

Diversity, relationships and community leaders – Public involvement tips and reflections from the RELAX (Reducing Levels of AnXxiety in pregnancy and after birth) research project



RELAX public advisers share ideas with researchers on clear ways to summarise study findings



Reducing Levels of Anxiety - in pregnancy and after birth

December 2025

Contents

About the RELAX study and reflecting on PPI	1
1. Plan for inclusivity from the start	3
2. Work your community connections	4
3. Values matter	5
4. Consider the evidence you need for reporting PPIE	6
5. Build in review discussions and reflection	8
6. Everything will take much more time than you anticipate	9
7. Relationships are important	10
Acknowledgements and reference	11

A RELAX study writing group

This report has been co-produced by Mary Newburn, patient and public involvement and engagement (PPIE) lead for the RELAX (Reducing Levels of AnXxiety in pregnancy and after birth) project; public involvement advisers, Abi Gay, Abigail Mensah, Siobhean McCarthy-Perham and Tanjida; and King's College London researchers, Britannia Volkmer, Colette Hirsch and Nathalie Towner.

About the RELAX study

Around 40% of pregnant women and new mothers experience high levels of worry and anxiety, which can negatively affect their daily lives. Anxiety can be fuelled by negative thoughts about the future, such as worrying, 'Will my baby be healthy?', or mulling over negative events from the past.

Researchers at King's College London secured funding from the NIHR in 2021 for a study designed to test an easy-to-use online training (called RELAX) for pregnant women and birthing people with mild to moderate anxiety. The training was designed to help reduce their worry and anxiety. The study¹, which began recruiting participants in June 2023, aimed to test whether adding RELAX to usual maternity care can prevent anxiety increasing during pregnancy and after birth. The study is now coming to an end: research publications are being prepared, with the main study results included in a plain English summary, as well as a journal article on public involvement.

Reflecting on patient and public involvement in RELAX

In this report, members of a study writing group share some reflections about public involvement in the RELAX project and our tips for others. We hope that this will help other groups and individuals interested in doing patient and public involvement (PPI) in research, including researchers, health service users, patients and communities.

At its best, PPI in research can improve the quality of research studies. When practiced as a democratic process it can give groups of people a voice about their healthcare options, build confidence and skills among those involved in co-design, and increase trust in research with communities. We hope our reflections and tips will help research groups work together creatively and to full potential.

'I feel it's been super-well organised – we've had lots of opportunities to have a voice and determine the direction.'

(RELAX online PPI impact meeting, October 2025)

Reflection is a key part of learning. It is useful to think about what has occurred, and to discuss and evaluate what has gone well, for whom and why. It is also helpful to consider what might be done differently going forward.

Over the course of the RELAX study, we had a multi-ethnic group of 20+ public involvement advisers, many with lived experience of perinatal anxiety, as well as some representatives of large organisations and smaller grassroots community organisations. A core group of 15 public involvement advisers continued to work with researchers until the end of the project. Mary Newburn, an independent patient and public involvement and engagement (PPIE) lead, chaired quarterly online PPIE advisory group meetings, the regular forum for PPI advisers and researchers to discuss many aspects of the study. This model has worked well. We have learned by reflecting from different perspectives on what elements have been successful and why.

Reflection can be done alone, but is even better when done with others. This might be as a research group or with someone quite separate from the process. People with related experience – and people who know little or nothing about research or public involvement in research – can be a useful sounding board or have creative ideas. Make a safe space to talk about PPI in research at the planning stage, along the way and at the end. This can help to make clear a range of perspectives. Here are some of our reflections on things we have learned.

1. Plan for inclusivity from the start

Equity, diversity and inclusion (EDI) are three important values to guide who you involve and how you work together. Team members have different experience and training on these concepts and related ones, such as 'cultural competency'. Share what all team members know and think about training needs. 'Trauma-informed' working may be important, too, depending on your study.



Working in small groups with flipchart paper and Post-it notes to capture ideas

The value of equity, diversity and inclusion

“Equity, diversity and inclusion shaped every stage of the RELAX project. Our public adviser group was multi-ethnic, with many women bringing direct lived experience of perinatal anxiety. This mix created a richer understanding of how culture, identity and personal history can influence the way anxiety is felt, interpreted and described. It also helped us design language and study materials that were culturally appropriate and sensitive to different forms of expression. Advisers challenged assumptions, flagged unseen barriers and helped the team check that everything felt respectful and accessible for a wide range of women.”

Abigail Mensah, public involvement adviser

We found that EDI only works when it is explicit.

