Welcome and Introductions

Justin Vale, Chair of the LCA Urology Pathway Group
Progress of the Urology Pathway Group

Justin Vale, Chair of the LCA Urology Pathway Group
Progress update: The Urology Pathway Group

- Implementation with TCST and London Cancer of a **new pan London 2ww form** for suspected urological cancers – update

- Review of **specialised urological cancer surgery configuration** across the LCA

- **Best practice prostate pathway** – inclusion of MRI pre-TRUS biopsy, amended guidance

- **Adoption of MRI pre-TRUS biopsy** across the LCA (see next slide)

- **Commissioning intentions 2016/17** – proposed changes or additions to next years commissioning intentions (see next slides)
Objectives for today

1. Up-date regarding the changing needs for bladder and prostate guidance

2. Understanding of timing and requirements for Treatment Summaries. How can the Pathway Group help with this?

3. Better understanding of cancer informatics and what you can do to improve quality of data and performance reporting

4. Opportunities and challenges of setting up an Open Access Follow-Up (OAFU) service to take back to your centre
Adoption of MRI pre-TRUS biopsy

All reporting Trusts confirmed they have:

- Implemented MRI pre-TRUS biopsy
- Clinical buy in for MRI pre-TRUS biopsy
- 71% Trusts (10/14) have reported an MRI backlog or challenges with MRI capacity, including reporting delays and access to MRI slots
- 71% (10/14) reported capacity issues with pathology / histology including access to and reporting time for TRUS biopsy.
- 14% (2/14) of Trusts repeat diagnostic testing on receipt of referral (repeat pathology only)

14 out of 14 Trusts responded
Key issues reported:

- Demand is outstripping capacity for MRI, TRUS biopsy and pathology
- Ability to train up personnel to undertake specialist work (radiologists, pathologists) does not fit with timescale for increase in demand
- Difficult to appoint urology CNSs and number of specialist CNS posts for each service
- Pathway redesign such as telephone triage / telephone results not possible due to lack of staff
- Tracking patients through the pathway
Commissioning Intentions 2016/17

• **All** prostate cancer services will be commissioned through a timed pathway in line with NCSI *(12/14 LCA centres reported compliant)*

• **70% of patients** will receive a Holistic Needs Assessment, attend a health and wellbeing event and receive a treatment summary

• **Providers to demonstrate** pathways in place for the management of treatment related fertility issues

• **40%** of new prostate cancer patients are followed up in a stratified follow-up *(open access follow-up)* community clinic
NICE Bladder Cancer Guidance

An overview of the changes

Mr Giles Hellawell, Consultant Surgeon, London Northwest Healthcare NHS Trust
Headlines

• Patient experience scores poorly throughout the LCA for most of the bladder NCPES questions (overall reported experience 88% of LCA tumour groups state excellent or very good Vs 83% for Bladder cancer alone).

• This could be due to a lack of CNS’ and the requirement for intensive surveillance.

• Overall published guidelines are broadly similar to current LCA guidance.
NICE new recommendations:

- MRI recommended for high risk patients considering radical treatment.
- LCA recommend using CT (enables imaging of the kidneys and ureter whilst high risk muscle invasive patients require chest imaging). No change in LCA guidance.
- NICE suggest that low risk non muscle invasive bladder cancer patients with no recurrence should be discharged at 12 months.
- The LCA Pathway Group advise discharge at 5 years of surveillance with no recurrence.
- The LCA supports recommendation of re running an annual patient experience survey with compliance to be considered for audit at a later date.
Cancer Outcomes and Services Dataset (COSD) - Urology

23rd September 2015

Steve Scott, Informatics lead, LCA
Overview – Cancer Outcomes and Services Dataset

• The Cancer Outcomes and Services Dataset (COSD) was introduced in January 2013 to replace the National Cancer Dataset

• COSD is the registry dataset, which is derived from trust feeds
  – MDT feed
  – Pathology feed
  – PAS feed
  – Radiology feed
  – Cancer Waiting Times Dataset
  – Death certificate (Direct from ONS)
  – *In same cases registry officers going through notes at trusts (being phased out)*

• Submitting COSD feeds to cancer registry included in NHS Trust standard contracts
COSD site specific data items – Prostate

_Cancer Care plan_
• PSA (Diagnosis) – PSA at time of diagnosis

_Treatment_
• PSA (Pre treatment) – PSA taken prior to each treatment

_Pathology_
• Gleason Grade (Primary/Secondary/Tertiary)
• Perineural Invasion
• Organ Confined
• Seminal Vesicles Invasion
• TURP tumour percentage (for TUPR only)
COSD site specific data items – Kidney

