

## Patient and Public Involvement (PPI) in abortion research: an exploratory survey

Patient and Public Involvement (PPI) refers to activities where members of the public or patients are actively involved in contributing to research or health-care service improvements as advisers or co-researchers, rather than taking part in research as a participant.<sup>1</sup> PPI has been relatively absent from abortion research but is increasingly a requirement of academic journals and research funders.<sup>2</sup> Anecdotally, researchers have expressed difficulty in engaging a patient population who value confidentiality and sometimes do not want to re-engage with services.

Furthermore, there has been no consensus on the best term to collectively refer to people who have had an abortion in research outputs and PPI materials. Understanding preferences around the terminology used could advance efforts to involve patients and the public in abortion-related PPI activities. Many journals require the use of gender-neutral language in research outputs.<sup>3</sup> Researchers have used the terms 'clients', 'service-users', 'patients' and 'abortion-seekers'. Some have reflected on the negative connotations of each term. For example, 'patient' implies illness and passivity, 'client' has connotations of a transactional relationship, and 'service-user' can be thought of as extractive.<sup>4,5</sup> Rarely have people who have had an abortion been asked what terminology should be used.

I sought the views of people who have had an abortion on:

- Being involved in PPI
- What language to use when collectively referring to people who have had an abortion in research and PPI activities.

I used an anonymous survey shared on social media (Twitter and Instagram) to ask abortion patients if they would participate in PPI in research, and whether they had any concerns. The survey comprised a combination of multiple-choice questions and free-text responses. I also asked which of the terms they prefer from 'clients', 'service-users', 'patients' and 'abortion-seekers', as currently these are the most commonly used terms, and asked them to suggest other terms in free-text responses. The survey was open between 23 May and 15 June 2022.

A total of 88 respondents completed the survey. Of these, 72% (n=63) said they would be interested in being involved in research, through either one-off (31%, n=27) or longer-term commitments (6%, n=5), and 56% (n=49) said they would be interested in both one-off and longer-term commitments. When asked to explain why they were interested in being involved in PPI initiatives, respondents cited reasons including "*the importance of focusing people that the research benefits in the wider conversation*"; "*to improve outcomes and experiences*"; "*to help change the perception of people who have had abortions*"; "*to break down stigma*"; because "*abortion research is lacking in diverse experiences*"; and to "*use lived experience to inform how we deliver services*".

Some 39% (n=34) of respondents said they had some concerns about being involved in PPI or would be involved with certain caveats. These concerns included being worried their "*experience was not representative of the norm*"; not wanting to "*remember the details*" of their abortion; being worried about "*stigma attached to abortion*"; and whether participation would invite "*harassment [from] forced birth groups*". Fifteen respondents (17%) said they would like to be involved but wanted to remain anonymous. Some felt they did not have anything valuable to contribute: "*I feel like my experience is probably not dissimilar to many abortion experience[s] and I feel like I don't have anything of real value to add to the research*".

Regarding terminology, 56% (n=49) said they preferred the word 'patient', 20% (n=18) preferred 'service-user', 8% (n=7) preferred 'abortion-seeker' and 5% (n=4) preferred 'client'; 11% (n=10) of respondents preferred another term, with equal numbers suggesting 'woman' or 'person'.

These findings suggest that a significant proportion of abortion patients may participate in PPI activities if designed in a way that meets their needs. Designing PPI that meets the needs of abortion patients may lead to more successful and meaningful involvement of the public and patients in research and should be a priority for researchers in the field. Scientific journals and those devising PPI activities may wish to consider the preferred terminology of people who have had an abortion when devising author guidelines and PPI resources.

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