- Early conversations about values, expectations and personal comfort levels encouraged trust and made it easier for public involvement advisers to speak freely.
- We adopted guidance developed with the ARC’s maternity and perinatal mental health theme for working in a group online to try to make everyone feel both fully involved and as comfortable as possible.

“Trauma-informed practice mattered too, especially because some public involvement advisers carried difficult memories linked to pregnancy or early parenthood. Small decisions, such as letting people keep their cameras off or offering content warnings, helped create a safer space.”

Abigail Mensah

2. Work your community connections

Researchers need community connections and links with relevant voluntary sector organisations. It takes time to build trusting relationships; finding community leaders or well-connected individuals is an important step. These people may run community interest companies, or work for charities or neighbourhood groups. Investing time to talk through what a study needs and what different contacts need and want is worthwhile.

- For pregnancy, maternal health or childhood studies, a personal relationship with a family centre or maternity and neonatal voices partnerships (MNVPs) lead can be a way to tap into community knowledge and expertise, and to connect with a diverse range of local parents.
- If you don't have these links, it is a priority to create them. It will take time to build trust and earn somebody's sought-after time. Going to their public meetings, if permitted, may be a way to show respect and a long-term commitment.
- Learn about the voluntary, community, and social enterprise (VCSE) sector in your area. The websites of local volunteer centres and your nearest Healthwatch can be a good place to start. Search for relevant groups on social media.

Building trust with local communities

In the RELAX study, three MNVPs contributed as well as multiple small networks and large charities.

"I have those links to the community that a researcher might not necessarily have. Going via someone like me can be really helpful for researchers. I know how to communicate, how to talk to different people. I think this is really important... again I'm not trying to criticise researchers, but I've worked with a fair few who are quite often very academic. They sit at the university, and they have their perception of life. But actually, if you're wanting to work with different people, with different levels of education in areas of deprivation and with different backgrounds, that can be really difficult. If you just come out of your office and go 'right, I want to talk to these people', you're not going to get them to open up and get a dialogue going. But if you've got those links with community workers, those people that are part of those communities, that makes a massive difference to whether or not you get grassroots support."

Siobhean McCarthy-Perham, Chair of the MNVP for Blackpool and Fylde

"For me, I would say think about 'a triangle of trust'. It's hard to reach to the specific community you want. For the RELAX study, you knew me, Mary, and I know you. I trusted you and my community trusted me. So whoever is connected to me, I can recruit them without any hesitation or any fear because I trust you and feel safe with you. The triangle of trust is the researcher or PPIE lead, the community leader and the community she works with."

Tanjida, public involvement adviser

Once a researcher has a positive connection, next time around, they will have people to contact. Public involvement adviser, Tanjida says: *"The RELAX opportunity has given us future opportunities to be involved in the other research studies."*

3. Values matter

At an early planning meeting, it may help to create a list of values that you want to adopt explicitly. Here is an example of a values statement developed by an ARC-adopted research study, the MUMS@RISC: [Charter for research engagement](#)

- A values statement like this could be developed using interactive small-group work, asking questions such as: 'What makes people feel... ..secure? ...valued? ...confident?'
- Take a look at others' work, consider inviting an external speaker for a team or wider department meeting, or several of you attend a relevant training event.

Reciprocity in involvement

The RELAX study was part of a series of department training events on 'involvement'. The RELAX public involvement advisers and the PPIE lead presented at one of the sessions. From the beginning, we adopted the principle of 'reciprocity', which means equity of give and take. Public involvement advisers should get as much from the study as they put into it. The study offered funded time for all public involvement work, training, named or anonymous acknowledgement and opportunities for advisers to be involved in data analysis, marketing, writing and communications, including speaking at webinars and a conference.



Working face-to-face, following many online meetings, enabled us to co-design a summary of results

4. Consider the evidence you need for reporting PPIE

If you aim to report the impact of PPIE in research, be sure to collect sufficient data in enough detail. The Public Involvement in Research Impact Toolkit (PIRIT), for example, may be a helpful guide. You may not be able to collect PPI data continuously, as this is time consuming. But think about a range of options, canvass views on priorities, and agree a plan. Think about how PPIE is influencing the study and the impact for advisers and researchers. Think about the following questions:

- Do your formal meetings need to be recorded with members' permission, so an accurate record of discussion can be transcribed?
- Does the automatic transcription, available on Zoom and Teams, assist with taking accurate minutes of discussion and agreements?
- Is it possible to capture 'You said, we did' statements?
- Take a look at [guidance for researchers on giving feedback to PPI contributors](#). Plans can be revised in review sessions later, if necessary.

