



## A national prostate cancer patient reported outcome measure (PROM) programme

Downing, A., Wright, P., Wagland, R., Watson, E., Butcher, H., Hounsome, L., ... Glaser, A. (2015). A national prostate cancer patient reported outcome measure (PROM) programme. Poster session presented at National Cancer Intelligence Network: Cancer Outcomes Conference 2015: United Against Cancer, Belfast , United Kingdom.

### Queen's University Belfast - Research Portal:

[Link to publication record in Queen's University Belfast Research Portal](#)

### Publisher rights

© 2015 The Authors

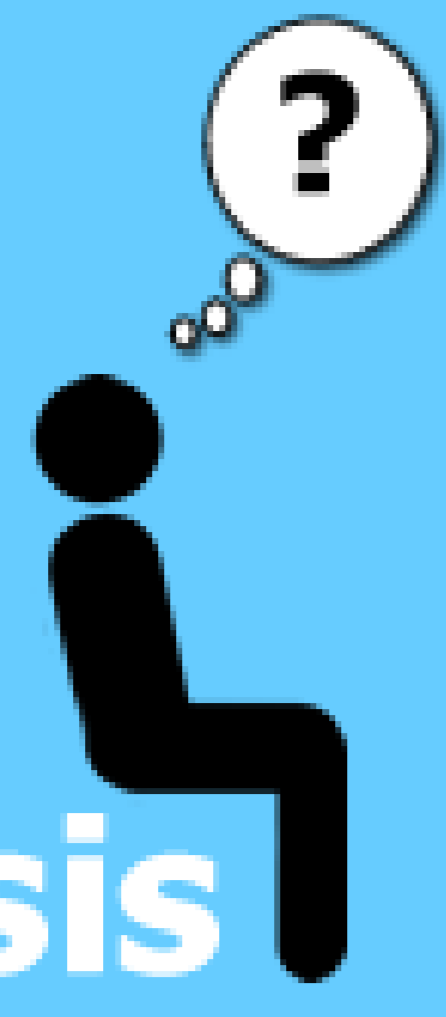
### General rights

Copyright for the publications made accessible via the Queen's University Belfast Research Portal is retained by the author(s) and / or other copyright owners and it is a condition of accessing these publications that users recognise and abide by the legal requirements associated with these rights.

### Take down policy

The Research Portal is Queen's institutional repository that provides access to Queen's research output. Every effort has been made to ensure that content in the Research Portal does not infringe any person's rights, or applicable UK laws. If you discover content in the Research Portal that you believe breaches copyright or violates any law, please contact [openaccess@qub.ac.uk](mailto:openaccess@qub.ac.uk).

# Life After Prostate Cancer Diagnosis



# A national prostate cancer patient reported outcome measure (PROM) programme

A Downing<sup>1</sup>, P Wright<sup>1</sup>, R Wagland<sup>2</sup>, E Watson<sup>3</sup>, H Butcher<sup>4</sup>, L Hounsome<sup>5</sup>, C Donnelly<sup>6</sup>, T Kearney<sup>6</sup>, R Mottram<sup>1</sup>, M Allen<sup>1</sup>, P Selby<sup>1</sup>, P Kind<sup>1</sup>, J Corner<sup>2</sup>, J Verne<sup>5</sup>, A Gavin<sup>6\*</sup>, A Glaser<sup>1\*</sup> \*Co-Principal Investigators

<sup>1</sup>Leeds Institute of Cancer and Pathology, University of Leeds, UK; <sup>2</sup>Health Sciences, University of Southampton, UK; <sup>3</sup>Department of Clinical Health Care, Oxford Brookes University, UK; <sup>4</sup>Service User, UK; <sup>5</sup>South West Knowledge and Intelligence Team, Public Health England, UK; <sup>6</sup>N. Ireland Cancer Registry (NICR), Queen's University Belfast, UK (NICR is funded by the Public Health Agency NI)

IN PARTNERSHIP



## Background

- Prostate cancer is the commonest cancer in men in the United Kingdom (UK) and the number of men with this disease is increasing.
- Its treatment may impact physically, psychologically and socially, 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

