

Working together on research involving vulnerable or disadvantaged parents in the first 1001 days of life

**Challenges and solutions for academic
researchers and voluntary and
community organisations**



1. Introduction

This briefing is based on a series of online workshops and interviews with academic researchers and voluntary and community sector organisations (VCSOs) working with parents during the first 1001 days of life. This period spans pregnancy and the baby's first two years, which is a crucial period for parents and their children's development and wellbeing.

The inclusion of parents in research can mean taking part either as:


- **research participants**, for example in a longitudinal study, qualitative interviews or a clinical trial, or
- in a **Patient and Public Involvement (PPI) role** where they help to inform or guide the research process as 'experts by experience'.

There are many small-to-medium VCSOs in the UK working with parents who are vulnerable or disadvantaged because of issues such as poverty, ethnicity, immigration status, mental health challenges, physical or intellectual disabilities, youth, and involvement with children's social care services or the criminal justice system. These parents face significant barriers of time, cost, language, confidence and trust in getting involved in research, so their experiences, perspectives and outcomes are often under-represented.

Academic researchers who are seeking to involve parents may approach VCSOs to recruit vulnerable or disadvantaged parents. The focus of this briefing is understanding and overcoming the challenges for researchers and small-to-medium VCSOs in working together in this way.

2. Challenges for VCSOs identified by VCSOs

- **Working out value:** We are overwhelmed with research requests from academics, students, government studies and the media. There are multiple requests from the same university and nothing seems to be joined up. We don't have the resources or knowledge to decide which are worthwhile, so we may say no to them all and miss valuable opportunities, or say yes to research that is weak and has no impact.
- **Researchers' unrealistic expectations:** Facilitating research is not part of our charitable aims, but we're expected to do it altruistically on top of our day-to-day work. It takes a lot of time and resources to support parents' involvement in research, including contacting and recruiting parents. We cannot "*just get a focus group together*" for you.
- **Supporting parents:** Taking part in research may involve talking about or listening to traumatic experiences, and parents may need support before, during and after sessions. Often this will fall to the VCSO – we need to be paid for the time this takes, and also for supporting the relationships between parents and researchers more generally.
- **Protecting parents:** If parents have a poor experience of research, we feel we have let them down and it puts them off future participation. It may also damage their trust in us, which has taken a long time to build. It's not just about being paid for their time - it's also about ensuring

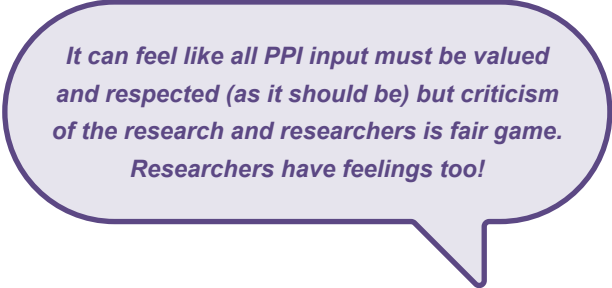


We are absolutely inundated with research requests and can't separate the wheat from the chaff

that the experience is respectful and empowering. We may be reluctant to put forward a parent if they will be the only person with that specific vulnerability in the project and if they will be expected to “publicly bleed”.

- **Power dynamics & missed opportunities:** We want power in research to be shared more equally. If we are brought in as an afterthought, we feel undervalued and we don't have the opportunity to influence the way the research is carried out or to have our participation properly costed. Our communities feel exploited if researchers extract their data and leave. It's better if we co-create the research from the beginning and there is accountability about what happens to the results - including reporting back what difference parents' participation has made.

3. Challenges for researchers identified by researchers



It can feel like all PPI input must be valued and respected (as it should be) but criticism of the research and researchers is fair game. Researchers have feelings too!

