

# Involving Older Adults in Supportive Care Research: What Do Older Adults Want - a Qualitative Study

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## Background

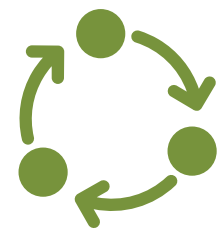
Adults aged 65 and over represent the majority of cancer diagnoses but remain under-represented in Patient and Public Involvement (PPI) initiatives. Little is known about how older adults perceive and wish to engage in research as partners rather than participants.

## Aim



This study aims to explore older adults' understanding, perceptions, and preferences regarding involvement in cancer research as PPI partners.

## Methods



A descriptive qualitative approach was adopted to undertake this study.

**Participants:** Sixteen older adults over the age of 65 who were living with or after a diagnosis of cancer.

**Data Collection:** Participants were purposively recruited via a regional cancer centre and cancer advocacy organisations. Participants engaged in one-to-one semi-structured telephone interviews, which discussed their experiences of cancer, and their perceptions of cancer-related issues which they believed were priorities for cancer research in the future.

**Data Analysis:** Thematic analysis.

## Sample Characteristics



Interview Participants: n=16

### Demographic Characteristics:

- Age: 66-81 years (Mean = 72.8, SD = 5.3 years)
- Gender: Female n=8, Male n=8
- Diagnosis: Multiple Myeloma n=6, Lymphoma n=6, Leukaemia n=3, Breast cancer n=1.
- Course of treatment: Active treatment n=11, Remission n=5.
- The majority of participants (n=12) had never participated in research prior to this study.

## Results

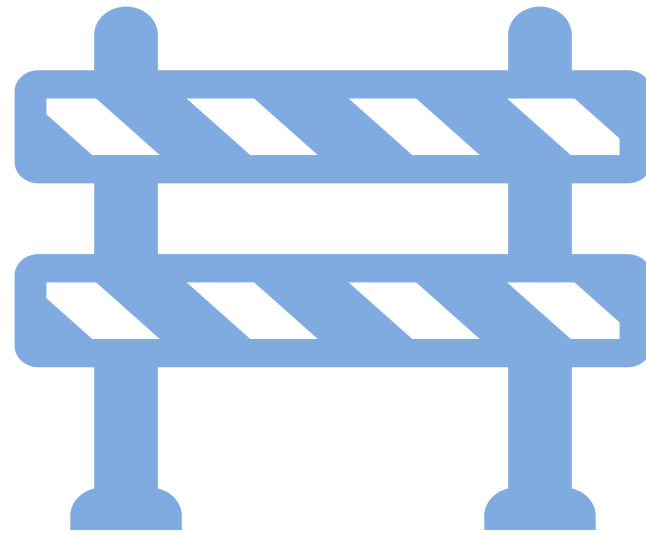


### Opportunities for Patient and Public Involvement (PPI)

Despite limited prior awareness, participants were enthusiastic about the potential of PPI to improve the relevance and impact of cancer research. They believed their lived experiences could enhance study design and foster greater empathy in the conduct of research.

*“I think from the social point of view and the sort of psychological point of view, people can help because if you ask them how were you feeling about, what did you feel, like when, those sort of questions, they can help with those and if they're willing, and I think they should be asked if it seems relevant” (P005)*

*“If a person who has gone through the experience is asking someone what their experience is, that maybe they might be able to jog a question or something that something happened to them or be empathetic with someone.” (P013)*



### Barriers to PPI

**Personal Barriers:** Concerns about confidence, knowledge, and health status reduced willingness to engage.

*“I don't know what insights I would have that would be particularly useful to cancer researchers.” (P016)*

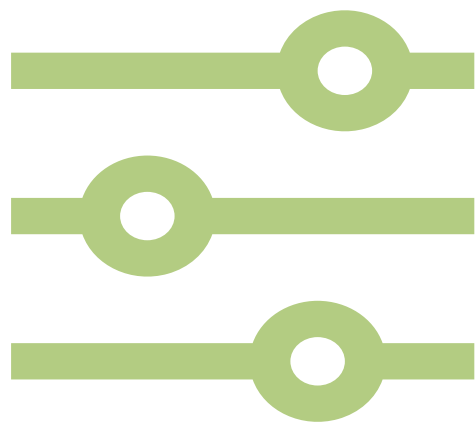
*“I would never start something that I couldn't finish ... Some days I'm good and some days I'm bad so I don't know if I would have the staying power, and I think that would stop me from saying, look it, yes I would love to do that.” (P012)*

**Systemic Barriers:** Opportunities were seen as sporadic, often dependent on clinical gatekeepers.

*“I don't know how you'd set it up... someone would have to ask me.” (P001)*

**Practical Barriers:** Physical limitations, fatigue, and digital literacy were common obstacles.

*“Zoom could work, but many older people mightn't know how to use it.” (P003)*



### Preferences & Support Needs for Effective PPI

**Flexible Involvement:** Remote options (phone, Zoom), scheduling around hospital visits, and written input were preferred.

*“Telephone interviews would suit older people with transport issues.” (P015)*

**Practical Considerations:** Length of time required for meetings required sensitivity and consideration of physical limitations of the PPI partner.

*“If it was an hour, I'd cope with it. I get very tired... and I'm always pottering around and I don't know what I'm at but I'm doing stuff, everything takes me twice as long because I have to use the stick. (P007)*

**Personalised Support & Training:** Participants asked for structured preparation and emotional support.

*“People might need training... we wouldn't all be experts.” (P008)*

## Conclusions

- This study provides insight to the complexities of implementing PPI involving older adults living with and after cancer, providing understanding of potential barriers to engagement of this group. To improve PPI inclusion among older adults, future initiatives should:
  - Enhance awareness and accessibility, ensuring more structured outreach.
  - Develop flexible and adaptive engagement models, including virtual, written, and hospital-based participation.
  - Offer psychological and practical support, ensuring emotional readiness and addressing physical limitations.
  - Prioritise inclusive recruitment strategies, engaging both direct and indirect stakeholders in cancer research.
  - Bridge technological gaps, providing training and accommodations for digital participation.
- Ultimately, equitable PPI practices must be guided by clarity, flexibility, and inclusivity, ensuring meaningful collaboration between older adults and researchers.

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