

# London Cancer Specialist Services Reconfiguration: Reference Documents

October 2013

Version 1.0

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# Document 1: London Cancer Memorandum of Agreement 2013-14



# **Integrated Cancer System - London Cancer**

Memorandum of Agreement: April 2013-March 2014

#### Introduction

This document updates and replaces *London Cancer's* previous Memorandum of Agreement, which covered the period from April 2012 to March 2013.

It restates the previous commitment of each of the signatories and *London Cancer* to deliver better cancer related outcomes and experience for our patients and local communities by working in partnership.

This Memorandum of Agreement incorporates the significant progress made together since July 2011 to develop effective governance and reporting frameworks, and the work undertaken since *London Cancer* was officially established in April 2012 to build a platform from which to deliver our collective vision.

To this end, the signatories are now agreeing to enter into this updated Memorandum of Agreement, which runs from April 2013 to March 2014. This Memorandum of Agreement may be superseded during this timeframe if more detailed proposals are approved and agreed to be implemented.

# **London Cancer**

London Cancer is an Integrated Cancer System for North Central and North East London and West Essex. It brings together providers from across the health community, academia and the voluntary sector to drive step change improvements in outcomes and experience for the cancer patients and populations we serve. Together the following provider organisations working with UCLPartners have to date led the co-creation of London Cancer:

•Barnet and Chase Farm Hospitals NHS Trust •Barts Health NHS Trust •Barking, Havering and Redbridge University Hospitals NHS Trust •Great Ormond Street Hospital for Children NHS Foundation Trust •Homerton University Hospital NHS Foundation Trust •Moorfields Eye Hospital NHS Foundation Trust •North Middlesex University Hospital NHS Trust •Princess Alexandra Hospital NHS Trust •Royal Free London NHS Foundation Trust •Royal National Orthopaedic Hospital NHS Trust •University College London Hospitals NHS Foundation Trust •Whittington Health

London Cancer is committed to working with its partners across the health community, academia and the voluntary sector in North Central and North East London and West Essex to deliver, by 2015, the following priority measures:

- Improved one year survival for patients within London Cancer\*\*;
- Improvement in patients self-reported experience of the care they receive; and

- Increased participation in clinical trials to 33% of all patients.
- \*\* used as a proxy measure for patients being diagnosed earlier in the course of their cancer

# Accountability, reporting and governance

London Cancer will continue to focus on transformation which can only be achieved through partnership, not on the business-as-usual improvements which will be driven by individual providers. This focus will enable London Cancer to drive change with its partners at pace and scale. To ensure there is clarity for stakeholders and that we avoid duplication of effort, we will continue to clarify carefully responsibilities.

All parts of the system will be responsible for driving forward leadership skills and behaviours that deliver an integrated partnership around patients and local populations. Furthermore, all parts of the system will work together to align objectives and priorities within the wider climate of multiple and sometimes competing pressures.

Working with the signatories below, *London Cancer* has developed core governance processes, which were approved in principle by the signatories to the original Memorandum of Agreement. These were set out in proposals from the *London Cancer* governance working group dated 17 October 2011.

At the centre of these proposals is the appointment of an independent skills-based Board to lead *London Cancer*. This Board met for the first time in February 2012 and, meets on a monthly basis.

From April 2013 through to March 2014 processes for agreeing and implementing responsibilities, reporting and governance processes and procedures will continue to be developed and reported along the lines of those already agreed in principle. These proposals will be consulted on and, in due course, be submitted for approval by the Trust Boards which are signatories to the Memorandum of Agreement.

The current structures within *London Cancer* and its key external relationships are set out at Appendix 1.

#### **London Cancer Board**

The membership of the *London Cancer* Board will continue to be agreed by Trust Chief Executives who are members of the UCLP Executive Group. The primary purpose of the *London Cancer* Board is to provide skills-based leadership for *London Cancer* that is independent of the provider and other institutions. The full terms of reference are detailed in Appendix 2.

London Cancer's Board will work closely with a range of stakeholders including in particular the signatories below and the Joint Development Group. This latter group is the forum for discussions between London Cancer and the commissioners for our system. It is chaired by the Chief Executive of the North East London Cluster on behalf of North East and North Central London's commissioners, and will continue through the NHS North and East London Commissioning Support Unit. The stated purposes of this group are to:

- Ensure that there is a common understanding and agreement across providers and commissioners regarding the priority changes in cancer care;
- Agree London Cancer's Service Plan to implement the agreed Model of Care<sup>1</sup> for Cancer in London; and
- Identify those service changes that require action by providers and commissioners and then to agree respective actions.