*Cancer Care Plan*
- Estimated glomerular filtration rate (at diagnosis)

*Pathology*
- Tumour necrosis indicator
- Perinephric fat invasion
- Adrenal invasion
- Renal vein tumour
- Gerot’s fascia invasion
COSD site specific data items – Bladder

**Cancer Care Plan**
- Hydronephrosis

**Treatment**
- Intravesical Chemotherapy received indicator
- Intravesical immunotherapy received indicator

**Pathology**
- Detrusor muscle presence indicator
- Tumour Grade (Low/High/Punlmp/N/A)
COSD site specific data items – Testicular

_Cancer Care Plan_
- Normal LDH
- S category (overall, AFP, HCG, LDH)

_Staging_
- Stage grouping (Testicular)
- Extranodal metastases
- Lung metastases sub-stage grouping

_Pathology_
- Rete testes invasion (Seminoma only)

COSD site specific data items – Penile

_Pathology_
- Corpus spongiosum invasion
- Corpus cavernosum invasion
- Urethra or prostate invasion
LCA approach to data quality COSD

• Establish feeds from all providers

• Focus on key data items in MDT feed
  – Number of cases submitted
  – Staging
  – Basis of diagnosis
  – Performance status
  – Clinical Nurse Specialist Indicator
  – MDT discussion indicator
Next steps – Analysis of COSD

- Reports looking at incidence/mortality/stage distribution and survival by stage reviewed by tumour specific groups to identify trends or areas for review and further information required

- Increased focus on other data items (e.g. performance status and co-morbidities)

- Review of linked together tumour reports compiled by cancer registry using all feeds (Level 3)

- Survival by stage information for more years and for more tumour groups
Lymphoedema following groin node dissection / radiotherapy in patients with urological cancers

Martine Huit
Lymphoedema CNS, Guy’s and St Thomas’ NHS Foundation Trust
LCA Lymphoedema Community of Practice member
Lymphoedema Community of Practice

• Set up to 2013 to provide expert clinical leadership about lymphoedema in the LCA

• Long acknowledged that lymphoedema is under-recognised in its early stages, and that access to services is highly inequitable

• LCA CoP service mapping and education mapping demonstrated this is the case in the LCA

• Also known that lymphoedema services are cost effect and that early intervention improves quality of life, patient experience, and reduces GP attendance and need for antibiotics

• LCA pathway developed to as a result
**Lymphoedema Management Pathway**

**Pre-Cancer Treatment**
- Risk of lymphoedema discussed at point of consent
- Baseline limb measurements (see appendix 1)
- Provide patient information

**Risk Factor Management**
- Include risk of lymphoedema within Treatment summary for those at risk
- Offer pre-habilitation. This should include:
  - Exercise
  - Skin care advise
  - Advise on maintaining a healthy weight

**Clinical Suspection**
- Identified by patient or any HCP
- HCP should:
  - Use agreed measurement tools (appendix 1)
  - Refer to lymphoedema specialist for full assessment
  - Ensure link to on-line GP letter included

**Clinical Diagnosis**
- Not confirmed/ILS Stage 0
  - At risk:
    - Offer referral to pre-hab
  - Not at risk:
    - Discharge
      - Include link to GP education within letter to referrer

**Definitive Diagnosis**
- Lymphoscintigraphy completed
- Results sent back to the treating service
- Lymphoscintigraphy results used to inform management decisions

**Treatment**
- **Standard Intervention**
  - Must include (unless contraindicated) skin care, exercise advise, MLD/SLD, containment, psychological support and weight management advise
  - Provide relevant education including providing patient information
  - **Intensive Treatment**
    - Must be available and be specialised
    - Should be available as an in-patient or domiciliary when clinically indicated
    - Referrals for social support should be made as necessary
    - Life expectancy should be taken into account when prioritising waiting lists
  - **Maintenance Treatment**
    - Provide GP and patient with management plan
    - Provide re-referral/early review criteria explicit
    - Ensure GP aware of prescribing for hosiery
  - **Palliative Treatment**
    - A flexible approach is needed
    - Should consider all of the above
    - Use palliative bandaging
    - Should include MLD
    - Waiting times should be considerate of prognosis
    - Referrals to other MDT members should be considered
    - Consider use of pumps
    - Consider surgical options
Lower limb and midline lymphoedema - Overview

Following lymphadenectomy cancer patients may be at risk of developing lymphoedema, this risk increases if they also have radiotherapy.

