

POPS2 Patient and Public Involvement (PPI): Avoiding tokenism and gathering meaningful feedback to shape research delivery

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■ Introduction

The importance of PPI (patient and public involvement) is widely recognized and enables participants to shape research. Continuous PPI is often a requirement of funders and ethical bodies. The challenge for study delivery is finding a way to undertake PPI in a meaningful way.

■ Aim

To collate the views of POPS2 (Pregnancy Outcome Prediction Study 2) participants by identifying areas of good practice, and those requiring improvement to enhance the participant experience.

POPS2 is a prospective study of nulliparous women with a singleton pregnancy which uses ultrasound scans and biochemistry to determine whether screening and intervention for preeclampsia or fetal growth restriction at term can correctly identify women at increased risk of complications and improve the outcome for mother and infant.

■ Method

Feedback from participants was collected by a participant experience survey. The survey was first given to 50 consecutive participants following their final study visit in late 2021. Views on waiting times, environment, ease of access and interactions with sonographers were sought. The survey was subsequently repeated in the summer of 2022 with 50 more participants.

	2021	2022
The sonographer was polite	49/49 (100%)	47/47 (100%)
The sonographer made me feel at ease	49/49 (100%)	47/47 (100%)
The sonographer listened to me	49/49 (100%)	47/47 (100%)
The sonographer explained the scan results	46/49 (94%)	46/47 (98%)
The sonographer gave me an opportunity to ask questions	47/48 (98%)	45/47 (96%)

Table 1: Table showing the participant feedback about sonographers from the 2021 and 2022 surveys.



Figure 1: Pictorial representation of the words used by participants to describe their experiences of POPS2 in the 2022 survey.

■ Findings/ Conclusions

Responses were overwhelmingly complementary for both surveys (Figure 1).

The 2021 survey highlighted the following areas for improvement:

- Women wanted reassurance that reporting of third trimester growth was not indicated in low-risk pregnancies
- Research scans should be co-ordinated with clinical scans
- Communication about upcoming appointments should be improved

The findings were disseminated to study staff. Following the 2021 survey additional staff training, as well as changes to information provided at consent and pre-appointment text messages was implemented. By repeating survey in 2022 it has been possible to monitor the impact of these changes (Table 1).

The cyclical approach describe above has enabled the study PPI for POPS2 to remain meaningful for both participants and study team, and thus avoided PPI becoming a tokenistic exercise.

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