Effective patient & public involvement in a national research project “Life After Prostate Cancer Diagnosis”

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The Research: background and context

Why research ‘Patient Reported Outcomes’?

Prostate cancer is the commonest cancer in men in the UK and its treatment can impact physically, psychologically and socially - affecting the health related quality of life (HRQL) of men and their partners/spouses.

It is important to measure outcomes of importance to patients and partners/ spouses so that services can be improved.

Aims of the research

To research the Health Related Quality of Life of men with prostate cancer

To describe levels of patient empowerment and explore the interaction between patient empowerment and HRQL

To explore if and how HRQL is associated with the disease, its treatment and/or patient characteristics with a view to informing healthcare policy and Service delivery.

Research Methodology

100,000 prostate cancer survivors, from all four UK countries will be invited to take part in a postal survey, with first cohorts within each country surveyed again, with a follow-up survey twelve months later.

The survey will include a range of research measures: Health Related Quality of Life, Social Difficulties Inventory, plus patient perspective measures (e.g. a Decision Regret Scale and a patient Empowerment Scale) plus a free-text box at the end of each section to capture any other important issues not covered.

In-depth telephone interviews will be conducted with a sample of 100 men who completed the survey along with a small number of partners/spouses.

Project Organisation

The Project comprises **six Work-Streams:** 1.Quantitative Surveys, 2. Qualitative Interviews, 3. Data Linkages, 4. Organisational Performance, 5. Health Economics, **6. PATIENT & PUBLIC INVOLVEMENT**

Patient & Public Involvement in Research – How it works . . .

PP1: Purpose & Rationale

1. Service Users act as ‘critical friends’, offering first hand experience of prostate cancer – its diagnosis, treatment & what its like to live with the disease.
2. This will ensure the research process, findings & recommendations are as relevant to service users as possible

Our Philosophy & Values

PPI, in this project, is predicated on a philosophy of ‘holistic co-production’ – this is to say that the researchers and the service users aim to work in partnership, mutually respecting the expertise and perspectives that each bring to all aspects of the research

Key mechanisms

Effective patient and public involvement is achieved through three mechanisms:

1. User Advisory Group (UAG)

The UAG comprises patients, health professionals and researchers (10 in all); it meets quarterly, and is responsible for leading PPI on behalf of the Project

2. Reference Group

The PCUK’s On-line Community of PCa patients, partners and carers can be called upon to act as a wider Reference Group – a valuable source of experience, advice & guidance on PPI issues to the Project team

3. Crowd Sourcing

The project will use Crowd Sourcing techniques to sense-check emerging findings and draft proposals.

Outputs and Outcomes

To date, Project PPI has made contributions to:

1. Design of Postal Survey (including incorporation of a ‘Patient Empowerment’ scale)
2. Project Protocol & Ethical Guidelines (including privacy impact statements, and complaints procedures)
4. Commentary on readability of survey questionnaire, topic guide, and response rate
5. Contributions to design of Project website
6. Reports to, & and representation on. Project Steering Group
7. Recommendations made to LAPCD team to make early start on:
   - a plan to maximise ‘Buy-in’ to recommendations
   - developing an Implementation Plan
   - developing a Project Impact analysis

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