Urological cancers - the incidence of lymphoedema is largely unknown, but varies according to the type and location of tumours and may be up to 50% in advanced stages of cancer and/or following its treatment. (Okeke et al 2004). GSTT – 2% of caseload urology related (750 patients registered with the clinic)

Appropriate, early intervention to treat lymphoedema can reduce psychological distress and improve functional ability, improving long term outcomes for patients and reducing cost to the NHS.

The development of current services within the LCA should consider what resources will be required and how patients will access a lymphoedema specialist.

Two initiatives recommended by the LCA:
pre and post operative screening to promote early recognition of signs and symptoms of lymphoedema triggering early referral to a specialist service – will require up-skilling key staff to undertake this work

ensure appropriate information is available to patients along their pathway of care
Development of Pathway

Current Pathway
- Aim to see the patient within 6 weeks of referral
- Assessed and treatment plan created
- Discharge when goals achieved; if goals not achieved need to determine underlying cause/s with appropriate referral to members of the MDT
- Average time registered with clinic = 2 years plus

Current ideas under development
- Pre-assessment education; piloted and to continue due to positive feedback from patients who attend
- To liaise with Urological team to discuss our input in any future Health and Wellbeing event developed for this group of patients
- Written information on lymphoedema included in GSTT booklets
- Investigate what support other HCP need to provide basic lymphoedema information to ‘at risk’ and/or those with early onset lymphoedema
- Pre and post operative screening – circumferential limb volume measurements
- Investigate where additional specialist involvement at key points is needed
What next for the urological Pathway Group?

- Why does there appear to be a low referral rate compared to other lymphoedema services within the LCA?
- What percentage of patients treated for urological cancer who undergo groin node dissection with/without radiotherapy go on to develop lymphoedema?
- Which treatment pathway leads to the highest number of patients developing lymphoedema?
- Are you providing the right information to ‘at risk patients’ or patients with early onset lymphoedema?
- Are you putting it in the treatment summaries?
- Are you referring people with early signs to your local services?
- How can you take the LCA pathway and the learning from GSTT forward?
- What else do you need from the CoP?
Tea/coffee break
Treatment summaries

First draft presentations and discussion

Chaired by Mr Justin Vale, LCA Urology Pathway Group Chair
TREATMENT SUMMARIES FOR PENILE/URETHRAL CANCER

Nick Watkin
September 2015
LCA forum
Challenges/Considerations

• Geographically diverse population

• Primary care clinicians potentially not familiar with rare disease and treatment

• Secondary Care may be reluctant to become involved

• Continuation of treatment
• Managing complications both physical and psychological
• Detecting signs of recurrence
Morbidity

- Local penile problems
  - Lichen sclerosus
  - Meatal stenosis
  - Urinary spraying
  - Chronic irritation/concern about skin appearance
  - Penile burying
  - Erectile/sexual dysfunction/altered sensation
- Lymphoedema
- Cellulitis

- Concern about recurrence
- Fear/guilt/embarrassment and failure to seek advice/help
Patient directed Pathway

- Treatment folder

- Clinical records
  - Copy letters from clinic to GP/Secondary care
  - End of first treatment summary given in clinic and explained face to face

- Patient information
  - Self examination booklet
  - Risk adapted surveillance timetable (with clinician sign off) and check list
  - Relevant morbidity advice sheets/aspects of survivorship
Prostate Open Access Follow up
“Challenges and Pitfalls”

Jo Sethi  Urology CNS
Imperial College Healthcare NHS Trust
Open Access Follow UP (OAFU)

Cancer patients are:

- Given the opportunity of self managing their follow up care.

- Tracked through diagnostic tests without the need for standard outpatient appointments.

- Stratified according to the staging of their cancer, risk of recurrence, late effects and ability to self manage.
Why the need for Change?

• Success of PSA Telephone follow up clinic

• Improve patient experience

• The opportunity for patients to self manage their follow up care.

• Overbooked clinics / Capacity
The Challenges

- Engaging Team
- Tracking Tool
- Phase 1
- CSW Role – New Role
- Managing Patients expectations
- End of treatment HNA
- Appropriate referral
Engaging the team- Urology Steering Group

- Met Bi-weekly with Colorectal and Breast teams
- Develop standard operational policy
- Patient /GP information
- Logistics- setting up clinics
- Updates- problem solving
- Sharing Good Practice
Engaging the Multi Disciplinary Team

Raising profile of OAFU

- Education event
- MDT Meetings
- Consultant Meetings
- CNS meetings
- Collaborative working
Tracking tool

Referral – Patient is referred in and a pathway is created.

