

Patient Reported Outcome Measures (PROMs)

Working to improve care of men with prostate cancer

A major three year project offering men a unique opportunity to give their feedback on their treatment experience

how it affected their lives over time compared to men who did not have prostate cancer



The study

- A major three year project offering prostate cancer survivors a unique opportunity to give their feedback on:
 - Their treatment experience
 - How it affected their lives
 - Over time (repeat surveys)
 - Compared to men who did not have prostate cancer - a normative study

UK WIDE SURVEY (WITH LINKS IN METHODS ETC TO AUSTRALIA, IRELAND AND CANADA etc)

N. Ireland
Approx 4,000
men to be
surveyed

Wales
Approx 8,000
men to be
surveyed



Scotland
Approx 12,000
men to be
surveyed

England
Approx 130,000
men to be
surveyed

Method

- Questionnaire survey of men 1-3 years after a diagnosis of prostate cancer and a comparison group of men without prostate cancer
- Interviews with a sample of men and their partners
- Link questionnaire results with other health data to better understand what affects men's outcomes
- Not surveying men who are in the National Prostate Audit (England & Wales)

Why?

- Men often experience physical symptoms such as impotence, incontinence, hot flashes/flushes and depression and have reduced quality of life after prostate cancer
- This study will investigate what matters to men with prostate cancer and their families
- **6 WORKSTREAMS**

Workstreams

➤ **Workstream 1: Survey development and delivery**

Objectives are to:

- comprehensively assess men's QoL following the diagnosis and treatment of PCa
- identify gaps in care

➤ **Work-stream 2: Qualitative Research**

Objectives are to:

- investigate experience of living with PCa, factors influencing outcomes for men and their partners/spouses, and perceived services gaps across treatment types and socio-demographic groups
- explore acceptability of electronic PROMs completion and direct clinical feedback of PROMs data to health providers
- inform PCa PROMs surveys in subsequent years

Interview Sample

- 4 main treatment types

Stratified by:

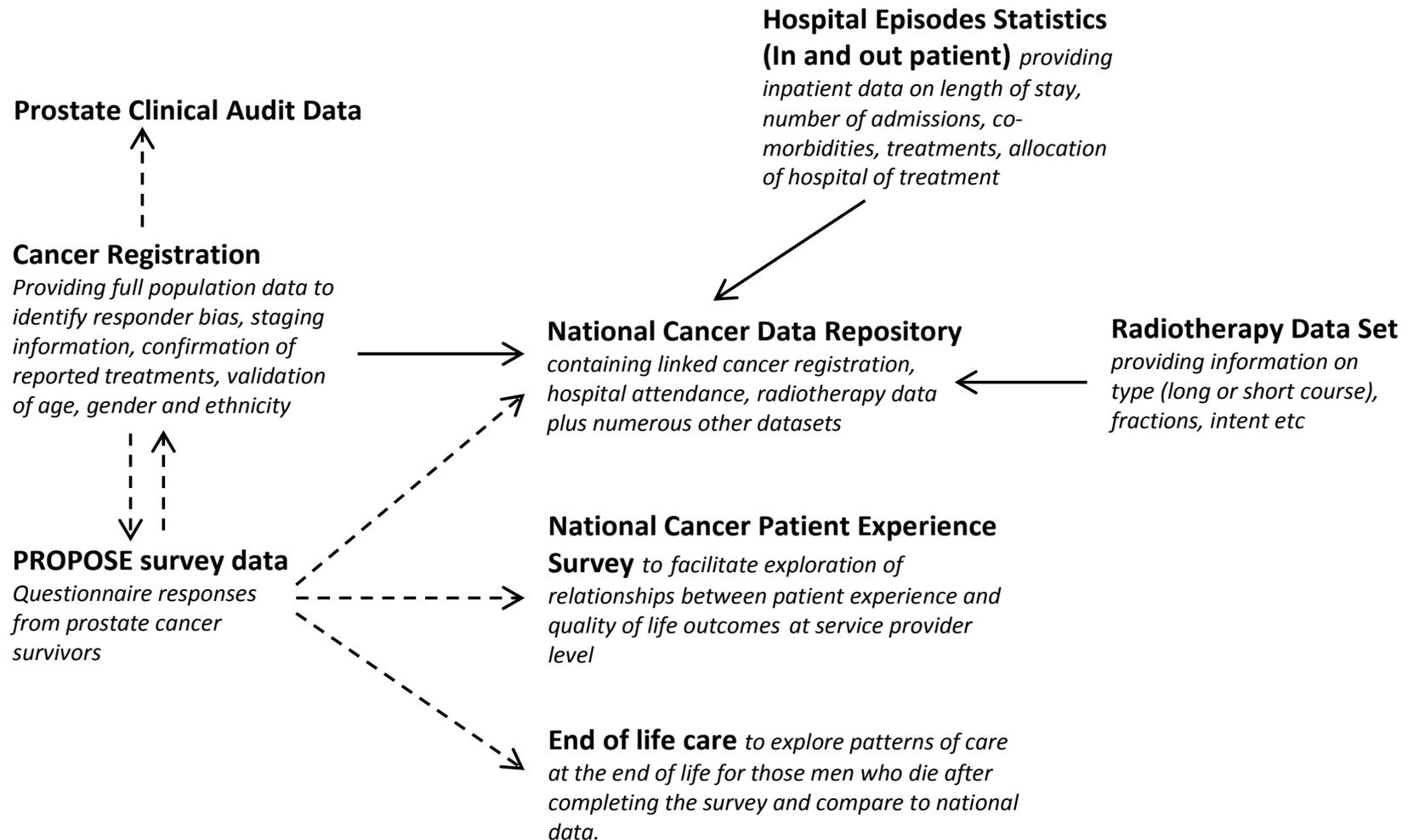
- Age (<65; 65-74; >75)
 - Time from diagnosis (12, 24, 36 months)
 - Representative PROMs scores
 - Deprivation
 - Sexual orientation
- BME and Carers samples representing each treatment type

