Life After Prostate Cancer Diagnosis

IN PARTNERSHIP

Evaluating the Impact of Patient and Public Involvement in the Life After Prostate Cancer Diagnosis Study

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BACKGROUND

While the patient and public involvement (PPI) evidence base has expanded significantly over the last decade, the reporting of PPI impact has often been inconsistent and partial. This makes it difficult to draw together our collective understanding of what works, for whom, why and in what context. The EQUATOR guidelines for the reporting of patient and public involvement (GRIPP2)[1] has been developed to encourage standardised reporting of PPI. We set out to evaluate and report the impact of a novel method of PPI in a large national study in the UK exploring Life After Prostate Cancer Diagnosis, (LAPCD) where the user advisory group (UAG) was integrated into the study as an independent work-stream.

[1] Staniszewska S, Brett J, Simera I, Seers K, Mockford C, Altman D, Moher D, Barber R, Denegri S, Entwistle A, Littlejohns P, Morris C, Suleman R, Thomas V, Tysall C, Susan Goodlad. GRIPP2 reporting checklists: tools to improve reporting of patient and public involvement in research BMJ 2017;358:j3453

METHODS

A link to an online survey was emailed to all researchers and service users in the research team (n=38) in 2018 at the end of this 3 year study. Semi-structured interviews were also conducted with 20 members of the research team. Participants were asked to reflect on the contexts, processes and mechanisms that influenced PPI impact, both positive and negative. They were also asked to describe the impacts and outcomes of PPI on the study. Survey results were reported using descriptive statistics and interviews were analysed with thematic analysis using the framework approach. Results are reported using the GRIPP2 guidance.

FINDINGS

CONTEXT

Positive factors

A positive group dynamic and diverse range of experiences
Strong leadership of UAG
Budget for honorarium and out of pocket expenses
Clear role and purpose of service users
Representation from England, Scotland, Wales and N Ireland

Negative factors:

Geographical distance between service users
Difficulty recruiting service users from 'hard to reach' groups and 'recent experience' men

PROCESSES/MECHANISMS

Positive factors

Collaborative working between UAG and researchers
Involved at all stages of the study
Camaraderie between researchers and service users – helped develop team spirit
PPI as separate work-stream – feeding into all other work-streams

Negative factors:

Time limitations – deadlines of researchers, guilt of using service users' time

EXAMPLES OF IMPACT/OUTCOMES ON STUDY

Project Protocol & Ethical Guidelines

Informed privacy impact statements

Inclusion of a 'Patient Empowerment' scale in survey & influencing chosen outcome measures

Design of study

A patient perspective on patient documentation and piloting of questionnaire

Contributions to project website

Members of steering group

Reflect matters of importance to prostate cancer patients throughout team meetings

Qualitative analysis

Helped identify themes from interview data and from free text data on questionnaires. Contributed to writing of qualitative papers

Implementation Plan

Wrote or contributed to lay summaries for published papers and website

Attended and presented at conferences and end of study events

"They were embedded from the start so it just kind of became second nature almost" UAG

"we operated brilliantly as a team...the dynamics were very good" *Researcher*

"We put together Terms of Reference for ourselves and discussed that…[and], we developed a good practice guide to managing things " UAG

"We work to quite tight timelines...and then [you have to] understand that they can't always operate to our timeframes" Researcher

"They're absolutely brilliant [academics] but I think we brought them down to ground sometimes... by saying 'don't forget what this is about" UAG

"I find it very interesting and rewarding …as well being able to make the contribution to something …you know it will be making a bit of a difference" UAG

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