Investigation – Investigations are undertaken to diagnose the patient and documented here.

Care Plan/MDT – Patients are discussed in an MDT and any care plans are documented. Patients that are potentially eligible for OAFU are also noted.

Diagnosis – Patient is diagnosed

Treatment – All treatments the patient has undergone or undergoing are documented.

CNS Contacts – Any communication the CNS has with the patient will be documented here. HNA’s (at diagnosis and end of treatment) are also documented here.

AHP Contacts – OAFU Support Workers document all communication with the patient here.

Follow Up – Flags the patient for OAFU.

This process above ensures that there is a complete record of the patient in one application.
Patient Tracking List

• The OAFU Patient Tracking List (PTL) provides a comprehensive guide to the management of post-treatment pathways and is focussed on practical advice that will help to ensure that patients are treated and followed up in a timely manner.

• Monthly PTL figures circulated

• Cancer support worker updates data in real time

• Somerset adapted to be used as a Flagging system.
Cancer support Worker

- New Role – sponsored by Imperial Charity, recruited August 2014
- Developed Virtual clinics Monday – Friday, reminding patients to have PSA
- Mini-HNA
- Training And Support by Clinical Psychologist
- Close Working with CNS
- Weekly OAFU meeting to review Results with CNS/OAFU Lead Consultant
- Unable to give PSA results
Phase 1

- Patient diagnosed with CA
  - Pt Rx with Surgery
    - Pt Rx with Rt ± Hormones
      - 6 months or less
        - 6 monthly PSA
        - See DR at 1 year
        - Back to OAFU (PSA every 6 months for first 2 years then annually)
      - >6 months
        - 6 month PSA then see at Hormone stop date, refer back to OAFU when ready

- Pt Rx just with Hormones
- Pt on AS
- Metastatic

Phase 1 OAFU
- OPD CNS HNA / explain OAFU
- Confirm hand over to OAFU CSW
- CSW confirms FU, track PSA, annual Tel Call

Phase 2 OAFU
- 3 monthly PSA
- See DR at PSA rise
  - PSA monitoring
  - Scheduled imagining
  - Surgical supervision

Phase 3 OAFU
- 3 monthly PSA
- See DR at PSA rise
Managing Patient Expectations - Transition to OAFU

The patient is supported during the follow-up period by appropriate education on signs and symptoms coupled with comprehensive patient information.
The London Cancer Alliance

OAFU Telephone Helpline / Email

**Helpline**

- Available Monday-Friday 9-5
- If patient has to leave a message, CSW will call back next working day.
- If patients have any concerns out of hours they should contact their GP or visit A&E.

**Email**

- There is a dedicated email address for OAFU which both the GPS and Patients can access.
- If the patient e-mails OAFU with a query, they will receive a telephone call back.
- GPs can communicate via email as they are on secure network.
The London Cancer Alliance
Pre Assessment

Patient has surgery/chemo/rad

End of treatment consultation

- Agree suitability for Self Managed pathway
  - HNA and Treatment summary
  - Awareness of signs and symptoms of recurrence
- Supported SelfManaged pathway information leaflet provided and reviewed with the patient
  - Programme of follow up
  - Frequency of diagnostic tests
    - Type of diagnostic tests
    - Indication of length of follow up

Options of follow up

Supported Self - Management
- Patient attends for diagnostic test
- Patient reports worrying signs or symptoms

Continue to follow up

If results are within range
- Patient and GP are informed by letter
- Date of next diagnostic tests indicated

If results are outside range
- Patient called to discuss the results and offered clinic appointment within 14 days. Letter to patient and GP

Helpline available to patients 9am-5pm. Out of hours: Patient should contact their Out of Hours GP service or visit local A & E
Exclusion Criteria (according to LCA risk stratification Guidelines)

- Patients who are under active treatment (i.e. with residual or metastatic disease)
- Patients that are assessed to be unable to self-manage, e.g. patients with severe learning disabilities or mental health issues
- Patients on clinical trials
- Patients whose cancer is of variant histology or non-PSA secreting
New patient end of treatment consultation

Consultant role

• Offers OAFU to eligible patient

• Obtains verbal consent and OAFU patient information is given

• Emails Prostate CNS / CSW to say patient who has had newly finished treatment is to be entered into OAFU.

