Brain CNS Cancer Clinical Forum

17th June 2013
Welcome

Dr Ron Beaney,
LCA Brain CNS Pathway Group Chair
Purpose of today

- Provide an update on progress of the LCA to date
- Agree priorities for Brain CNS cancer across the LCA
- Explore data and metrics for Brain CNS cancer
- Identify people to become involved in guideline development and other sub groups
- Develop an LCA survivorship plan for Brain CNS cancer
- Encourage networking and shared learning across the LCA
## Agenda

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<td>Kate Haire</td>
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<td>LCA Brain CNS Cancer Pathway</td>
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<td>Nicola Glover</td>
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<td>Next steps and close</td>
<td>Ron Beaney</td>
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Introduction to the London Cancer Alliance

Dr Shelley Dolan,
LCA Associate Clinical Director
London Cancer Alliance (LCA)

• The LCA was established in 2011 as the integrated cancer system across west and south London.

• We work collaboratively with 17 NHS provider organisations, including two academic health science centres, and the voluntary sector.

• We provide comprehensive, integrated cancer patient pathways and services within formal, governed structures to drive improvements in patient cancer outcomes and experience for the population we serve.
The 2 Integrated Cancer Systems: London Cancer & London Cancer Alliance
Milestones for LCA

- Cancer Case for Change published December 2009;
- Model of Care published August 2010;
- 2011 Core Planning Group,
- 2012 Interim Clinical Board, Members Board,
- 6 first wave Pathway Groups established:
  - Lung, Breast, Osephago-Gastric, Survivorship, Palliative Care, Acute Oncology.
- 2012 M.O.U. signed by Boards of 17 Providers
- 2012 Appointment of Independent Chairs
- Dec 2012 Appointment of Clinical Director and Associate Clinical Director.
- 2013 Formal appointment of all Pathway Chairs
- Final Pathway Groups established
  - Including Brain CNS
London Cancer Alliance

Working with all 17 NHS provider organisations, the LCA has developed the following governance framework:
Governance Appointments December 2012

• Dr Neil Goodwin - Chair Members Board
• Dame Gill Morgan - Chair Clinical Board
• Prof Arnie Purushotham - Clinical Director
• Dr Shelley Dolan - Associate Clinical Director
Pathway Groups – Tumour Specific

- Lung
- Breast
- Colorectal
- Brain CNS
- Oesophago-Gastric
- Children and Young People
- Gynaecology Oncology
- Haemato-oncology
- Head and Neck
- HPB
- Skin
- Urology
Cross Cutting Groups

• Early Diagnosis
• Acute Oncology
• Palliative and end of life care
• Patient experience and information

• Radiotherapy
• Survivorship
• Mental Health & Psychology
• Chemotherapy closer to home and medicines optimisation
The LCA vision

“To provide equitable, world-class cancer care, health outcomes and patient experience for Londoners, delivered through comprehensive and seamless pathways, based on national and international standards, research and evidence”
LCA - Objectives

• Promote prevention/early detection by supporting GPs and influencing public health messages

• Ensure equitable access to excellent clinical care through integrated pathways across primary, secondary, tertiary, community and third sectors

• Provide local services where possible and centralised services where necessary

• Collaborate in world class research and innovation in cancer care

• Raise the profile and improve clinical education across the system
Questions
NHS Structure and commissioning arrangements

Dr Kate Haire
Commissioning of cancer pathway

Prevention

Early Detection

Direct Access to MRI

Assessment and diagnosis – common cancers

Assessment and diagnosis – rare cancers

Acute Oncology Service

Treatment

- Surgery: rare cancers
- Surgery: common cancers
- Chemotherapy
- Radiotherapy
- Stereotactic Radiation therapy

Survivorship

Neuro-rehabilitation

Palliative care

3rd Sector

LA

NHS England
Primary care contracts
Specialised services

CCGs
NHS England: Specialised Services

• NHS England: strategic planning through service specific Clinical Reference Groups (CRGs):
  • 74 CRGs are clustered around the five national Programmes of Care
  • Interim service specifications (final versions in the autumn)
  • Cancer relevant CRGs - include:
    ▪ Site specific
    ▪ Cross-cutting
    ▪ Specialised Cancer (Chairs of site-specific CRGs)