How public advisers shaped the study

The RELAX study used meeting minutes, as a key source of evidence on public involvement advisers' views. The RELAX study team, with the support of the NIHR Maudsley Biomedical Research Centre and NIHR ARC South London communications teams and public advisers created bespoke social media messages and study accounts on [Facebook](#) and X, supported by ARC communications. Here are some suggestions that public involvement advisers made to support recruitment to the study:

- Nice photographic images (one or two may need better resolution)
- Perhaps change phrases used e.g., '... worry a lot' to '... feel you worry a lot'
- 'Online training programme', the word 'training' may put some people off
- A few small icons may help to break up text and draw attention to important things
- Ethics approval details could be added
- Add a QR code to social media posts
- Provide links to reliable sources of support
- Consider giving examples of how worry feels, e.g. in a thought bubble, such as 'racing or repetitive thoughts, physical symptoms like tummy upset, headaches, panic attack'
- Acknowledge that most pregnant women worry to some extent during pregnancy

While not all the suggestions were acted upon, revisions and comments were exchanged by email over the following weeks up to the social media launch, and start of recruitment, late in June 2023.

Overall, public involvement advice also increased the relevance of the training scenarios in the study and the accessibility and sensitivity of the language used. Co-planning of the study website and the marketing and communications, including recruitment videos, testimonials and social media featuring ethnically diverse women, was a study strength. There was a focus on 'relatable realism' and a clear, empathetic 'look and feel'.

The screenshot displays the RELAX study website. The header includes the RELAX logo and navigation links for 'Contact us' and 'Quick Exit'. A left-hand navigation menu lists: 'About RELAX', 'Participant Information Sheet', 'Meet The Team', 'Our Research', 'Testimonials', and 'FAQ'. The main content area features a video of a pregnant woman sitting on a bed with a dog. Below the video are several links: 'About the RELAX study', 'What the RELAX sessions involve', 'Who can join the RELAX study?', 'About us', 'Thank you', and 'More Information'. A text block explains that RELAX stands for 'REDucing Levels of AnXIety' and lists two bullet points: '40% of pregnant women and new mothers experience anxiety.' and 'The RELAX study is testing a new online training for pregnant women who worry.' On the right side, there is a 'Registration' section stating the study has reached full capacity, followed by a 'Returning participant' section with email and password input fields and a 'Login' button. At the bottom right, the 'Supported by' section features logos for King's College London and NIHR (National Institute for Health and Care Research).

5. Build in review discussions and reflection

Build in reviews and reflection as you go along, audio-record (with permission) and write things down. This is valuable as public involvement is a complex process. It is impossible to think of everything or address every aspect of PPIE aims and methods in advance. It should be a dialogue enabling all the different players involved in a study to reflect on what might need more thought or attention:

- It is important to consider what is going well. Acknowledge positive achievements together
- Make space to think about what needs to be developed further. Maybe ask 'What one thing might improve our public involvement work?'
- It may be helpful to talk in twos or threes, so the groups are small and less daunting than a larger forum.

Different ways to connect with public involvement advisers

In the RELAX study, in 2023, during a reflections and feedback discussion, there was a request for the PPIE Advisory Group to meet more frequently.

Public involvement adviser Siobhean said: *"If we've not had like a catch up for a while, if I'm then expected to turn up and remember everything we discussed several months ago... You know, for the researchers it's their everyday working, whereas for a PPI person sometimes it's not. But having those catch-ups or those brief emails, it doesn't even need to be a lot, but just keeps us feeling involved."*

In 2025, 13 RELAX study public involvement adviser attended one of two online meetings with the study's PPIE lead to discuss the impact of public involvement had made in the study, for them personally and for the research. They felt the way the PPIE had been carried out was impressive:

- 'Public involvement adviser in RELAX has been quite a trail blazer'
- 'It's been a good opportunity for me.'
- Public involvement in RELAX 'is quite way ahead – better than other projects.'
- 'Not tokenistic'
- 'No question was too small or too daft'

The public involvement advisers said that meeting online was good because it made it possible for people from all around the country to advise on the design and marketing of the study, making it inclusive geographically and more convenient for everyone. However, the advisers felt that meeting up face-to-face, at least once, early in the project would have helped to develop relationships and confidence. The final advisory group meeting was held in person to co-design a plain English summary of results, to mark the end of the study and celebrate public involvement. While not everyone could attend, those who did, including three who travelled long-distance, found it worthwhile.

6. Everything will take much more time than you anticipate

Like every other aspect of research, doing public involvement well takes time, thought and effort. So, it's important when planning to double and triple the time you think might be needed. At the funding application stage, be sure to budget for all the time and expertise you will need to achieve your goals and build in flexibility. Include a development phase in your plan and workshops for exploring how to work together and collaborate. Before submitting a funding application, try to think outside the box:

- Consider peer researchers' roles, a community PPI lead or co-designing the study with a charity partner / or several stakeholder groups
- Adequate funding for group and charity time and expertise can make a big difference
- Take time to budget together for all the necessary time and financial costs. Aim to focus on what really matters.