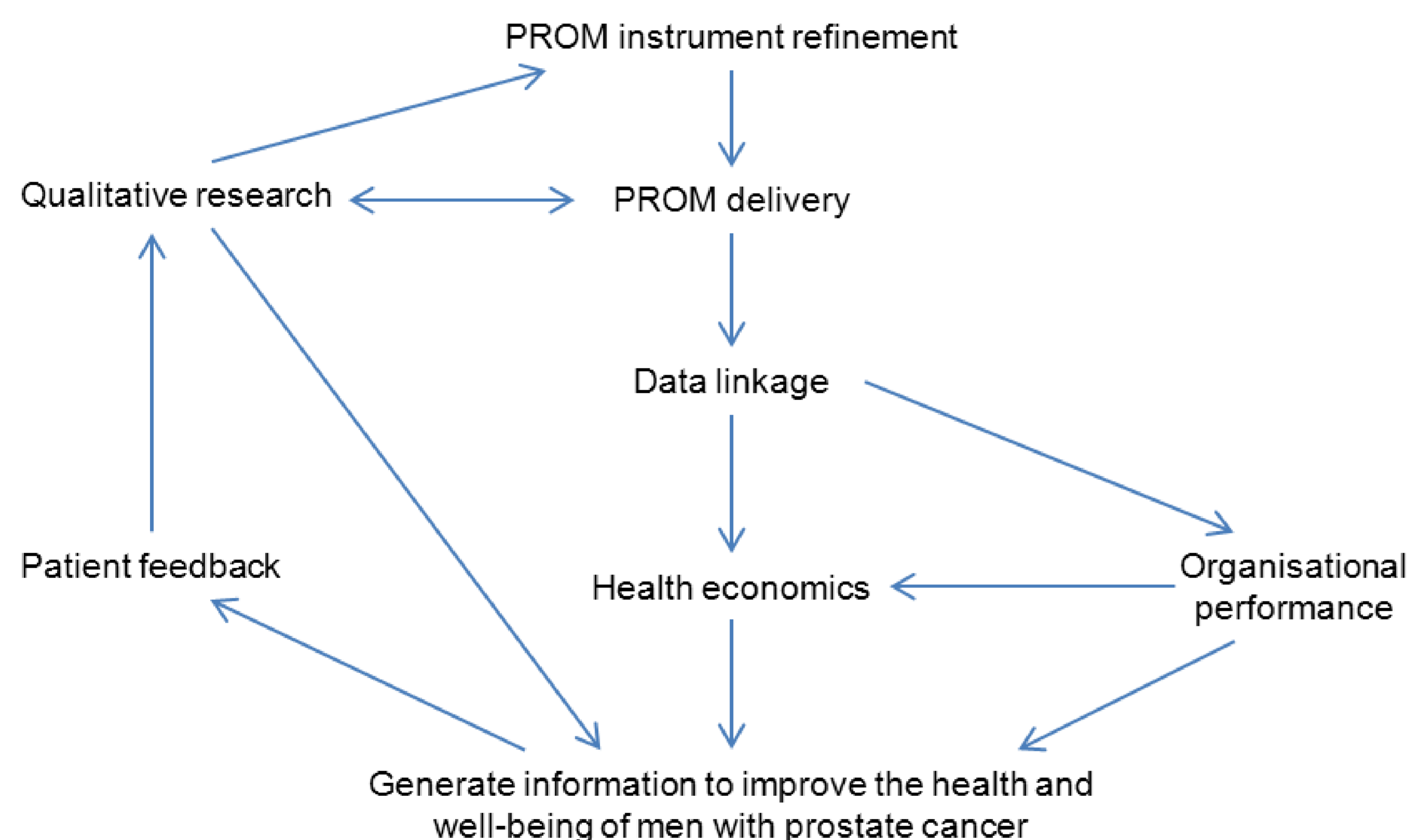
Through a series of interlinking work-streams (Figure 1) we will:

- 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 with a view to inform healthcare policy and service delivery;
- 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;
- inform development of health care policy and service delivery.

