Managing clinical outcomes for urological cancers

Netty Kinsella
Uro-oncology nurse consultant
The Royal Marsden
Presentation Overview

- Variation in access to treatment across the LCA
- Introduce the LCA Best Practice Prostate Pathway
- Pathway benefits
- Implementation challenges
- Next steps
Approximately $\frac{1}{8}$ of total 62 day LCA waits are prostate

- 9 LCA trusts failing the 62 day target for prostate
- LCA reporting 78.6% for prostate against 85% target
- Performance variation between 38-96%
LCA 62 Day Performance 2014/15

- Patients accounted for at trust where they had their first 2WW appointment
- Trusts or treatment groups with less than 10 cases excluded from analysis though included in overall LCA figures.
- Where trusts have more than one site with more than 10 cases these have been separated in the analysis
- Duplicates have manually been removed from the dataset

<table>
<thead>
<tr>
<th>Site code</th>
<th>Trust Name</th>
<th>Number of cases</th>
<th>Median Wait</th>
<th>Number of breaches 62 standard</th>
<th>% in target (62 day standard)</th>
</tr>
</thead>
<tbody>
<tr>
<td>RYJ01</td>
<td>St Marys Hospital - Imperial</td>
<td>29</td>
<td>81</td>
<td>18</td>
<td>37.9%</td>
</tr>
<tr>
<td>RYJ02</td>
<td>Charing Cross Hospital - Imperial</td>
<td>39</td>
<td>75</td>
<td>24</td>
<td>38.5%</td>
</tr>
<tr>
<td>RJ611</td>
<td>Croydon University Hospital NHS Trust</td>
<td>96</td>
<td>58</td>
<td>32</td>
<td>66.7%</td>
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<tr>
<td>RQM01</td>
<td>Chelsea and Westminster Hospitals NHS Foundation Trust</td>
<td>13</td>
<td>58</td>
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<tr>
<td>RFW01</td>
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<td>55</td>
<td>14</td>
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<tr>
<td>RV831</td>
<td>Central Middlesex Hospital - North West London Hospitals</td>
<td>13</td>
<td>50</td>
<td>1</td>
<td>92.3%</td>
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<tr>
<td>RYQ50</td>
<td>Queen Elizabeth Woolwich - SLHT</td>
<td>129</td>
<td>48</td>
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<tr>
<td>RJ7</td>
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<td>46.5</td>
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<tr>
<td>RV820</td>
<td>Northwick Park Hospital - North West London Hospitals</td>
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<td>45</td>
<td>2</td>
<td>97.7%</td>
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<tr>
<td>RVR05</td>
<td>St Helier Hospital</td>
<td>55</td>
<td>45</td>
<td>14</td>
<td>74.5%</td>
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<tr>
<td>RAS01</td>
<td>Hillingdon Hospital</td>
<td>12</td>
<td>44</td>
<td>2</td>
<td>83.3%</td>
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<tr>
<td>RYQ30</td>
<td>Princess Royal University Hospital - SLHT</td>
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<td>43</td>
<td>27</td>
<td>72.7%</td>
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<tr>
<td>RJ100</td>
<td>Guys and St Thomas' NHS Foundation Trust</td>
<td>211</td>
<td>42</td>
<td>33</td>
<td>84.4%</td>
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<tr>
<td>RVR50</td>
<td>Epsom Hospital</td>
<td>71</td>
<td>42</td>
<td>13</td>
<td>81.7%</td>
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<tr>
<td>RAS02</td>
<td>Mount Vernon Hospital - Hillingdon Hospital NHS Trust</td>
<td>50</td>
<td>39.5</td>
<td>2</td>
<td>96.0%</td>
</tr>
<tr>
<td>RJZ01</td>
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<td>88</td>
<td>39.5</td>
<td>8</td>
<td>90.9%</td>
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<tr>
<td>London Cancer Alliance Overall</td>
<td>1138</td>
<td>48</td>
<td>243</td>
<td>78.6%</td>
<td></td>
</tr>
</tbody>
</table>
LCA Prostate Median Wait to treatment

GSTT and Kings
Key Factors in improving efficiency in a urology cancer pathway

- Establishing a dedicated clinic
- Establishing a dedicated team
- Protocols for MRI prostate – Radiology
- Ring fencing radiology slots
- Same day/One-stop access to ultrasound, Flow rate, flexible cystoscopy
- MDT Coordination / Cancer trackers
Mapping the 2WW Prostate Pathway

