

## Patient and Public Involvement and Engagement: Consumer voices in palliative care research



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## Background

Patient and Public Involvement/ Engagement (PPIE) is highly valued, but under-researched.

#### Aim

To report an evaluation of the PPIE input embedded within a larger project.

### Methods

11 qualitative interviews:
3 PPIE representatives,
8 researchers/clinicians.
Thematic analysis. UK NHS ethics approval.

# Findings



Maisie: PPIE member

**Example PPIE project activities and roles:** Co-investigators involved prefunding; monthly meetings; budgetary control; choosing outcome tools; co-facilitating workshops; writing blogs/poems; attending the ethics committee meeting; speaking from first-hand experience

**PPIE 3:** "We developed these hourly meetings or half-hour meetings after the main meeting, just to decipher in plain English that we knew what was going on. And that was a really good idea. So, I think we're always well looked after."



Irene: PPIE member



Margaret: PPIE member

**Academic 3:** "I've just enjoyed it more than meeting with academics all the time. It's made me think a lot about communicating to non-academic audiences [...] I'm thinking 'okay how am I going to make this easier to understand"

## Impact and change due to PPIE involvement

- (i) PPIE made changes to the study throughout
- (ii) PPIE felt their input was valued
- (iii) Many academics in the team also had lived experiences, which they also shared, complicating assumptions about unitary identities.