• Derogation

• Work programme priorities 2013-14:
  ▪ Service specification
  ▪ CQUIN
  ▪ Quality metrics

CRG information: http://www.england.nhs.uk/npc-crg/
NHS England: Primary Care

Primary Care Contracts

Local Area Teams (LATs)

• Core services
  “CCGs – as groups of GP practices – will have a duty to support the NHS England in improving the quality of primary medical care”

• Enhanced services

QOF: Cancer (NICE)

The contractor establishes and maintains a register of all cancer patients defined as a ‘register of patients with a diagnosis of cancer excluding non-melanotic skin cancers diagnosed on or after 1 April 2003

The percentage of patients with cancer diagnosed within the preceding 15 months who have a review recorded as occurring within 3 months of the practice receiving confirmation of the diagnosis

No new indicators for cancer in the QOF consultation for 2014/15
London Clinical Commissioning Groups

- Support through Commissioning Support Units / Cancer Commissioning teams
- CCG Council / Cancer Commissioning Board – pan-London approach?
CCG Outcomes Indicator 1.4: Under 75 mortality rate from cancer: Age/sex standardised rate per 100,000 population

Darker shades = higher mortality rate (80-180/100,000)
Public Health England (PHE)

• 4 Regional Offices

• London Office is a region and centre; 3 patches

• Functions
  – PH Intelligence including cancer registries
  – Health Improvement Team: obesity, exercise, mental health, smoking, alcohol
  – National Cancer Screening Programme
  – Healthcare public health (specialised commissioning)
  – Health Protection (>60% of workforce)
  – Reducing inequalities

• PH Outcomes Framework:
  – <75 years mortality rate cancer
  – Cancer diagnosed at stage 1&2
  – Cancer screening coverage
Transforming Cancer Services: Commissioning Priorities 2013-14

- Reducing variation in cancer services
  - Breast
  - Lung
  - Colorectal
  - Brain

- Implementing an early detection strategy

- Improving patient experience: HNA, treatment plans and summaries

- Delivering care closer to home - palliative care

- Implementing a chemotherapy strategy (national work)

- Implementing a radiotherapy strategy (national work)
LCA Strategic Priorities

Key issues for pathway groups

– Clinical service plan to deliver Model of Care
– Transforming Cancer Services Programme Priorities (site specific and cross-cutting) – includes brain CNS as one of the 4 priority pathways
– Research and innovation
– Matrix working with cross-cutting pathway groups
– Resources: prioritisation of pathway group work programme
– Flexibility to take account of emerging priorities (CRGs / national policy)
– Feeding into CRG to influence national work
– Work of London Cancer Integrated Cancer System
Questions
Brain CNS Cancer Pathway and its challenges across the LCA

Dr Ron Beaney,
LCA Brain CNS Pathway Group Chair
## LCA Provision of Brain CNS Cancer Services

<table>
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<tr>
<th>Location</th>
<th>Organizations</th>
<th>Specialties</th>
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<tbody>
<tr>
<td><strong>North West London</strong></td>
<td>Imperial College Healthcare NHS Trust (Charing Cross)</td>
<td>Neurosurgery and neuro-oncology</td>
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<tr>
<td></td>
<td>St George’s Healthcare NHS Trust, The Royal Marsden NHS Foundation Trust (Sutton)</td>
<td>Neurosurgery, Neuro-oncology</td>
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<tr>
<td><strong>South East London</strong></td>
<td>King’s College Hospital NHS Foundation Trust, Guy’s and St Thomas’ NHS Foundation Trust</td>
<td>Neurosurgery, Neuro-oncology</td>
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<td></td>
<td>Mount Vernon Cancer Centre</td>
<td>Neuro-oncology</td>
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LCA Objectives

• Promote prevention/early detection by supporting GPs and influencing public health messages

• Ensure equitable access to excellent clinical care through integrated pathways across primary, secondary, tertiary, community and third sectors

• Provide local services where possible and centralised services where necessary

• Collaborate in world class research and innovation in cancer care raise the quality and profile of clinical education across the system

• Improve patient experience with reference to the national cancer patient survey
Pathway Group Specific Objectives

• Model of care
• Best practice commissioning pathway
• Cross cutting priorities
• Amalgamation of network guidelines
• Other priorities
Model of Care Key Recommendations (I)

 Commissioners should **reduce** the number of brain and CNS cancer **surgical service providers** from seven to four, and **neuro-oncology** services should be **located** on these sites.

