

Evaluating the impact of patient and public involvement (PPI) in the Life After Prostate Cancer Diagnosis (LAPCD) study

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Background:

Insights from patient and public involvement (PPI) can help researchers understand what it is like to live with cancer, and thus make cancer research more relevant to the needs of service users (patients and carers). Evaluation and reporting of PPI in health studies is important to build a strong evidence base concerning what works for whom and in what circumstances. We evaluated the impact of PPI in a large national study in the UK exploring Life After Prostate Cancer Diagnosis (LAPCD).

Methods:

An online survey was mailed to all researchers and service users (N=38) in 2018 at the end of this three year study, followed by semi-structured interviews (n=30). Analysis of survey and interview data was informed by realist evaluation principles. Results were reported using the GRIPP2 guidelines.

Results:

Strong contextual factors and robust processes for PPI facilitated positive impacts on the LAPCD study. Contextual factors included strong leadership of the service user group, commitment and expertise of the service users, clear roles, a positive attitude to involvement from researchers, and sufficient funding for PPI. Processes included a strong collaboration between the service users and the other research team members developed by embedding the PPI into a work-stream that ran alongside all the other 5 work-streams in the study. PPI impacts are reported on the design of the study, sense checking of patient information, at team meetings, analysis of qualitative data, paper writing, developing lay summaries, and dissemination of results. The study size and geographical distance sometimes created challenges for both service users and researchers. More formal feedback channels were suggested for future PPI.

Conclusion:

Well-resourced, carefully planned PPI ensured effective involvement and positive impacts on the LAPCD study.