➤ **Work-stream 3: Data Linkage**

Objectives are to:

- ensure maximum exploitation of survey data through linkage with existing health datasets
- identify factors associated with good/poor QoL outcomes in order to inform future service delivery

Proposed data linkages



*Dashed lines denote proposed linkages, solid lines represent existing linkages. This diagram reflects linkages for England. Similar linkages are possible for the devolved nations.

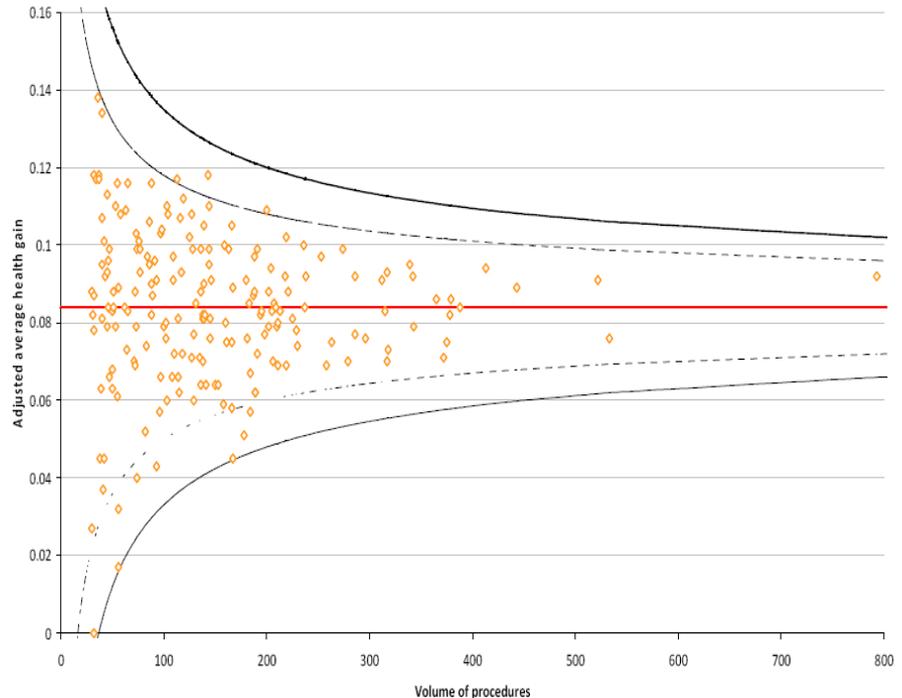
➤ **Work-stream 4: Organisational Performance and Benchmarking**

Objectives are to:

- compare outcomes across provider organisations, nationally, and internationally
- identify changes/improvements in outcomes over time
- feedback to relevant organisations in a timely manner

Identification of Outliers

- Funnel plots
- Takes account of volume - min 30, ideal 150+
- Assumes normative data
- Alert 5% level
- Alarm 0.2%