Challenges

- Three providers currently to reduce to two based on London populations
- In reality catchment area for LCA centres is wider than London
- Neuro-oncology only currently collocated on one site
Model of Care Key Recommendations (II)

Rapid access diagnostic one-stop clinics with access to MRI should be established for patients with suspected brain tumours. These clinics could be run under the care of neurologists.

Challenges for the LCA

- Suspected Brain CNS cancers usually present via A&E
- One stop?
- Where would these RACs be located?
  - Access to MRI
  - Neurologists
Model of Care Key Recommendations (III)

**Base of skull and pituitary tumours** should be differentiated from other head and neck cancers. **Two centres** should be commissioned for their treatment in London, collocated with two of the five specialist head and neck centres which also have neurosurgery services.

There should be two **spinal cord specialist multidisciplinary teams collocated** with the two centres in London for base of skull and pituitary tumours.

**Challenges for the LCA**

- Availability of accurate data to inform planning due to small numbers
- Co-location with head and neck/neurosurgery
- Adequate spinal surgical on-call rota for MSCC (ideally within 24 hours of diagnosis)
There is a shortage of **neuro-psychologists** nationally: this expertise needs to be present at the neuroscience centres.

**Neuro-rehabilitation** services and **dedicated** beds should be collocated with neuroscience centres and offer **rapid access** to appropriate levels of neuro-rehabilitation closer to home.

- How many neuro-pyschologists in LCA and where are they located?
- Dedicated beds for neuro-oncology?
- Access to community neuro-rehab closer to home
- Provision for those patients with palliative care needs and those with shorter prognosis CNS tumours
Best Practice Commissioning Pathway

- In contracts for 2013/14
- This commissioning best practice pathway includes tumours that start in the brain (primary tumours), central nervous system (CNS) lymphomas, and those which occur as a result of cancer spread from other parts of the body such as the breast or lung (secondary tumours).
- The ICS pathway groups will be responsible for managing the whole pathway, agreeing the approach to delivering clinical best practice pathways, and providing clinical leadership to co-ordinate delivery across the Integrated Cancer Systems.
# LCA Cross Cutting Priorities

<table>
<thead>
<tr>
<th>Cross cutting group</th>
<th>Brain CNS Cancer</th>
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<tbody>
<tr>
<td>Early Diagnosis</td>
<td>- Rapid Access Diagnostic Clinics</td>
</tr>
<tr>
<td>AOS</td>
<td>- MSCC chapter of guidelines</td>
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<tr>
<td></td>
<td>- Availability of MRI for MSCC</td>
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<tr>
<td>Radiotherapy</td>
<td>- Current arrangements for stereotactic radiotherapy across LCA</td>
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<tr>
<td>Patient Experience</td>
<td>- Develop model for obtaining patient feedback for Brain CNS Cancer</td>
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<tr>
<td>Survivorship</td>
<td>- Scoping of provision of and access to neuro-rehab services across LCA</td>
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<td>- Survivorship specific issues at Forum</td>
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<tr>
<td>Palliative Care</td>
<td>- Develop criteria for referral to specialist palliative care</td>
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Other Priorities

- Amalgamation of network clinical guidelines
- Research
  - Improving access to clinical trials
  - Opportunities for collaboration
- Quarterly Forums
- Peer review compliance
- Other priorities we may have missed
Challenges for the Pathway Group

• Delivering all of the above
• Implementation of LCA clinical guidelines once agreed
• Effective communication with wider clinical community
Questions
Survivorship – the implications for patients with brain CNS cancer

Nicola Glover, LCA Survivorship Lead and Lead AHP
Survivorship: a brief history

• A relatively new term
• First discussed in any detail in Cancer Reform Strategy
• Proliferation of work since including:
  – Dec 2007: National Cancer Survivorship Initiative announced
  – January 2010: NCSI vision published
  – November 2011: BJC supplement on survivorship research
  – 2012: PROMs pilot survey
  – 2013: Living with and Beyond Cancer: Taking action to improve outcomes
  – 2013: Cancer Rehabilitation. Making excellent cancer care possible
But what exactly are we talking about?