It is recognised by the signatories to this document that the Joint Development Group has an important role to play in ensuring that system level commissioning objectives and requirements are taken into account and, as appropriate, incorporated within the overall plans and objectives of *London Cancer*.

# **Cancer Pathway Boards**

Cancer pathway boards are in place for each major cancer type, with a competitively appointed senior clinical leader. The boards have representation from all relevant providers, users, primary care and public health. They have taken over the responsibilities of the previous network site-specific groups of NCL and NEL Cancer Networks but with additional executive responsibility as below. Cancer pathway boards are accountable to the *London Cancer* Board and:

- Lead the co-design, implementation and management of adherence to integrated care pathways, including implementation of Model of Care recommendations appropriate to the pathway;
- Offer pathway-specific advice to commissioners;
- Build relations across the pathway, including public health and public/ patient engagement;
- Identify best practice and support its roll out; and
- Undertake governance roles for partners around peer review and Multidisciplinary Teams (MDTs).

**Provider Trusts**, which are signatories to the Memorandum of Agreement, will continue inter alia to be:

- Accountable to commissioners for meeting national and local quality standards at local sites e.g., waiting times, patient-experience, complaints, incidents, and peer review including MDTs;
- Responsible for day-to-day operational management of cancer care, including supporting implementation of relevant recommendations emanating from *London Cancer* Pathway Boards, and responsible financial management of cancer services;
- Responsible for contract negotiation and review with commissioners;

<sup>&</sup>lt;sup>1</sup> Commissioning Support for London, A Model of Care for Cancer Services, 2010

- Responsible for comprehensive, accurate capture of a common data set (including staging) and feeding this to a system-wide database for provision to Thames Cancer Registry, national audits, etc.; and
- Responsible for regulatory compliance.

#### Members and Stakeholders Council

A combined UCLPartners and NCEL Local Education and Training Board (LETB) members and stakeholders council will be the forum where *London Cancer* will present to our population. This will operate on the principles of openness and transparency. As a minimum, *London Cancer* will ensure compliance with the requirements within the Health and Social Care Act 2012 around patient involvement and public accountability.

# Mutual responsibilities

Each of the signatories below recognises:

- The obligations that each provider organisation, UCLPartners and *London Cancer*, and their Boards have to patients, regulators, commissioners, governors, members and staff;
- The objectives of London Cancer (as set out in this Memorandum of Agreement);
- The crucial and central interests of patients; and
- The interests of commissioners.

Each of the signatories to the Memorandum of Agreement also recognises that to deliver the objectives of *London Cancer* will require co-operation and collaboration between providers and other partners across the pathway.

This will necessitate different ways of working and will be in the form of:

- Sharing reliable, complete and timely information with Cancer Pathway Boards and the London Cancer Board;
- Engaging fully and co-operating with other parts of the pathway;
- Investing in appropriate equipment;
- Engaging in MDTs in the right manner;
- Co-operating and collaborating in key clinical appointments; and
- Reduced waiting times, improving the quality of patient experience and delivering superior outcomes.

It is accepted that where these behaviours can't be evidenced, the capacity and capability of a signatory to the Memorandum of Agreement to contribute effectively to the delivery of the objectives of *London Cancer* may be in doubt.

In such circumstances, and where the clinically evidence based shortfall is not satisfactorily rectified, it is recognised that the *London Cancer* Board may recommend sanction. Following discussion with commissioners, this may result in a decision to decommission services or the removal of a provider from *London Cancer*.

London Cancer further agrees to:

- Keep information which is shared with it confidential as appropriate;
- Report to each of the organisations impacted at the earliest opportunity any matter which may risk an organisation and its reputation;
- To act only on clinical evidence, and only then once a full impact analysis has been undertaken and shared;
- Seek to consult and include wider representation wherever possible; and
- To act in a manner independent of all organisations within London Cancer.