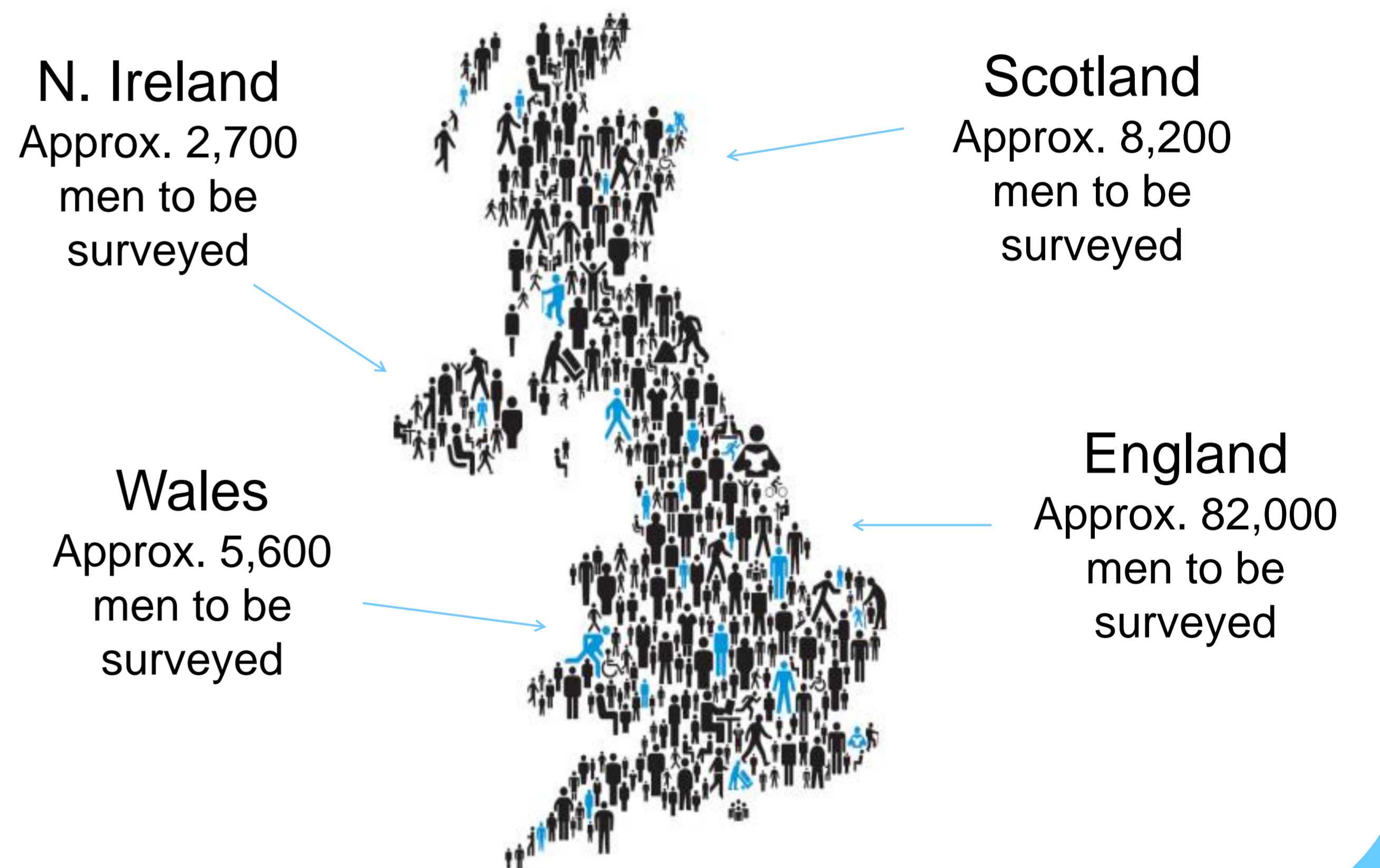
## Methodology

- We will identify prostate cancer survivors in all four UK countries through cancer registration or hospital administration systems. Eligible men will be between 15-39 months post-diagnosis (~100,000; Figure 2).
- The first cohorts within each country will be surveyed twice, 12 months apart, with second de novo cohorts surveyed once (Figure 3).
- We have developed a comprehensive survey using generic and cancer-specific measures of HRQL, including EQ-5D, EPIC-26 and the Social Difficulties Inventory, plus patient perspectives measures (the Decision Regret Scale and Patient Empowerment Scale).
- The survey will also include a free text box at the end of each section to capture any other important relevant issues not covered.
- The survey data will be linked with administrative health data (e.g. Hospital Episodes Statistics, Radiotherapy Data Set) in order to maximise the amount of clinical and treatment information available.
- We will also conduct telephone interviews with a sample of men who complete the survey (~100) along with a small number of partners/spouses (~20).

## Figure 1: Study overview



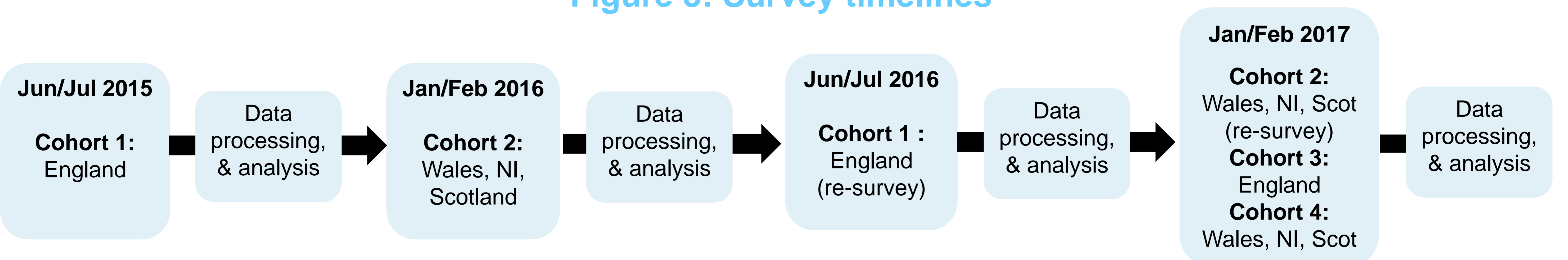
## Figure 2: Survey numbers



## Dissemination of results

We will use traditional (reports and academic papers) and innovative methods (such as an electronic reporting tool) to ensure that results are widely available to men and their families, the funders, the NHS, social care, voluntary sector organisations and the research community.

## Figure 3: Survey timelines



Contact details: Amy Downing [a.downing@leeds.ac.uk](mailto:a.downing@leeds.ac.uk) Study website: [www.lifeafterprostatecancerdiagnosis.com](http://www.lifeafterprostatecancerdiagnosis.com)