“...the physical, psychosocial and economic issues of cancer, from diagnosis until end of life. It focuses on the health and life of a person with cancer beyond the diagnosis and treatment phases. Survivorship includes issues related to the ability to get health care and follow-up treatment, late effects of treatment, second cancer and quality of life. Family members, friends and caregivers are also part of the survivorship experience.”

National Cancer Institute, accessed 18/04/2012
Or in picture form...
NCSI Framework

• Information and support from the point of diagnosis
  – Support in making treatment decisions
  – Early cancer rehabilitation
  – Early work/education support
  – PROMS

• Promoting recovery
  – Recovery package
  – Physical activity/diet

• Sustaining recovery
  – Risk stratification
  – Remote monitoring
NCSI Framework-continued

• Managing consequences of treatment
  – Failure to address has significant impact on pt, NHS and economy
  – Begin monitoring early, during active treatment
  – Use novel treatments with less (known) side effects e.g. IMRT
  – PROMs

• Supporting people with active and advanced disease
  – Every bit as important as other stages
  – Less developed than other areas
  – Palliative care is an essential component
Where’s the evidence?

- Breast
- Colorectal
- Prostate
- Lymphoma
- Lung

- Results were generally positive
  - Vast majority focused on breast, colorectal and prostate
  - Risk-stratification didn’t work for lung
Issues for Brain/CNS

• Some of it has to be done, and seems achievable?
  – Recovery package
  – Diet/physical activity
  – Work/education support

• Some of it is a Brain/CNS priority, but is more tricky?
  – Access to (early) rehabilitation
  – Supported self-management

• What are the specific issues?
<table>
<thead>
<tr>
<th>Symptoms</th>
<th>Deficits</th>
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<tr>
<td>• Seizures (10-30%)</td>
<td>• Cognition (80%)</td>
</tr>
<tr>
<td>• Headache (a.m.) (50%)</td>
<td>• Weakness (78%)</td>
</tr>
<tr>
<td>• Behavioural problems</td>
<td>• Visuo-perceptual (53%) (Blurred vision, changes to sight, tunnel vision, floating objects)</td>
</tr>
<tr>
<td>• Cognitive problems</td>
<td>• Sensory loss (38%)</td>
</tr>
<tr>
<td>• Progressive focal neurological deficit:</td>
<td>• Continence dysfunction (37%)</td>
</tr>
<tr>
<td>• dysphasia</td>
<td>• Other - behavioural, seizures, headache.</td>
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<tr>
<td>• dysphagia</td>
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<tr>
<td>• hemiparesis and/or</td>
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<tr>
<td>• sensory changes</td>
<td></td>
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<tr>
<td>• balance problems</td>
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Variable

3 or more - 75%
5 or more - 40%

(Mukand et al. 2001)
Rehabilitation: Analogy: Betty’s Brolly

Quality of Life

Rehabilitation = ‘getting back to normal’

Hackman D (2011) Physiotherapy Research International 16(4) pp 201-217 DOI: 10.1002/pri.506
Rehabilitation; a research review

• **1º CNS & rehabilitation (mainly IP units)**

  • **Improved function**
    • (Marciniak et al. 1996 (USA), Gill-Body et al. 1997 ([OP] Sherer et al. 1997 ([OP])(USA), Bell et al. 2008 ([OP]) O’Dell et al. 1998 (USA), Sliwa & Marciniak 1999 (USA), Giovagnoli, 1999 (Italy), Marciniak et al. 2000 (USA), Huang et al. 1998, 2000, 2001a&b (USA), Cole et al. 2000 (USA), Mukand et al. 2001 (USA), Garrard et al. 2004 ([UK]), Greenberg et al. 2006 (USA), Tang et al. 2008 (USA), Geler-Kulcu et al. 2009 (Turkey), Vargo 2011 (USA), Formica et al 2011 (Italy), Hackman 2011([OP]) ([UK])

