Public Engagement in Cancer Survivorship Research
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INTRODUCTION

- Public involvement has become well established within health and social care policy, helping to empower individuals and communities to play a greater role in shaping health and social care services.
- Consequently, public involvement has become strongly embedded in health research and interest has grown in understanding the difference it makes to research.
- A systematic review (Brett et al, 2014) found that public involvement enhanced the quality and appropriateness of research, notably, the development of user friendly research materials.

METHODS

Aim: The study aimed to compare self-management in people living with and beyond cancer from rural and urban areas.

Mixed methods design (self-completion postal questionnaire and a series of qualitative in-depth interviews with people living with and beyond cancer)

The questionnaire collected data on health behaviours (Walker et al, 1995); patient activation (Hibbard et al, 2005) and cancer-related self-efficacy (Foster et al, 2013).

The interviews collected data on the barriers and facilitators to self-management in rural and urban settings.

PUBLIC ENGAGEMENT

- Study aimed to include members of the public and people affected by cancer from the outset.
- Patient representative on the project Steering Group who had a past diagnosis of cancer and experience as a carer. Opportunity to contribute to and comment on all aspects of the study.
- Further four public representatives recruited through a local support group and conference.

- Research materials (cover letter, information sheet, questionnaire and consent form) piloted with all representatives. Feedback received via email and telephone and suggested changes fed back into final materials that were used in data collection.

- Study participants: people living with and beyond cancer who were post-treatment. Quantitative sample (n=227); Qualitative sample (n=30).
- Participants had the opportunity to opt in to receive a summary of results.

POST-STUDY ENGAGEMENT

- All study participants who requested a summary of the results will be sent this once data analysis is complete.
- The lead researcher is working with local and national comms teams at Macmillan Cancer Support to ensure that findings are disseminated appropriately via social media, press releases, as well as, academic outputs.
- There are plans in place to host a public and stakeholder engagement event at the University towards the end of 2018 to disseminate the findings from the research.

References

Walker, S., Sechrist, K., & Pender, N. (1995). The Health-Promoting Lifestyle Profile II. Omaha: University of Nebraska Medical Center, College of Nursing.