• Writes clearly on the Clinic Outcome Form – ‘OAFU’

All Clinic outcome forms will be left at reception so that the CSW can collect the OAFU referrals

• Requests PSA on CERNER
MDT agrees eligibility for OAFU (Post staging)

End of treatment Consultation

Clinic Follow up appointment with Nurse - HNA / Care Plan

Patient enters OAFU

OAFU Telephone follow up with Cancer Support Worker

Patient has PSA

Some patients excluded from OAFU (e.g. Mets, trials)

Results within range

Patient and GP sent standard Trust letter

CSW records outcome on Somerset

Results outside range

Urgent opa with Consultant

Re-entry OAFU or exit OAFU
Current Prostate PTL

Please find attached your regular Cancer Open Access Follow Up - Patient Tracking List (PTL).

Report title: Cancer Open Access Follow Up- PTL
Purpose of report: For the proactive management of patients on Cancer Survivorship
Data source: Somerset
Run date: 11th September 2015

The report shows:
• Total 180 Patients for Breast.
• Total 21 Patient for Colorectal.
• Total 410 Patients for Urology - Prostate.
Patient feedback

“Phone answered, don’t need to go around the houses”

“No more waiting hours to see Dr’s”

“Service developed for me”

“Brilliant”

“Less disruption to my working life”

“Thanks”

“Reassuring- to know you are there (helpline)”

“I want to see the Dr, I have paid in all my life, is that too much to ask?”
Any Questions?
Holistic Needs Assessment (HNA)

*Increasing awareness and use in the LCA, and how far we have come*

Netty Kinsella, Nurse Consultant, Royal Marsden Hospital
Urology 1st April 2014- 31st March 2015 HNA Figures
Top 10 Most Commonly Reported Concerns from People with Prostate Cancer (n=341)

- Sexual concerns
- Passing urine
- Worry, fear or anxiety
- Sleep problems
- Fatigue
- Constipation or diarrhoea
- Sadness or depression
- Hot flushes
- Transport or parking
- Pain
Top 5 Reported Concerns by People with Prostate Cancer by Pathway Stage

- Sexual concerns
- Worry, fear or anxiety
- Transport or parking
- Passing urine
- Constipation or diarrhoea
- Sleep problems
- Hot flushes
- Fatigue
- Memory or concentration

At Diagnosis % (n=185)
On Treatment % (n=58)
End of Treatment % (n=93)
Top 10 Most Commonly Reported Concerns By People With Bladder Cancer (n=71)

1. Worry, fear or anxiety
2. Passing urine
3. Sleep problems
4. Fatigue
5. Information needs
6. Sadness or depression
7. Dry, itchy or sore skin
8. Other medical condition
9. Anger, frustration or guilt
10. Memory or concentration

Pain
Top 5 Reported Concerns of People with Bladder Cancer by Pathway Stage

- Worry, fear or anxiety
- Passing urine
- Sleep problems
- Fatigue
- Information needs
- Making plans
- Changes in weight
- Sadness or depression
- Dry, itchy or sore skin
- Other medical condition
- Constipation or diarrhoea
- Sore or dry mouth
Top 10 Most Commonly Reported Concerns of People with Kidney Cancer (n=75)

- Worry, fear or anxiety
- Sleep problems
- Pain
- Fatigue
- Dry, itchy or sore skin
- Breathlessness
- Sadness or depression
- Memory or concentration
- Changes in weight
- Eating or appetite
Top 5 Most Commonly Reported Concerns by Male (n=50) Female (n=25)
Implementing HNA’s
What's not worked?

“Random”

– Capturing patients in clinic
– Capturing patients at pre-op assessment
– Capturing patients in 1:1’s
– Telephone reviews following eHNA
– HNA’s completed by medical team
What's worked?

“Structure”
– Telephone clinics
– Survivorship clinics
– During pre and post tx seminars (eHNA)
– 1:1’s (combined with treatment summaries)
– Macmillan Cancer Support Workers
Questions

• What will work with your patient group?
• Can you target key points in the patient pathway?
• Can AHP’s help with this process?
• Can you start with just one tumour group?
• Can you get help from expert patients volunteers?
Summary and close

Justin Vale, Chair of the LCA Urology Pathway Group
Closing remarks

For your information:

Next NAEDI blood in your pee campaign – March/April 2016

Thank you all for coming today

Please contact Elizabeth Pegers, LCA Project Manager for any queries or comments regarding today’s event or the work of the Pathway Group.

If you would like a copy of the slides including the data and metrics, please submit a request from your Trust email account to Lizzie at: epegers@nhs.net

The date of the next forum is 28th January 2016 – save the date