Day 0
2WW Prostate Referral from GP to 2WW/Admin Team

Day 1-2
2WW/Admin Team contact Pts for pre-investigation
- PSA Test
- MSU

Day 3 - 5
2WW/Admin Team book Pts for clinic (send referral letter to Urology)

Day 6 - 8
Urology OPA designated 2WW prostate
-One stop clinic
(Flexi, US/S, FR+PVR, MRI)

Day 9 - 13
MRI

Day 14 - 20
TRUS Bx

Day 14
TP Bx

Day 14 - 20
TRUS Bx

Day 21 - 31
LMDM + Histology results given to pt in dedicated diagnostic clinic

Day 31 - 62
SMDM + OPA Treatment decision + Radical treatment

Day 31 - 62
Bone Scan - Start hormones on day

Clinical Dx

D/C to GP
R/V in Prostate clinic
## GSTT Audit

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Pre pilot (70 patients) N(%)</th>
<th>Pilot (65 patients) N(%)</th>
<th>P value</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Investigations carried out</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ultrasound</td>
<td>16</td>
<td>18</td>
<td>0.455</td>
</tr>
<tr>
<td>Cystoscopy</td>
<td>5</td>
<td>6</td>
<td>0.620</td>
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<tr>
<td>TURP + TP bx</td>
<td>3</td>
<td>2</td>
<td>0.735</td>
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<tr>
<td>TRUS bx</td>
<td>27</td>
<td>9</td>
<td>0.001</td>
</tr>
<tr>
<td>TP bx</td>
<td>9</td>
<td>9</td>
<td>0.812</td>
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<tr>
<td>MRI</td>
<td>38(54)</td>
<td>17(26)</td>
<td>0.001</td>
</tr>
<tr>
<td>Bone scan</td>
<td>3</td>
<td>2</td>
<td>0.735</td>
</tr>
<tr>
<td><strong>Diagnostic outcomes</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Patients with diagnosis of prostate cancer</td>
<td>31(40)</td>
<td>24(37)</td>
<td>0.466</td>
</tr>
<tr>
<td>Watchful waiting</td>
<td>9(29)</td>
<td>7(29)</td>
<td>0.991</td>
</tr>
<tr>
<td>Active surveillance</td>
<td>11(35)</td>
<td>4(17)</td>
<td>0.120</td>
</tr>
<tr>
<td>Radical treatment</td>
<td>11(35)</td>
<td>13(54)</td>
<td>0.165</td>
</tr>
<tr>
<td>Patients discharged to GP within 7 days</td>
<td>14(20)</td>
<td>37(57)</td>
<td></td>
</tr>
<tr>
<td>Patients discharged after 31 days</td>
<td>34(49)</td>
<td>4(6)</td>
<td></td>
</tr>
<tr>
<td><strong>Unnecessary investigations</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>TRUS bx</td>
<td>11(16)</td>
<td>0</td>
<td>&lt;0.0001</td>
</tr>
<tr>
<td>TP bx</td>
<td>2(3)</td>
<td>0</td>
<td>0.497</td>
</tr>
<tr>
<td>MRI</td>
<td>17(45)</td>
<td>0</td>
<td>&lt;0.0001</td>
</tr>
</tbody>
</table>
Impact - Benefits

- Reduced 2WW waiting times
- Reduced 62 day waiting times
- Reduction in unnecessary biopsies and scans
- Reduction in same day cancellations for biopsies
- Reduced burden on resources
- Patient satisfaction
Urological cancers - side effects

- LUTS
- Sexual dysfunction
- Fatigue
LUTS Assessment

- Relevant medical history
- Current medications
- Physical Examination – Penile exam (rule out phimosis or other penile pathology)
- Urinalysis
- Check MSU
- Frequency volume chart – nocturnal polyuria
- Check drinking habits
- IPSS
### International prostate symptom score (IPSS)

**Key:**
- Voiding symptoms - blue
- Storage symptoms - pink

**Incomplete emptying**
- Over the past month, how often have you had a sensation of not emptying your bladder completely after you finish urinating?
  - Not at all: 0
  - Less than 1 time in 5: 1
  - Less than half the time: 2
  - About half the time: 3
  - More than half the time: 4
  - Almost always: 5

