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

H Butcher1, A Downing2, P Wright3, R Wagland4, E Watson4, L Hounsome5, C Donnelly6, T Kearney6, R Mottram2, M Allen2, P Selby2, P Kind7, J Corner3, J Verne5, A Gavin6*, A Glaser*; *Co-Principal Investigators

1Service User, UK; 2Leeds Institute of Cancer and Pathology, University of Leeds, UK; 3Health Sciences, University of Southampton, UK; 4Department of Clinical Health Care, Oxford Brookes University, UK; 5South West Knowledge and Intelligence Team, Public Health England, UK; 6Northern Ireland Cancer Registry, Queen’s University Belfast, UK

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.

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.

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.

Project Organisation

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

PP1: Purpose & Rationale
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 Sourcing sense-check findings and will use Crowd techniques to emerging draft proposals.

Outputs and Outcomes
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

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)

Contact details: Hugh Butcher, hughbutcher757@gmail.com; Adam Glaser, a.glaser@nhs.net; Anna Gavin, a.gavin@qub.ac.uk