



QoL tools in Bladder Cancer – a review

BAUS Oncology Annual Meeting
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Overview


▶ Background

- QoL in Bladder Cancer

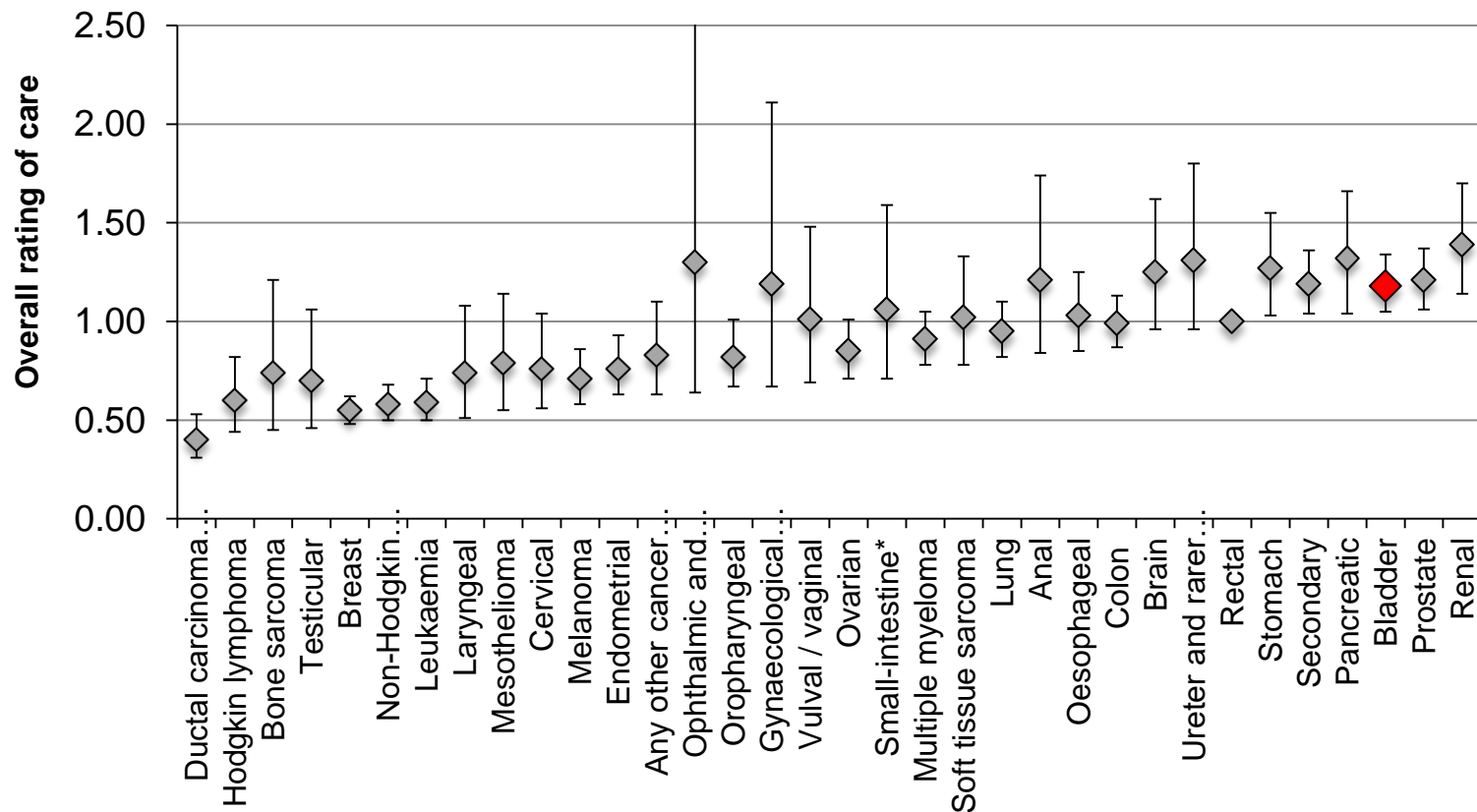
▶ Tools

- Questionnaires
- Instrument selection
- Qualitative approaches

▶ Use of PROMs – in Bladder Cancer and beyond

- Novel applications
 - Strategies to improve uptake
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QoL in Bladder Cancer – the challenge