- **Timelines:** Research proposals are often initiated in response to funding calls, and we want to involve VCSOs in developing our applications but feel guilty asking for their time when there may be no funding for this stage. We realise that VCSOs and parents can be frustrated at how long it can take between an application and a funding decision, and between the start and end of a research project.
- **Building and maintaining relationships:** Recruitment of parents works best when we already have a relationship of trust with a VCSO, but we also want to widen participation and avoid burden by working with different organisations. This is in tension with the short deadlines of funding applications, which create pressure to go back to known organisations. It's hard to initiate new relationships when VCSOs are so busy and are being approached by many other researchers, and when small VCSOs may not understand the breadth of what research is or how it works. We don't have the time as individuals to maintain the strong relationships we would like to have with multiple organisations.
- **Reciprocity:** We are committed to giving something back to the VCSOs and parents so they benefit from participation in ways that go beyond payment. However, we worry that they give so much but we are limited in what we can offer in return as individual researchers. We are embarrassed at our institutional policies that make payment and reimbursement of expenses so complex and bureaucratic.
- **Clarity about roles:** It can be hard to explain a PPI role in a project, and specific tasks can vary from project to project, so we need to manage expectations. VCSOs need to understand that research focuses on specific (and often pre-determined) questions, not general topics. Parents need to understand that they will mostly be asked to talk not about their lived experience but from their lived experience about issues connected to the research. They are not expected to 'represent' their community, only to be themselves. They don't need to try to become researchers - their distinctive perspective is valued in its own right.
- **Respect needs to go both ways:** VCSOs are rightly passionate about the issues they are trying to address, but it's important that we work together as mutually respectful colleagues, even when someone is upset at the limitations of what we can do and how we can do it.

- **Impact of PPI:** There are sometimes good reasons (scientific or practical) why we can't follow the advice of a PPI participant. This doesn't mean that we haven't listened to them, but we know it can feel that way.
- **VCISO 'expert' or individual parent?:** We work with both individual parents and with VCISO staff as part of PPI, depending on the research project and the specific task. We don't always have the skills, time or resources to support individual parents appropriately in a PPI role.

4. Good practice suggestions for VCISOs from VCISOs and researchers

- Concentrate on taking part in a **small number of studies** and supporting parent participants really well.
- Seek **academic support** in assessing research participation requests. It may be useful to have an academic on your Board.
- Develop and use a **checklist for dealing with research requests**. If these points have not been covered in the research request, ask for clarification from the researchers.
- Work with researchers as **mutually respectful colleagues**, recognising your different and complementary contributions.

Example checklist for assessing research requests:

- Is this research question or topic within our strategic aims?
 - Is this research likely to have impact?
 - Will any impact benefit our community?
- Do we have capacity now?
- Is the lead-in time before submitting the research proposal realistic?
- Are we a last minute, tokenistic add-on or will we have a chance to influence how the research is done?
- Is the purpose of involving parents clearly defined?
- Is the way they want to do the research safe and trauma-informed? What will the emotional impact on parents be?
- Will there be adequate support for parents both routinely or if a difficult situation arises?
 - Will the researchers give or arrange this support, or will we?
 - Does the research team have the skills and expertise to make parents' experience safe and fulfilling?
- Practicalities: have they got funding to pay parents for their time, and for childcare, travel, interpreters?
- What are parents likely to get out of participating?
- Choosing parents to approach – is it appropriate to invite everyone, or should we consider which individual parent may have the most to contribute and may gain the most?
- How will researchers share the results of the research with the community and with decision makers – how will it influence change?