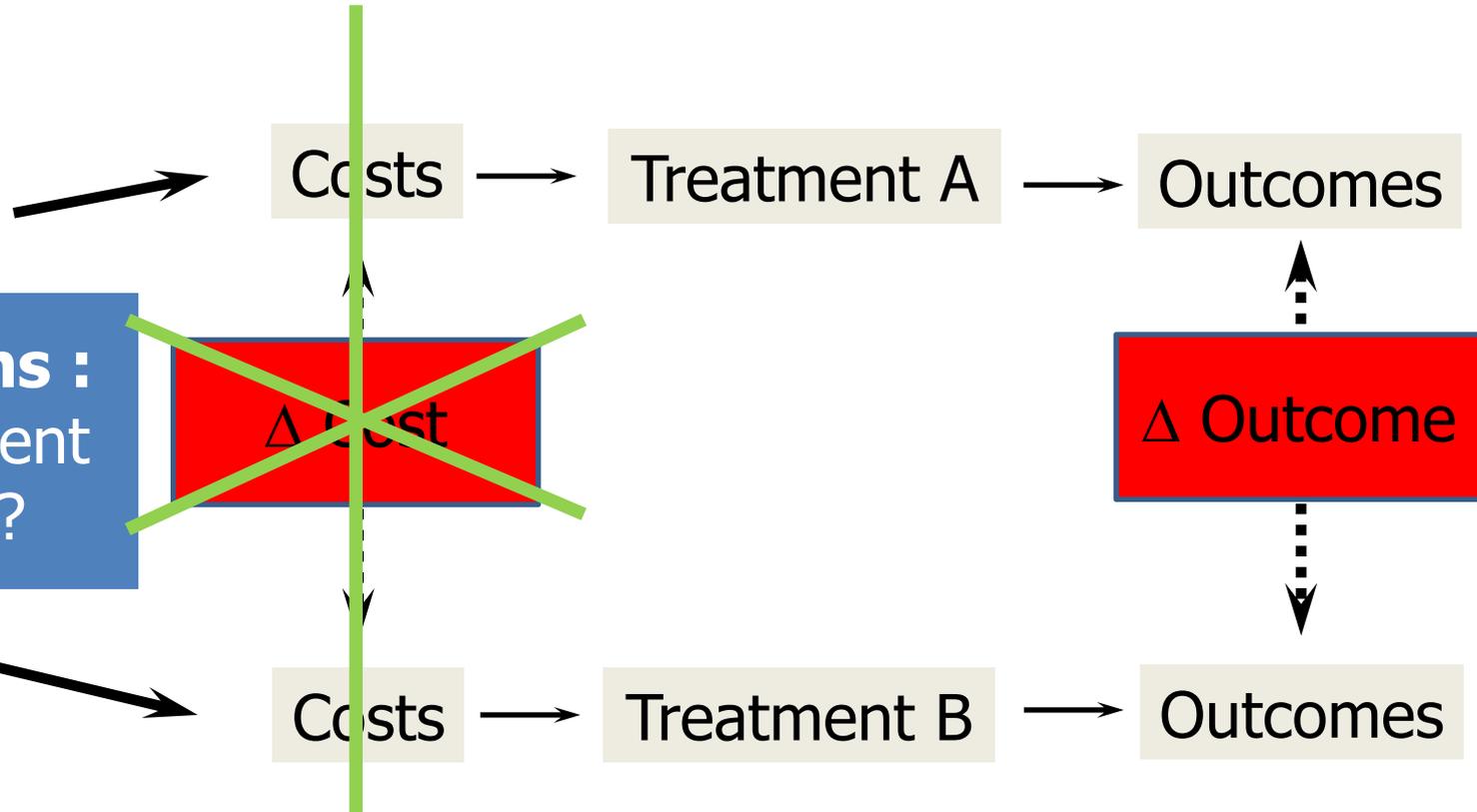


➤ **Work-stream 5: Health Economics**

Objectives are to:

- enhance value of PROMs data by expanding range of (non-clinical) applications for which they can be used
- establish the use (and usefulness) of patient-centred values in quantifying patient reported outcomes

Health economics



Does the **extra** benefits (outcomes) justify the **extra** cost ?

➤ **Work-stream 6: Patient and Public Involvement (PPI)**

Objectives are to:

- explore the feasibility and acceptability of Participatory Health Research using 'crowdsourcing'
- sense check findings from qualitative research (Workstream 2) and interpretation of PROMs data

Expected Outcomes

- Help plan for ongoing care and treatment
- Support improvements in health service performance
- Increase debate about how patient reported outcomes can be used to drive improvements in patient care
- Inform how we value patient reported outcomes in society
- Produce reports for each of the four UK nations aimed at NHS and decision makers
- Submit research articles for peer review
- Provide feedback to service users and public
- Develop a toolkit to enable organisations to look at own organisation and compare with others

Timescales

- Preparation work began March 2014
- Contracts signed Autumn 2014 !!
- First surveys in England and Wales (Jan 2015), Northern Ireland (Jan 2016) and Scotland (Oct 2016)
- Repeat surveys England and Wales (Jan, Oct 2016), Northern Ireland and Scotland (Jan, Oct 2017)
- Results will be made public mid 2017 to ensure widest benefit of this research

The team

- Work will be carried out by senior researchers from:
 - University of Leeds
 - Queen's University Belfast
 - University of Southampton
 - Oxford Brookes University
 - Public Health England
 - Patients will help shape the research

- Work will be led by Adam Glaser (Leeds) and Anna Gavin (QUB) with assistance from Hugh Butcher, Jessica Corner, Conan Donnelly, Amy Downing, Luke Hounsome, Paul Kind, Peter Selby, Julia Verne, Richard Wagland, Eila Watson, Penny Wright and senior advisors from Wales and Scotland
- Clinical and Scientific Advisory Group – led by Professor Peter Selby, User Advisory group – led by Mr Hugh Butcher