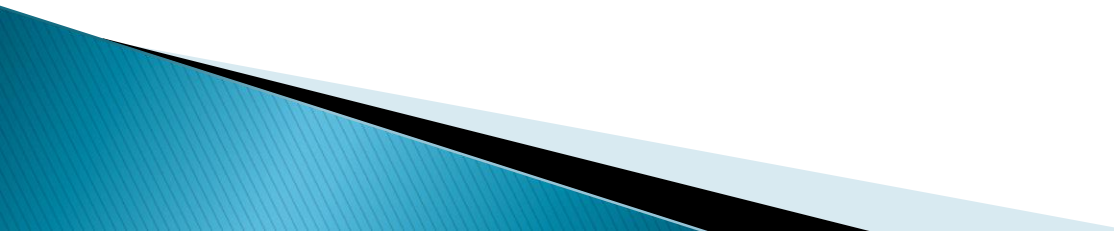
QoL in Bladder Cancer – the challenge

- ▶ NCPES 2015 – significantly poorer scores
 - Multiple domains
 - Diagnostic delays
 - CNS details (80.0 vs 89.9%)
 - Information giving (including financial)
 - Different to prostate (same teams?)
- ▶ Living with and beyond Bladder Cancer
 - DoH pilot survey (Oct 2015)
 - 673 patients
 - “Real world” rather than trial setting
 - 99 items – FACT, SDI, EQ5D
 - 70% had some urinary symptoms

<http://www.ncpes.co.uk/index.php/reports>

<https://www.england.nhs.uk/wp-content/uploads/2015/10/proms-bladder-cancer.pdf>

Why is patient experience & QoL so poor?

- ▶ Significant functional impact
 - ▶ Invasive investigations
 - ▶ Frequent follow-up
 - ▶ Low profile – “neglected cancer”
 - ▶ Socio-demographic characteristics??
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QoL instruments available

▶ Generic QoL

- Non – cancer specific: EQ-5D-5L/3L, SF36
- Cancer specific – FACT-G, EORTC QLQ C30

▶ Bladder cancer specific

- FACT-BI, BI-Cys, BCSI
- EORTC subscales: NMIBC24, BLM30
- BCI, BUSS

▶ Non – QoL symptom scores

- PRO – CTCAE
- Kings Health (urinary function)

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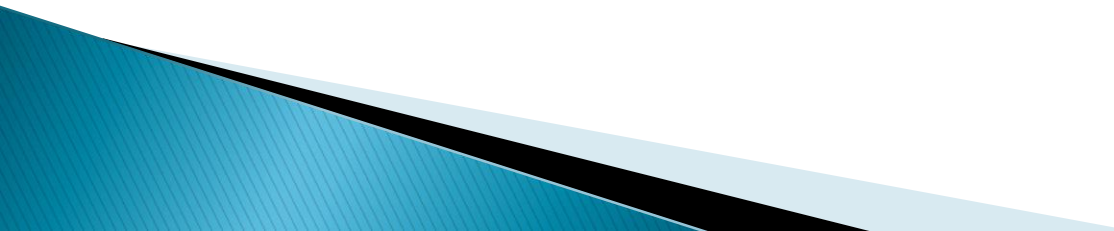
▶ Bladder cancer specific

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Instrument selection

- ▶ What are you trying to measure?
 - ▶ Is health economics relevant?
 - ▶ Who might you want to compare with?
 - ▶ What resources do you have?
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FACT: Functional Assessment of Cancer Therapy

▶ FACT-G

- 27 items
- 4 domains: Functional, Physical, Social/Family, Emotional

▶ FACT-BI

- 13 item additional concerns:
 - Urinary function, Sexual function, Bowel function, Appetite, Weight, Appearance, Ostomy appliance

▶ FACT BI-Cys

- 17 items, specific to patients post cystectomy

▶ FACT BCSI & NCCN FACT BCSI

- Can be used independently of FACT-G

EORTC

- ▶ **QLQ C30**

- 30 items
- 5 domains: physical, role, social, emotional, cognitive

- ▶ **NMIBC 24**

- Intravesical therapies and worry due to repeated cystoscopy

- ▶ **BLM 30**

- Catheter, urostomy, body image

- ▶ <http://groups.eortc.be/qol/eortc-qlq-c30>

EQ-5D-5L

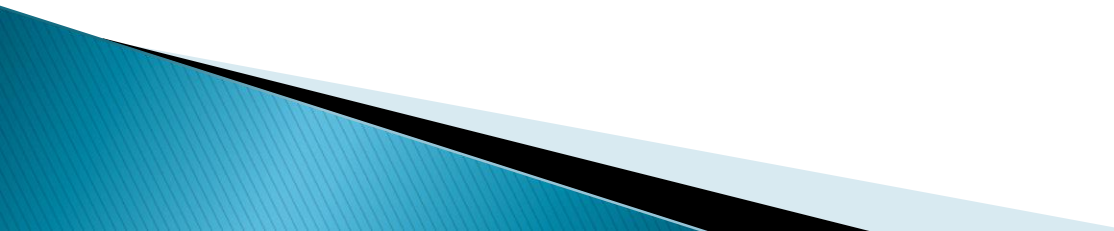
- ▶ QALY calculation
- ▶ “Today”
- ▶ 5 domains (3 or 5 response levels)
 - Mobility
 - Self care
 - Usual activities
 - Pain/discomfort
 - Anxiety/depression
- ▶ Visual analogue scale
- ▶ Yields 3125 different health states!