5. Good practice suggestions for researchers from researchers and VCSOs

- Involve VCSOs at the **earliest possible opportunity**, ideally in the design of the research.
- Consider carefully whether the **roles in your research** are best filled by a VCSO representative, by individual parents, or a combination.
- **Be clear about the planned role** and put it in writing – scope, time commitment, payment and any support. But also listen to the VCSO's advice about their community, and adapt if necessary.
- For individual parents, **consider carefully the potential psychological impact** if they will be asked to talk about or listen to traumatic experiences. Plan and cost in support from your research team, a professional counselling service, or the VCSO.
- Try to **co-ordinate with other researchers from your university**, so that a small local VCSO is not over-burdened with multiple approaches on different projects.
- Look beyond the 'usual suspects' – **widen opportunities for collaboration** with new VCSOs and parents who do not have experience of research.
 - But ... the first contact with a VCSO to invite participation is crucial – explain how you want to work with them on an issue that's important to them and their aims, and how the research will benefit their community.
 - And ... be sensitive to the priorities of individual VCSOs. Some VCSOs may object to participating in research that is led by outsiders to the community and about research questions that have not been initiated or co-created by the community; others may see value in this participation.
- **Cost into research proposals payment to VCSOs** for any time they will spend recruiting parents and supporting their participation.
- **Be transparent about the overall timeline** of the research – including the gap between application and a funding decision, and the gap between doing the research and publication.
- **Consider reciprocity** – is there anything that you or your team can offer to participants, beyond payment? For example, for parents: training, a job reference, or a certificate recognising their participation to assist with building a CV? For VCSOs: a talk or newsletter article about the research, or evidence to help them make the case for their own funding?
- If you are paying parents with **vouchers**, ask the VCSO which shops are available locally.
- **Share the results of the research** with the VCSO, parents and communities affected, so parents can see and be proud of their contribution.
- **Support parents as PPI participants** throughout (see box).
- Consider **your own training needs**. Would you benefit from deepening your understanding of how to be trauma-informed when working with parents?
- Work with VCSOs as **mutually respectful colleagues**, recognising your different and complementary contributions.

Supporting parents as PPI participants

- If you are inviting participation from parents from minoritised communities, ensure that they are **not the only person** from that community in a meeting – consider recruiting a small group of parents.
- Recognise that becoming familiar with PPI is a process, and **check-in with them regularly** to talk about how they are experiencing it and if there is anything that needs to change. Ask them how much contact they would like if there are long gaps during the research.
- Give them an **induction that explains the research process and their role**, and clarifies the importance of focusing on the research question.
- Do not make **assumptions about access to technology** – do they need phone data to join an online meeting, and which online platform are they comfortable using? Discuss with them how to share information in a format that will be most useful (e.g. presentations for meetings sent by post ahead of a meeting, rather than trying to see one on a small screen).
- **Run inclusive meetings.** Set a tone that is respectful of all perspectives and do not use academic jargon. Ensure everyone has an opportunity to contribute. Consider making a group agreement together at the beginning of the project that sets out what will happen at meetings, including expectations, confidentiality and support. Refer to this at the beginning of each meeting.
- Arrange **psychological support** if needed (or arrange this with the VCSO).
- **Make administration as easy as you can** – plain language contracts, a simple payment process.
- **Be generous with co-authorship**, and be realistic about how much you can expect if papers are written after the project is finished and co-authorship time has not been costed.
- Give as much feedback as possible about **how their participation has made a difference** to the research. If they have made a specific suggestion which is not taken forward, explain why this decision was made.

6. Wider recommendations

Funders should:

- Work with VCSOs to **identify research questions that matter to communities.**
- **Be realistic about the burden they create for small VCSOs** in the competitive bidding process for research grants. VCSOs may be approached by multiple academic teams for the same funding call and may be expected to invest unpaid time in collaborating on proposals. They may have to assess proposals from different teams and decide which invitation to accept.
- As a minimum, **inform the VCSO before naming them in a funding call** as an example of a relevant third sector organisation.

Researchers, VCSOs, funders and PPI specialists should work together to:

- Create **training and accreditation for parents who participate in PPI**, to support and recognise their skills development. This could be linked to the development of onward career pathways for peer supporters or community ambassadors who have supported other parents as well as having their own lived experience.

7. Acknowledgments

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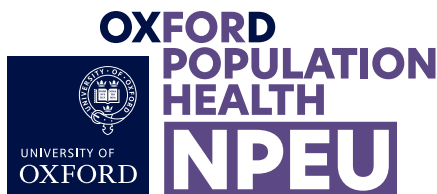
VCSO participants: Kate Chivers (Birth Companions), Vicki Hook (Acacia), Helen Lloyd (Newham Nature), Claire Mills (A Better Start Blackpool), Sumayya Mulla (Happy Moments), Kevin Stoodley (North East Young Dads and Lads), Amanda Smith (Maternity Engagement Action), Celia Suppiah (Parents 1st)

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