic women were even more socially isolated than normal. I liaised closely with the charity promoting the project to offer ongoing pastoral support and signposting where needed after completion of interviews.

4. Remuneration for participation

- It is imperative that some form of recompense be made available for those participating in research, in recognition of their time and experience, and to move away from research being extractive (see also the 'Recompense for involvement in research' section below).

Data analysis and interpretation

- Consider involving research participants and experts by experience in the analysis and / or interpretation of data.

- Time taken for this involvement must be appropriately recompensed.

- The benefits of involvement in data analysis and interpretation must be weighed against the burden of doing so, especially for women in precarious circumstances who may have caring, income generation, and other responsibilities. Care should be taken to ensure any involvement in analysis must not place an undue burden on those taking part, and any time taken for involvement in this way should be recompensed.

- Consider appropriate ways in which participants can participate in analysis and interpretation that is meaningful for them, such as holding workshops to provide a space in which participants can reflect on the data, and using participatory and creative methods.

- Consider opportunities for participants or experts by experience to receive relevant training in data analysis, where appropriate.

Dissemination

- Informing research participants about the findings of a study is really important and respects their contribution.

- Collaborate with experts by experience and organisations who work with childbearing women seeking sanctuary to ascertain the best means for sharing research findings. For example, holding a workshop to feedback findings, co-creating an animation or video to communicate findings, or producing a short and easy-to-understand report, using a combination of text and images.

- Signpost women to a location in which other research findings are shared, such as a study website, so those who are interested can learn more.

- Consider involving participants and/ or experts by experience in conference or other presentations, where appropriate.

- ·Consider the inclusion of experts by experience and inter-cultural research assistants as co-authors on academic papers, ensuring they have the opportunity to participate in the writing of papers and research outputs.

- Some women chose to participate in a study as a means of having their voice heard - as researchers we have a responsibility to respectfully amplify whatever they have shared with us as part of the research process.

Recompense for involvement in research

- When involving women in research with lived experience of being a refugee or asylum seeker, whether as part of PPI or research participation, it is vital that they are adequately recompensed.

- Comprehensive guidance exists for general considerations with regards to payment and recognition for public involvement in research, that includes budgeting for involvement and making clear what payment and/or recognition will be offered, and suggested payment rates.[5] There are however specific or additional factors that need taking into account when participants are refugees or asylum-seekers:
  - Ensure that travel costs are budgeted so that those involved in the research have all travel costs reimbursed.
  - Pay for expenses in advance so there is no delay with reimbursement.
  - Provide flexibility with how payments are made.
  - Payments in the form of gift vouchers (such as high-street shopping vouchers) are a more appropriate when recompensing those without a right to work (including most asylum seekers). Involving participants in advance in the selection of the type of voucher that is given ensures that remuneration is meaningful.
  - Be prepared to send vouchers in a way that is most accessible to recipients, for example, sending a photo of a voucher by WhatsApp or providing a physical voucher instead of a voucher code by email.

- Consider allocating role titles for those involved in research, depending on the level of responsibility, such as 'Public and Patient Involvement (PPI) Coordinator' or 'PPI Contributor', to place meaningful value on these roles.

- Consider other forms of recompense for research involvement such as food, accredited training opportunities or job references.[6]

Interpreting and translating

- It is vital that language barriers do not prohibit involvement in research, whether as part of PPI work or as a participant and therefore adequate funds need to be built into research projects to cover interpreter costs.

- All written materials should be translated and back translated for accuracy, ensuring that the language used is culturally appropriate and acceptable.

- Bear in mind that English-speaking participants may still benefit from the help of an interpreter during interviews to fully understand what is being asked by a researcher and to express themselves.

- Suitable interpreters should be identified. For many women involved in research, this may mean identifying a female interpreter, particularly when discussing issues around reproduction or sexual health that are considered a sensitive topic in some cultures.

- Interpreters should be comprehensively briefed in advance of data collection. This briefing may include a discussion about the extent to which the interpreter is free to add prompts during interviews, ways in which certain words or phrases are interpreted to convey the intended meaning[7], as well as taking time to establish a good working researcher-interpreter rapport.

- Researchers should be aware that conducting interviews with interpreters takes additional time. Consider allocating either additional time or asking fewer questions as appropriate to the research design and participants' needs.

- Interpreters should be acknowledged for their role in shaping the production of knowledge - they are not merely conduits of communication but active in the way that meaning is conveyed in research[8], often acting as cultural mediators as well as interpreters. In some cases this acknowledgement might include co-authorship of a published paper.

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