Others

▶ BCI

- 34 items
- Urinary, bowel and sexual function

▶ BUSS

- 10 items plus Visual Analogue Scale
 - Wide scope – including mental health, fatigue, body image, relationship with cancer team
 - Relatively new, not fully validated
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Qualitative approaches

- ▶ Dig deep in smaller numbers of patients
- ▶ Explore patient agenda and potentially uncover ideas outside the healthcare model
- ▶ Not just a means to an end (e.g. PROM development)
- ▶ Cerrutto et al Health and Quality of Life Outcomes 2014 12: 46
 - 30 patients post cystectomy + ileal conduit
 - Positive & negative profiles

**PROMs – is it all just for
appearances?**


Potential uses

▶ Tick-box

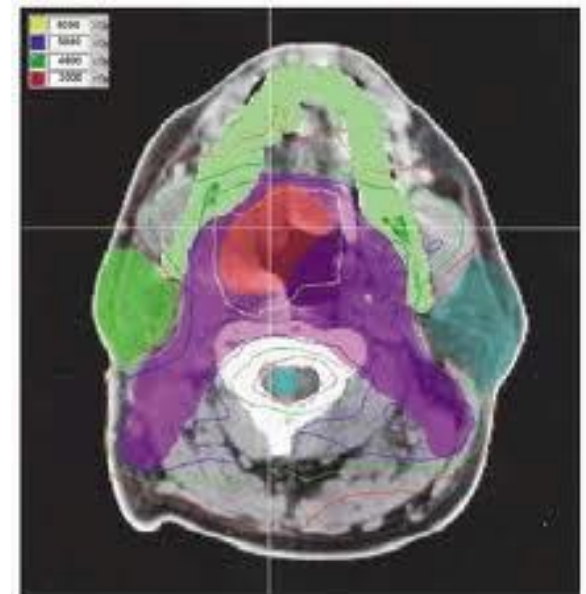
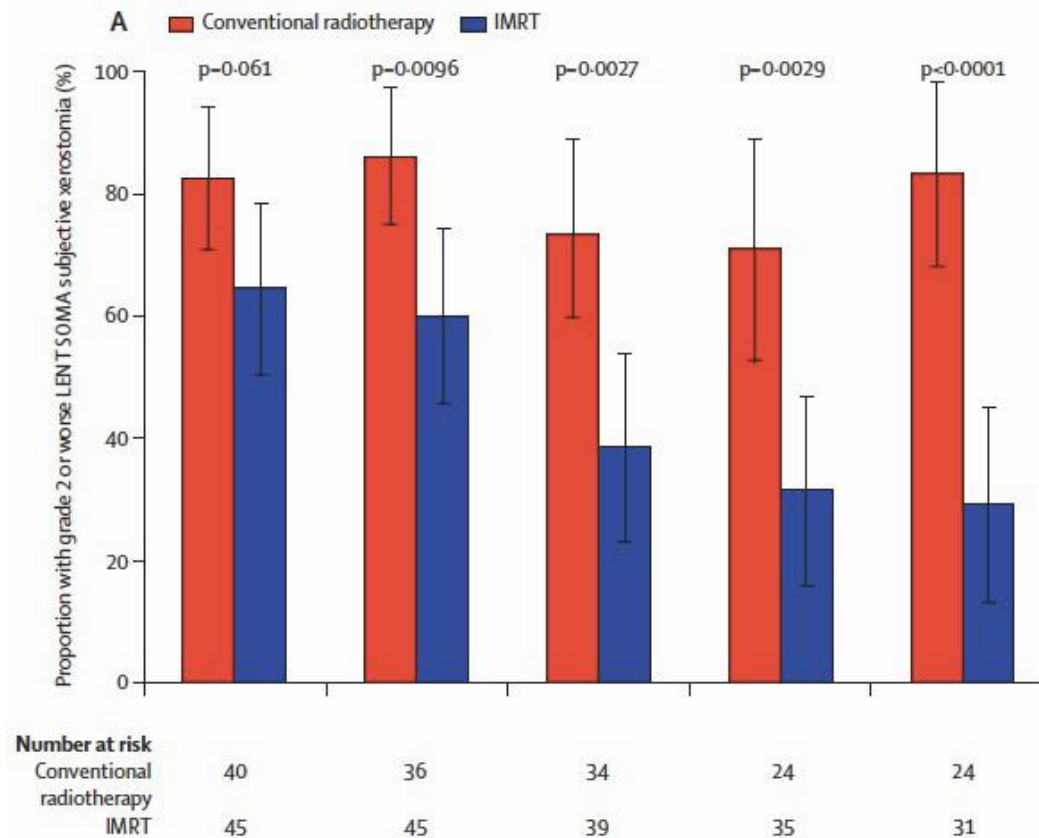
▶ Research