Tim Peachey, Interim CEO  BARNET AND CHASE FARM HOSPITALS NHS  TRUST  Signature	Julie Lowe, CEO  NORTH MIDDLESEX UNIVERSITY HOSPITAL NHS TRUST Signature
Peter Morris, CEO BARTS HEALTH NHS TRUST	Yi Mien Koh, CEO
Signature Peter Movon	WHITTINGTON HEALTH Signature
Averil Dongworth, CEO BARKING, HAVERING AND REDBRIDGE	Melanie Walker, CEO
UNIVERSITY HOSPITALS NHS TRUST	PRINCESS ALEXANDRA HOSPITAL NHS TRUST
Signature Averil Dongworth	Signature La Salle
Jan Filochowski, CEO	David Sloman, OEO
GREAT ORMOND STREET HOSPITAL FOR	ROYAL FREE LONDON AS FOUNDATION TRUST
Signature	Signature
	V. Comments
Tracey Fletcher, CEO	Rob Hurd, CEO
HOMERTON UNIVERSITY HOSPITAL NHS FOUNDATION TRUST	ROYAL NATIONAL ORTHOPAEDIC HOSPITAL
Signature Tracey (let las	Signature
John Pelly, CEO	Sir Robert Naylor, CEO
MOORFIELDS EYE HOSPITAL NHS FOUNDATION	UNIVERSITY COLLEGE HOSPITALS NHS FOUNDATION TRUST
TRUST Signature	Compos
Signature	Signature
David Fish, MD	Kathy Pritchard-Jones, CMO
UCLPARTNERS	LONDON CANCER
DAG	Kathy Pathchar Dones
Signature	Signature



# London Cancer Board

Chair: Pelham Allen, CMO: Kathy Pritchard-Jones NEDs: (co-opted)

Tony Brzezicki (GP, SWL)
Tim Walls (MD, Newcastle)
Elizabeth Benns (ICPV charity)
Emma Ream (Prof. Nursing, Kings)

Joint Development Group

**London Cancer** Operational Leads' Group

#### Subgroups

# Research Implementation

Nick Lemoine, Barts Health

> Education, Training and Workforce

#### **Cancer Pathway Boards**

Brain & Spine: A. Elsmore, Barts & J. Rees, UCLH

Breast: R. Roylance, Barts Health

• Colorectal: M. Machesney, Barts Health

• Gynaecology: T. Mould, UCLH • Haematology: K. Ardeshna, UCLH

**London Cancer** 

Medical Directors' Forum

Head & Neck: S. Whitley, Barts Health & PAH

Lung: S. Janes, UCLHSkin: D. Chao, RFH

• Upper GI (OG): D. Khoo, BHRT & M. Mughal, UCLH

Upper GI (HPB): A Millar, NMUH
 Urology: J Hines, Barts Health

# Expert Reference Groups as of July 2012

- Cancer Partnership Groups
- Network Acute Oncology
   A Tookman, PEU
- A. Tookman, RFH E. Boleti, RFH
- Chemotherapy
   C. Gallagher, Barts Health
- Nursing
  J. Douglas, BHRT
- Primary Care & Prevention
- Psychosocial Support
- M Barrington, Barts Health
- K. Piggott, RFH C. Cottrill, Barts Health

Radiotherapy

# Specialist Boards

- Children and Young People:
- D. Hargrave, GOSH R. Hough, UCLH (pan-North London)
- Sarcoma:
- J. Whelan, UCLH
  A Hayes, RMH
  (pan-London & South East)

#### Workstreams

# **Living With and Beyond Cancer**Sharon Cavanagh

#### Clinical Information Astrid Mayer,

Earlier Diagnosis

RFH

TBC



#### Appendix 2: London Cancer Board: Terms of Reference

London Cancer is an Integrated Cancer System for North Central & North East London and West Essex. It brings together providers from across the health community, academia and the voluntary sector to drive step change improvements in outcomes and experience for the cancer patients and populations we serve.