"For other researchers, a few lessons stand out. Plan for diversity from the start and budget for it. Share responsibility for learning about cultural competence, rather than placing the burden on advisers from minority backgrounds. Invite feedback often and be ready to adjust plans quickly. When EDI becomes part of the working culture rather than a separate task, it strengthens the research and the relationships behind it."

Abigail Mensah

Using social and digital media to stay in touch

As mentioned above, the RELAX PPIE Advisory Group wanted more frequent meetings to keep in closer touch with project developments, so this change was made. A WhatsApp group was created and used to keep public involvement advisers up-to-date with small informal bites of information at low cost. Each person chose whether they wished to join the WhatsApp group.

"The WhatsApp group makes you really feel part of something. It also helps to keep the study clear in your brain. Because a lot of people do a lot of different things, it's helpful to have quick and easy reminders on your phone."

Siobhean McCarth-Perham, public involvement adviser

In April 2023, Mary Newburn asked the RELAX PPIE Advisory Group how they felt things are going and if there is anything more (or less) they needed. We discussed forming a writing group to produce a blog about PPIE in the study, and interest in producing a study newsletter to provide individuals, charities and community groups with updates. Five newsletters were produced in all.

7. Relationships are important

Everyone finds it easier to go back to school after the holidays or drag themselves into work on a Monday morning if they are looking forward to seeing and catching up with friendly people whom they know and care about.

“The more opportunities there are for the whole team to interact, share something about themselves that is not related to the project and have a laugh (or extend empathic listening) the more easily the wheels will turn. When everyone feels valued and heard in a safe space, things are more likely to spark and to flow.”

Mary Newburn, PPIE lead

Valuing and celebrating involvement in the study

The RELAX study PPI lead valued meeting face-to-face with the researchers and sharing some social occasions together, such as lunch or attending seminars. The PPIE WhatsApp group was a key friendly space for RELAX. The tone of the online meetings was designed to be low-key, though with a lot of information to exchange they could be demanding as well as rewarding.

One public adviser described involvement with the study as “the light in the dark” (PPI Impact meeting, Sept 2025). Informal chats were offered in a smaller group after the main meeting. The PPIE lead was an independent person whose primary focus was public involvement; getting to know the public involvement advisers and working with them was fundamental to the role.

At our final celebratory face-to-face meeting, we worked in small groups, shared food and recorded our thanks with a certificate, a role description for each adviser’s personal development records, offers of a reference and details of possible future research opportunities. Plus customised bars of RELAX chocolate and a thank you card!

“I think it’s important to start with relationships and how important it is to hold a safe space. And to value the PPI members and what they’re saying, creating a respectful atmosphere where everyone feels heard and shares those ideas of respect for each other. That’s how you begin to build those relationships and you need to make an effort to maintain the good relationships, too.”

Abi Gay, public involvement adviser

We hope you find these tips, illustrated with examples from the RELAX study, useful. It’s never too late to build on what has gone before. Some additional feedback – or providing a ‘1 year on’ update via a blog, newsletter or social media can make a positive difference to completing the feedback loop and making public involvement advisers feel valued.

Acknowledgements

Thank you to all the public involvement advisers and researchers on the study. We are grateful to Michele Harris-Tafri and Nick Sarson, communications co-leads at ARC South London, for their support during the study.

This study is supported by the National Institute for Health and Care Research (NIHR) Applied Research Collaboration South London (NIHR ARC South London) at King's College Hospital NHS Foundation Trust. The views expressed are those of the author(s) and not necessarily those of the NIHR or the Department of Health and Social Care.

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Reference

Volkmer B, Sawjani Y, Newburn M, Bennett J, McGovern M, Bridle L, Towner N, McCabe L, Clark K, Webster S, Hylton-Potts A, Mayer L, Senevirante G, Bick D, Newby J, Goldsmith K, Moulds ML, Hirsch C. RELAX (REducing Levels of AnXIety): a study protocol for a parallel two-arm randomised controlled trial evaluating a web-based early intervention for pregnant women with high levels of repetitive negative thinking to prevent escalating anxiety during pregnancy and after birth. *Trials* (2024) 25:709. <https://doi.org/10.1186/s13063-024-08516-9>

¹The RELAX study is a randomised controlled trial testing a training which aims to prevent anxiety from increasing using cognitive bias modification.