A national study of prostate cancer patient reported outcomes

Eila Watson, on behalf of the LAPCD study team (see below)

Department of Applied Health and Professional Development, Faculty of Health and Life Sciences, Oxford Brookes University

Background

- Prostate cancer is the most common cancer found in men in the UK and the number of men with this disease is increasing.
- Treatment may impact on physical, emotional and social wellbeing, affecting the health-related quality of life (HRQL) of men and their partners/spouses.
- In addition to improving treatments, it is important to measure outcomes of importance to patients and partners/spouses so that services can be tailored to meet men’s needs.

Study aims

Through a series of interlinking work-streams (see below) we will:
- describe the HRQL of men with prostate cancer using qualitative and quantitative methods;
- explore if and how their HRQL is associated with or predicted by disease, treatment and/or patient characteristics;
- describe levels of patient empowerment and explore the interaction between patient empowerment and HRQL;
- undertake a study of men without prostate cancer to determine levels of symptoms in the community for comparison.

Overview of Work Streams

- PROM instrument refinement
- Qualitative research
- PROM delivery
- Data linkage
- Health economics
- Organisational performance
- Patient feedback
- Generate information to improve the health and well-being of men with prostate cancer

Methodology

- Prostate cancer survivors between 15-39 months post-diagnosis will be identified in all four UK countries through cancer registration or hospital administration systems (~100,000 men).
- The survey we have developed will use measures of HRQL, plus patient perspectives measures.
- We will also conduct telephone interviews with a sample of around 100 men and 20 partners/spouses.

Survey numbers

- N. Ireland
  Approx. 2,700 men to be surveyed
- Scotland
  Approx. 8,200 men to be surveyed
- Wales
  Approx. 5,600 men to be surveyed
- England
  Approx. 82,000 men to be surveyed

Dissemination

In addition to traditional dissemination routes, innovative methods, such as an electronic reporting tool will ensure that results are widely available to men and their families, the funders, the NHS, social care, voluntary sector organisations and the research community.

Impact

- Through links with the Department of Health in each of the four nations, study findings will be used to influence the development of health care policy across the UK.
- The study is funded by Movember and Prostate Cancer UK who plan to use the findings to initiate changes to health policy and service delivery. The findings will also influence services provided by the charity sector.
- By specifically addressing the experiences and outcomes of Black men with prostate cancer, the study will help improve future service provision for this group of men who have a higher incidence of prostate cancer and are at risk of poorer outcomes.
- By feeding back measures of organisational performance to hospital Trusts, the findings will influence the provision of local services.

Study Team

Principal Investigators
A Glaser, University of Leeds
A Gavin, Queen’s University Belfast;

Co-Investigators
Oxford Brookes University
E Watson, L Matheson

University of Southampton
R Wagland, J Corner, C Rivas, J Nayoan

University of Leeds
A Downing, P Wright, R Mottram, M Allen, P Selby, P Kind

Queen’s University Belfast
C Donnelly, T Kearney

Public Health England
L Hounsome, J Verne

Service User UK
H Butcher

Contact details: Eila Watson, ewatson@brookes.ac.uk; Adam Glaser, a.glaser@nhs.net; Anna Gavin, a.gavin@qub.ac.uk