NPCA Patient Survey: Impact of Patient Reported Outcome Measures (PROMs)

NPCA
National Prostate Cancer Audit

Patients want PROMs

- High survey response rates demonstrate that patients strongly support PROMs
- Survey sent to >25,000 men diagnosed April 2015 – Sept. 2016>> 73% responded
- Survey sent to >10,500 men diagnosed April – Sept. 2018 >> 78% responded
- Patient information, lay summaries and slide sets

'Men who have been recently diagnosed are often keen to find out what other men, in similar circumstances, chose for their preferred treatment and what were the results of the treatment (how it affected their quality of life)' NPCA PPI Forum member

How PROMs outputs are used by the public*

*Information synthesis includes feedback from the NPCA PPI Forum

'Men use the results from the survey to look at how local NHS trusts compare with the national results and to see those which are above/below national standards' NPCA PPI Forum member

Reflections from a patient representative

Steve Allen, Tackle Prostate Cancer

What do patients expect of their treatment:

- No side effects
- Minimal impact on quality of life
- Equilibrium between quantity and quality of life

Much can be gained from the NPCA results reporting on patients' experience of care following diagnosis, and the side effects and quality of life following radical surgical or radiotherapy treatment. For instance, information on such problems as incontinence and sexual dysfunction are of paramount importance to patients and are reported by the NPCA. As the NPCA only started reporting for men diagnosed from 2014, information on the 'quantity of life' will be reported after further follow-up.

Performance indicators are used each year so that direct comparisons by hospital can be made and changes can be identified – all very much to the benefit of patients.

Read the full blog here

'PROMs are important for audits of services that aim to improve/protect functional outcomes. For men with localised prostate cancer undergoing radical treatments they provide a measure of the safety of care' NPCA Project Team member

Clinicians/providers accept PROMs as authoritative information

- PROMs provide additional information over and above what clinical/routinely collected data provide
- Changes in clinical measures may not always translate into benefits for patients
- Use of PROMs as performance indicators and outlier process to stimulate both national & local QI
  - Individual provider-level results, reports, outlier improvement plans

The impact of using PROMs measures to stimulate QI and support for ongoing data collection were key themes during the NPCA QI workshop '*Reducing treatment-related toxicity after radical prostate cancer treatment*'. The priorities for improving the quality of care for prostate cancer patients are explored here.

'Given the similar survival results, PROMs results are especially important as a guide to help inform patient treatment decision-making for localised disease'
NPCA QI workshop attendee

Improvements due to PROMs: examples from radiotherapy centres*

- Improved communication both within radiation oncology groups and across disciplines
- Regular inter-disciplinary meetings set up to discuss nuances of practice including case selection, contouring, dosimetry and follow-up processes
- Updates of local radiotherapy practice protocols
- Audit of treatment set-up to establish whether further reduction in margins are feasible
- Implementation of routine peer review processes for contours and plans
- Programme initiated for fiducial marker insertion
- Comparison of set up and dosimetry between treatment machines in the same department
- PROMs programme set up within individual centres to collate outcomes for radiotherapy patients
- Improved training for staff members involved in patient follow up

*Reported to the NPCA Project Team during the outlier process and NPCA QI workshop

'Understanding variation [in urinary and erectile function] between providers is important to drive quality improvement initiatives' NPCA QI workshop attendee

Using PROMs to compare the impact of ongoing changes in practice on functional outcomes:

- Robotic, laparoscopic or open radical prostatectomy British Journal of Cancer. 2018; 118:489-494
- Hypofractionated or conventionally fractionated external beam radiation (EBRT) J Clin Oncol. 2020; 38:744-752
- EBRT with or without brachytherapy boost Radiotherapy and Oncology 2021; 155;48-55

'Patients need to understand the likelihood, severity and duration of the side effects from potential treatment options in order to make an informed decision about initial treatment' NPCA QI workshop attendee