**Frequency**
- Over the past month, how often have you had to urinate again less than two hours after you finished urinating?
  - Not at all: 0
  - Less than 1 time in 5: 1
  - Less than half the time: 2
  - About half the time: 3
  - More than half the time: 4
  - Almost always: 5

**Intermittency**
- Over the past month, how often have you found you stopped and started again several times when you urinated?
  - Not at all: 0
  - Less than 1 time in 5: 1
  - Less than half the time: 2
  - About half the time: 3
  - More than half the time: 4
  - Almost always: 5

**Urgency**
- Over the last month, how difficult have you found it to postpone urination?
  - Not at all: 0
  - Less than 1 time in 5: 1
  - Less than half the time: 2
  - About half the time: 3
  - More than half the time: 4
  - Almost always: 5

**Weak stream**
- Over the past month, how often have you had a weak urinary stream?
  - Not at all: 0
  - Less than 1 time in 5: 1
  - Less than half the time: 2
  - About half the time: 3
  - More than half the time: 4
  - Almost always: 5

**Straining**
- Over the past month, how often have you had to push or strain to begin urination?
  - Not at all: 0
  - Less than 1 time in 5: 1
  - Less than half the time: 2
  - About half the time: 3
  - More than half the time: 4
  - Almost always: 5

**Your score**

**Date:**

**Attach patient identifier**
*Request fasting glucose with GP if yes to either question
**Please check that the patient is not already on an alpha blocker
e.g. doxazosin
**Tamsulosin is also contraindicated in Glaucoma
The Royal Marsden

*Request fasting glucose with GP if yes to either question

** Please check that the patient is not already on an alpha blocker e.g. doxasozin

**Tamsulosin is also contraindicated in Glaucoma
IPSS 20-35
Refer to LUTS clinic
Male Sexual Dysfunction Referral Pathway

Erectile dysfunction is the inability to attain and maintain an erection sufficient for satisfactory sexual performance.

History:
- Sexual history is essential to differentiate psychological from physical causes or mixed picture (e.g. presence of early morning erections/ability to masturbate?
- Enquire about lifestyle
- Consider the following pathophysiology in history
  - Vasculogenic: e.g. CVD, hypertension, diabetes mellitus, hyperlipidaemia, smoking, major surgery
  - Neurogenic: e.g. MS, Parkinson’s disease, CVA, alcoholism, diabetes, tumours
    - Hormonal: e.g. hypogonadism, thyroid hyperplasia
  - Anatomical: e.g. Peyronie’s disease, congenital
- Drug induced? (1)

Examination:
- Cardiovascular, neurological and endocrine
- Genitourinary
- Digital rectal examination (if appropriate) to eliminate Ca prostate

Investigations:
- FBC, U&Es, LFTs, fasting glucose & lipids
- Total testosterone (measure in the morning between 8-11 am)
- If testosterone result is low, confirm with second sample and also check SHBG, LH, FSH & prolactin
- PSA (if appropriate and only after appropriate counselling)

Referred: Young man who has always had difficulty with ED
- History of trauma to genital area
- Perineal/testicular pain/abnormality on examination

Psychological cause
- Consider trial of PDE-5 inhibitor (5)
- Refer to psychosexual counselling

Refer to appropriate specialist if abnormal:
- Hormone profile
- Endocrine
- Lipid profile
- Cardiac risk factors
- Cardiology
- Raised PSA
- Urology

Give lifestyle advice as appropriate (2)
- Assess patient's needs and expectations

Treat reversible causes & reassess (3)

No reversible causes

Unsuitable/unable to take PDE-5 inhibitors (4)

No better

No response

Trial of PDE-5 inhibitor (5)

No response

Refer Patient to Andrology Service

Via EPP (ED Referral) or One Stop Clinic (Mr Shabir/Mr Zarbakhsh)
Radical Prostatectomy

Nerve Sparing
TWOC
PDE-5 inhibitor OD twice weekly PRN

6-8 Weeks Post-op
Commence vacuum therapy 10 minutes daily

3-6 Months Post-op
If no erections after 3-4 months try changing to different PDE-5 inhibitor at maximum dose for at least 8 doses. Start Alprostadil (Emla cream or C2) if needed. Continue with vacuum device.

6-12 Months
Ensure tried all PDE-5 inhibitors and Alprostadil. If PDE-5 inhibitors are not effective. If no response consider combination therapy under guidance of andrology team.

12 – 24 Months
If no return of erectile function discuss penile implant.