- Comparison of new treatments/technologies
- Evaluation of high cost treatments
- Analysis – timely, profile, thorough?

▶ Real-world

- Diagnosis
 - Identification of concurrent needs
 - Stratification of treatment/follow-up
 - Trigger for FU Ix
 - Evaluation of treatment
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PARSPORT –Treatment comparison



Composite endpoints – FOCUS 2

- ▶ MRC FOCUS2 trial
- ▶ Primary outcome
 - QoL (oral vs IV chemo)
- ▶ Overall Treatment Utility
 - “whether treatment had been worthwhile”
 - “how much interfered with usual activities”
 - Lack of progression & toxicity

START trial – Comparison to clinician graded scales

▶ START A & B

- Adjuvant RT trials
- 3 different dose/fractionation schedules
- Interest in normal tissue effects

▶ PROMs, clinician grading and photographs

- All differentiated between the treatment groups
- BUT on an individual patient level there was low concordance between patient and clinician grading

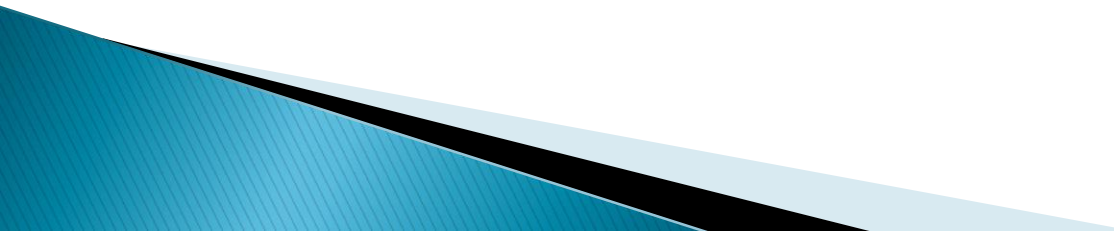
Direct electronic data capture

▶ PROMs

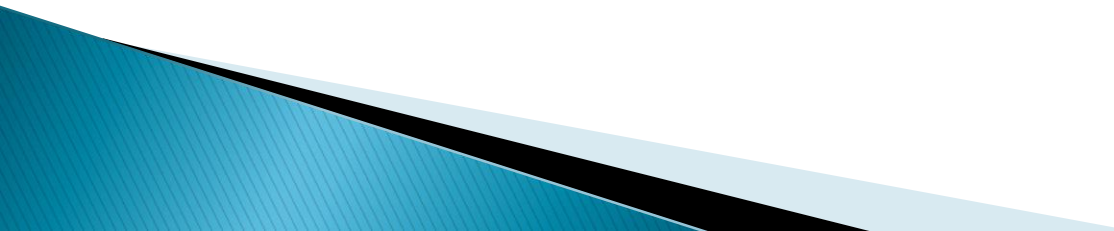
- Expensive
- Time consuming to interpret

▶ Electronic versions increasingly available

▶ Exploratory study

- Prostate cancer – starting new systemic treatment
 - EORTC QLQ C30 & PR 25 at 0 & 3 months
 - Optional remote completion
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Summary

- ▶ Personal preference for FACT over EORTC
 - Less chemo -specific
 - Now within a context of non-malignant disease
 - ▶ EQ-5D-5L
 - Little additional burden
 - Ubiquitous and linked to QALYS
 - ▶ Significant contribution to make but need to be used intelligently
 - ▶ Critical to embed within routine clinical care
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Q-ABC – coming soon...

- ▶ QoL after treatment for MIBC (cystectomy/RT)
- ▶ Qualitative study
 - QoL and decision-making
 - Patients and carers, 1–2 years post treatment
- ▶ National prospective PROMs study
 - Contemporaneous cohorts of RT & surgical patients
 - FACT-BI, EQ-5D-5L, Kornblith Fear of Recurrence Scale
 - Health Economics:UK Cancer Costs Questionnaire