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This poster describes some of the experiences of six bereaved older carers\* involved in research activities following their participation in a research project funded by Macmillan Cancer Support: **The older carers support needs research development project**

### Project Aims

- 1) to study the experiences and priority support needs of older carers looking after someone with cancer approaching the end of their life
- 2) to encourage and facilitate meaningful and ongoing involvement of carers as partners in the research process

Research partners were recruited from 29 participants in focus groups conducted in June and July 2010

19 indicated interest in staying involved in research; 10 invited to an introductory course about research and public involvement in it  
Two-day research course run in October 2010 and attended by one current and seven bereaved older carers

### Findings

Many older carers support needs and concerns are similar

End of life care experiences of older carers contrast substantially

Some differences in experience related to the formal support services provided older carers

Carers saddened and angered by the contrasting experiences of support services

Carers want reasons for contrasting experiences of support services to be examined

Carers want support services improved and delivered in ways that ensure all older carers are supported equally well

### Outcome

Several older carers got involved in research

to use their personal experiences to make a difference and influence change

to help improve support services for older carers looking after someone with cancer approaching the end of their life

"Although unsure about the process, four of us arranged to meet and the two who couldn't join us kept in touch by phone and sent their reflections by email. I saw **reporting our experiences** could be useful for others considering getting involved in research, would have value for myself, and could add to the influence of the report findings".

"When we were asked to **review the draft report** it felt like we were being taken seriously, as proper partners. We thought the report title needed changing and that abbreviations and research terms should be explained or avoided as they present a barrier to understanding for non-professional researchers. When I saw the final version our comments had been taken account of - I felt valued and listened to".

"I contacted a local cancer support group to see if they'd like to hear about the research. Despite some practical problems at the start, I enjoyed talking about the findings and felt it was valuable for them: it prompted lots to speak about their own experiences and led on to a discussion about inequalities in care provision. I enjoyed my part in **publicising the research findings**".

"We went to a **Cancer Experiences Collaborative conference**. There was a fascinating programme and it was a great opportunity to talk to a number of palliative care experts. We also met and compared notes with research partners from other areas". "I was amazed how much work goes into research and how important research evidence is in trying to improve end of life care. It was very motivating - I'm now involved in other projects because this has given me an interest in the power of research".

## Our Involvement What we have done so far and How we have found it

"Even though we meet infrequently we worked as a team: we seem on a similar wavelength". "We've varying experiences but a common motivation. **Co-writing a briefing paper** was a key part of us telling the story - a key part of the legacy". "I'm so proud to have contributed: I've never done anything like this before and encourage others to get involved - if I can do it, anyone can! The sense of achievement is great knowing one's voice can help to make a difference".

"Taking part in this project has opened the door to more research opportunities. I'm now a lay member of a **research development group** looking into improving ways of researching and evaluating palliative care... sometimes stuff goes over my head, but the group are really helpful and supportive, and I feel they value my input".

"I'm pleased to be **involved in a new research proposal** - it's very interesting too".

"I never expected getting so many interesting opportunities, but it's provided me with a springboard into research. I've **done courses in research methods and ethics** - sometimes scarily challenging, but rewarding".

### Conclusion

**Older carers are enthusiastic, skilful and knowledgeable partners in research, and both research and services benefit from our involvement**