

Evaluating the impact of patient and public involvement (PPI) in the life after prostate cancer diagnosis study (LAPCD)

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Background:

While the PPI evidence base has expanded significantly over the last decade, the reporting of PPI impact has often been inconsistent and partial. Inconsistent reporting creates a fragmented evidence base making it difficult to draw together our collective understanding of what works, for whom, why and in what context. We set out to evaluate and report a novel method of PPI in a large national study in the UK exploring life after a prostate cancer diagnosis, where PPI was integrated into the study as an independent work-stream

Aim:

To evaluate the impact of patient and public involvement in the life after prostate cancer diagnosis study

Methods:

A link to an online survey was emailed to all members of the research team (n=38), including researchers, service users, in 2018 at the end of this 3 year study. Semi-structured interviews were conducted with 16 members of the research team. Survey results were reported using descriptive statistics and interviews were analysed with thematic analysis using the framework approach. Results were reported using the GRIPP2 guidelines

Results:

Embedding PPI into the study as an independent work-stream was identified as a particular strength, and benefitted from effective organisation and leadership. Research team members recognised that a supportive environment that valued PPI was fostered which helped sustain engagement. Case studies of PPI methods used that showed impact on the study are reported

Conclusion:

Providing PPI as an independent funded work-stream helped provide the contextual and process factors important to enable service users to have a real impact on the LAPCD study.