Non-nerve Sparing
TWOC

6-8 Weeks Post-op
Commence vacuum therapy 10 minutes daily
Start injections if needed

3-6 Months Post-op
Continue with vacuum device and injections. 6 months – discuss option of penile implant if not happy with above treatment.
Fatigue

- Fatigue management programmes
- Exercise – community and hospital based programmes
  - Ramblers association
  - Health walk www.walkingforhealth.org.uk
  - CanRehab www.canrehab.co.uk/
- CBT and self management techniques
Scenario 1

- 63 Year old man
- Caucasian Extraction
- No Family History
- DRE small nodule
- PSA 3.8
- Would you refer?

Individualized Risk Assessment of Prostate Cancer

**Results**

Based on the data provided, the person’s estimated risk of biopsy-detectable prostate cancer is 34%.

The 95% Confidence Interval for this prediction is 31.6% to 36.4%.

[More information about the confidence interval](#)

The person’s estimated risk of biopsy-detectable high grade prostate cancer is 7%.

The 95% Confidence Interval for this prediction is 5.4% to 8.6%.

[More information about the confidence interval](#)

**Your Information**

- Race: Caucasian
- Age: 63
- PSA Level: 3.8 ng/ml
- Family History of Prostate Cancer: No
- Digital Rectal Examination: Normal
- Prior Prostate Biopsy: Never Had A Biopsy

[Another Calculation]
Post-treatment
12 months post RALP

12 months post-op
- **LUTS**
  - IPSS 18 (instability sx)
  - QoL 4

**Erectile dysfunction**
- Unilateral nerve spare
- On-demand PDE-5 minimal effect
Scenarios 2

- 78 Year old man
- Caucasian Extraction
- No Family History
- DRE normal
- PSA 4.6

Would you refer?

Individualized Risk Assessment of Prostate Cancer

<table>
<thead>
<tr>
<th>Race</th>
<th>Caucasian</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>78</td>
</tr>
<tr>
<td>PSA Level</td>
<td>4.6 ng/ml</td>
</tr>
<tr>
<td>Family History of Prostate Cancer</td>
<td>No</td>
</tr>
<tr>
<td>Digital Rectal Examination</td>
<td>Normal</td>
</tr>
<tr>
<td>Prior Prostate Biopsy</td>
<td>Never Had A Biopsy</td>
</tr>
</tbody>
</table>

Results

Based on the data provided, the person's estimated risk of biopsy-detectable prostate cancer is 37.7%.

The 95% Confidence Interval for this prediction is 34.9% to 40.5%.
[More information about the confidence interval]

The person's estimated risk of biopsy-detectable high grade prostate cancer is 13.2%.

The 95% Confidence Interval for this prediction is 10% to 16.3%.
[More information about the confidence interval]
12 months post treatment
EBRT + Hormone therapy

- Fatigue
- Hot flushes
- Erectile dysfunction
- LUTS
Survivorship pathway - Urology
The Recovery Programme

- **Holistic Needs Assessments** and care planning at key points of the care pathway,

- **A Treatment Summary** completed at the end of each acute treatment phase, sent to patient and GP

- **A Cancer Care Review completed by GP or practice nurse to discuss the person’s needs, and**

- **A patient education and support event**, such as a Health and Wellbeing Clinic, to prepare the person for the transition to supported self management, which will include advice on healthy lifestyle and physical activity.
The Recovery Package (NCSI/Macmillan 2012)
London Holistic Needs Assessment

For each item below, please tick yes or no if you have been a concern for you during the last week, including today. Please also tick discuss if you wish to speak about it with your health professional. Choose not to complete the assessment today by ticking box □.

Date:

Name:

Hospital/NHS number:

Please tick the number that best describes the overall level of distress you have been feeling during the last week, including today:

10 □ Extreme distress
9 □
8 □
7 □
6 □
5 □
4 □
3 □
2 □
1 □
0 □ No distress

Practical concerns

Physical concerns

Yes No Discuss

Yes No Discuss

Care responsibilities
□ □ □

High temperature
□ □ □

Housing or finances
□ □ □

Wound care
□ □ □

Transport or parking
□ □ □

Passing urine
□ □ □

Work or education
□ □ □

Constipation or diarrhea
□ □ □

Information needs
□ □ □

Indigestion
□ □ □

Difficulty making meals
□ □ □

Nausea and/or vomiting
□ □ □

Grocery shopping
□ □ □

Cough
□ □ □

Preparing food
□ □ □

Changes in weight
□ □ □

Bathing or dressing
□ □ □

Facing or opposite
□ □ □

Laundry or housework
□ □ □

Changes in table
□ □ □

Family concerns

□ □ □

□ □ □

□ □ □

Sore or dry mouth
□ □ □

Relationship with children
□ □ □

Feeding swallows
□ □ □

Relationship with partner
□ □ □

Breathlessness
□ □ □

Relationship with others
□ □ □

Pain
□ □ □

Emotional concerns

□ □ □

□ □ □

□ □ □

Dry, itchy or sore skin
□ □ □

Loneliness or Isolation
□ □ □

Tingling in hands or feet
□ □ □

Sadness or desolation
□ □ □

Hot flashes
□ □ □

Worry, fear or anxiety
□ □ □

Mistreatment or being bullied
□ □ □

Anger, frustration or guilt
□ □ □

Fatigue
□ □ □

Memory or concentration

□ □ □

Sleep problems
□ □ □

Propriety

□ □ □

Communication
□ □ □

Sexual concerns

□ □ □

□ □ □

□ □ □

Other sexual condition
□ □ □

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1. Sexual concerns
2. Sleep problems
3. Fatigue
4. Passing urine
5. Worry, fear or anxiety
Good practice......

- Consistency in correspondence
- Diagnostic summary
- Treatment summary
- Discharge summary (transfer of care)
Health and Well-being events

- Key points: Pre, Post and Discharge
- Peer support
- Closer to home events
  - Maggies Centre – Charring Cross
  - Wimbledon Guild
  - Butterfly Centre ESH
  - The Purley Centre - Croydon
Pre-Treatment Health and Well-being Event

- Pre-habilitation
  - setting the scene
  - Setting expectations
# Post Treatment Health and Well-being Events

<table>
<thead>
<tr>
<th>Time</th>
<th>Session</th>
<th>Session Duration</th>
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</thead>
<tbody>
<tr>
<td>13:30 – 13:50</td>
<td>Keeping Active</td>
<td>20 mins</td>
</tr>
<tr>
<td>14:15 – 14:40</td>
<td>Eating Well After Prostate Cancer Treatment</td>
<td>25 mins</td>
</tr>
<tr>
<td>14:40 – 15:05</td>
<td><strong>TEA BREAK &amp; Dimbleby Centre – our services</strong></td>
<td>25 mins</td>
</tr>
<tr>
<td><strong>Session 2: Dealing with the after effects of treatment</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>15:05 – 15:20</td>
<td>Good fluid intake: It's not just for treatment, it's for life!</td>
<td>15 mins</td>
</tr>
<tr>
<td>15:20 – 15:40</td>
<td>Continence</td>
<td>20 mins</td>
</tr>
<tr>
<td>15:40 – 16:10</td>
<td>Management of erectile dysfunction after treatment for prostate cancer</td>
<td>30 mins</td>
</tr>
<tr>
<td>16:10 – 16:25</td>
<td>Managing hot flushes</td>
<td>15 mins</td>
</tr>
<tr>
<td>16:25 –</td>
<td>Close</td>
<td>5 mins</td>
</tr>
</tbody>
</table>
Post-Treatment Health and Well-being event

- Psychological support
- Exercise
- Benefits
- The discharge summary and managing late effects of treatment
- You and Your GP
  - The benefits of primary care follow up
  - Concerns
  - Navigating the system
- Team work
- Reassurance
Survivorship pathway - RALRP

- **Meet Key worker**
  - PROMS baseline (HNA, IPSS, IIEF, EORTC, EPIC)
  - Pre-Treatment H&W event
- **4/52 post Tx – telephone call with key worker**
  - PROMS review
  - Completion of Post treatment summary
- **8/52 face to face review with consultants team**
  - PROMs review
  - Histology and PSA review
- **3-6 monthly review in Multi-prof survivorship clinic** (Telephone or face to face)
  - PROMS review
  - Completion of survivorship summary

- Discharge/Transfer of care at 2 years
- Invite to post treatment H&W event
- Completion of discharge summary
All responders said that they would recommend the events to other men

I am so glad that there are things I can do to feel better

Excellent - I would recommend to everyone

I understand so much more about my treatment and feel much less scared now

I was too embarrassed to ask questions myself but I was able to listen to all the other men and learnt so much

I cried when I heard that other people were going through the same things as we were

This has put years on my life expectancy

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