  • **Function & QOL**

  • **QOL & hope**
Rehabilitation; a research review (II)

- **Cognitive rehabilitation**
  - Cog rehabilitation effective for patients with 1° CNS tumours
    - low numbers case series/cohort

- **Early identification & referral recommended**
  (Mukand et al. 2001, Fox and Mitchell 2006, Molassiotis et al. 2010)

- **Phase III RCT ongoing (N= 150)**
  (Taphoorn et al. 2008)
Aphasia

- Limited evidence
- Cancer-related language disorders are undertreated \(\text{(Paratz, 2011)}\)
- Comparison made to aphasia associated with stroke
- 25% of patients with primary brain tumours experience language disturbance as part of their initial presentation \(\text{(Recht, McCarthy et al. 1989)}\)
- Cerebral reorganization can occur in response to the tumour, initiating the redistribution of language \(\text{(Duffau, 2005)}\)
- SLT input recommended
- About 51% experience progressive neurological symptoms, including speech and motor deficits \(\text{(Sizoo et al., 2010)}\)
- SLT services, including speech and swallowing treatment, assistive technology, or augmentive and alternative communication devices, should be considered for use with terminal patients \(\text{(Pollens, 2004)}\)
Service access for patients with 1°CNS tumours

• Poor professional knowledge/attitudinal barriers/referral denied

• Barriers: professionally reported
  – Professional knowledge & behaviour
  – Systems & services
  – Disease & its effects
  (McCartney et al. 2011)

• Limited access to services; patient/carer reported
  (Faithful et al. 2005, Janda et al. 2008)

• Timing of referral to access services where services are offered?
  – Hospice linked services show good access
  – But? when are patients referred?
  (Arber 2009)

• Carer support
  – Limited, usually reactive
  (Janda et al. 2008, Arber 2009)
  – Required from family on diagnosis, others as disease progress at time
  (Sherwood et al. 2011)
Starting points?

- HNA
- Treatment summaries
- Health and Well-being events
- Rehabilitation Mapping
- PROMs
- Education, education, education???
“I was seen by a Physio but told there was nothing they could do for me”
“my family had to fight with the GP for me to go to an in-patient rehab unit”
“I didn’t know I could see a Physio”
“I only knew of accessing (OT) services through my sister in law being an OT”

“If I consider how I was before; I couldn’t sit up, I was hoisted to the chair or toilet.”
“Now I’m independent. I can wash, cook, clean. I’ve probably learnt more ‘life skills’ than I had before I had the tumour. I can remember how I was after the surgery and that inspires me.”
Questions
Round Table Discussion

Two key points from each group
Areas for discussion

• Challenges facing delivery of brain CNS cancer services
  – Solutions
  – How can we demonstrate these will improve outcomes for patients

• Data and metrics
  – audit

• Survivorship
  – Rehab closer to home
  – Neuro-psychology provision
  – Treatment summaries
  – Health and wellbeing events

• Communication between Pathway Group and MDTs
Round Table Feedback

Two key points from each group
Next steps and close

Dr Ron Beaney, LCA Brain CNS Pathway Chair
Next Steps and Close

- Development LCA brain CNS specific survivorship plan
- Baseline audit for completion
- Agree LCA set of Brain CNS metrics
- Draft clinical guidelines
- Next quarterly forum
  - Wednesday October 16th
  - Share findings from baseline audit
- Ongoing effective communication between MDTs and Pathway Group
What would we like from you?

- Own the agenda and implementation
- Identify any other priorities
- Work effectively through the Brain CNS Pathway Group
- Deliver LCA programme across & through MDTs
- Focus on priorities
- Build strong relationships across LCA, share ideas
- Be proactive and responsive
- Be supportive, collegiate, influence & reason
- Please call Dr Ron Beaney, members of the Brain CNS Pathway Group or Programme team to discuss issues anytime you need to

Speak and act on behalf of the London Cancer Alliance
And finally

• Thank you for your active involvement

• Confirm which guidelines you would like to be involved with

• Please complete feedback forms to inform future forums

Any questions please contact:

Michelle Bull

mbull@nhs.net

(020) 7811 8888
Thank you

Presentations will be available on the LCA website:
www.londoncanceralliance.nhs.uk