Together the following provider organisations working with UCLPartners have to date led the cocreation of *London Cancer*:

•Barnet and Chase Farm Hospitals NHS Trust •Barts and the London NHS Trust •Barking, Havering and Redbridge University Hospitals NHS Trust •Great Ormond Street Hospital for Children NHS Trust •Homerton University Hospital NHS Foundation Trust •Moorfields Eye Hospital NHS Foundation Trust •Newham University Hospital NHS Trust •North Middlesex University Hospital NHS Trust •Princess Alexandra Hospital NHS Trust •Royal Free Hampstead NHS Trust •Royal National Orthopaedic Hospital NHS Trust •University College London Hospitals NHS Foundation Trust •Whipps Cross University Hospital NHS Trust •Whittington Health

Note: subsequent to the approval of the Terms of Reference on 28 February 2012, the following events have occurred:

- With effect from 1 March 2012, Great Ormond Street Hospital for Children NHS Trust has been awarded foundation trust status and is now Great Ormond Street Hospital for Children NHS Foundation Trust;
- With effect from 1 April 2012, Royal Free Hampstead NHS Trust has been awarded foundation trust status and is now Royal Free Hampstead NHS Foundation Trust; and
- With effect from 1 April 2012, Barts and the London NHS Trust, Newham University Hospital NHS Trust and Whipps Cross University Hospital NHS Trust merged to form Barts Health NHS Trust.

#### London Cancer - mission and aims:

London Cancer's mission is to improve survival from cancer and experience of care for its patients and local communities. We aim to achieve this by leading a radical redesign of how cancer services are delivered across a population of nearly 4 million people in North Central and North East London and West Essex. This will be driven by all provider Trusts in London Cancer taking collective responsibility for the quality and outcomes of integrated care pathways, working in partnership with patients, primary care, commissioners, public health and the voluntary sector. Our ambition is to create a new model of cancer care for the NHS that empowers patients, facilitates equitable access to best practice and innovation and increases value for the health economy. We aim to support our staff to be leaders in cancer care – locally, nationally and globally. Ultimately, London Cancer aims to create a "virtual comprehensive cancer centre" serving the whole population of North Central and North East London, that comprises all of its partner organisations and is recognised globally for the excellence of its patient care and outcomes, education, training and research.

As partners we have developed *London Cancer* through engagement efforts reaching over 1000 staff, patients, carers, primary care and the voluntary sector, with the vision to:

- Be *patient-focused* through listening, communication, involvement, information, education, choice, and personalisation. Patient need and the patient journey will be the organising framework for care
- Optimise care along a co-ordinated pathway through earlier diagnosis, excellent treatment for all, local treatment where appropriate, compassionate aftercare and empowering/supporting patient self-management
- *Embed research* for personalised care, equitable access to trials, the discovery of new treatments and evaluating new ways of working together with patients
- *Increase value* through superior outcomes for patients per pound invested; continual improvement over time against our previous performance

The current priority measures are, by 2015, to:

- 1. Improve one year survival for patients within London Cancer\*\*,
- 2. Improve patients self-reported experience of the care they receive
- 3. Increase participation in clinical trials to 33% of all patients.

#### **London Cancer Board - purpose:**

The primary purpose of the London Cancer Board is to provide skills-based leadership for *London Cancer* that is independent of the partner institutions, to ensure the successful delivery of *London Cancer's* mission and goals, including:

- Setting and directing London Cancer's overall strategy
- Driving innovation, change and shaping new models of cancer care
- Securing behaviours and commitment from partners and participants along cancer pathways which are consistent with the overall goals of *London Cancer*
- Agreeing national and international benchmarks against which to measure and promote improved performance and changed models of cancer care
- Making evidence-based, clinically led and deliverable recommendations to commissioners of cancer care across North Central and North East London
- Influencing and informing the development of national strategies for value based healthcare in the NHS
- Horizon scanning to provide advance notice of new and emerging cancer technologies and practices that might require evaluation, consideration of clinical and cost impacts, or modification of clinical guidance prior to launch in the NHS

<sup>\*\*</sup> used as a proxy measure for patients being diagnosed earlier in the course of their cancer

The *London Cancer* Board will work with Cancer Pathway Boards, subgroups and work-streams, to ensure that on an ongoing and continuous basis, *London Cancer* takes steps to drive improvements and new models in cancer care for patients and its population.

#### Key responsibilities:

- To set, update and direct delivery of the overall strategy for *London Cancer* (including consideration and challenge of Pathway Board, key subgroup and work-stream plans)
- To prioritise consideration of potential cancer pathway changes taking into account and balancing:
  - likely impact on outcomes, patient experience and meaningful patient voice within the relevant cancer pathway
  - · overall impact of change within and beyond cancer services
  - healthcare value, reflecting both cost and quality
  - potential resulting impact for treatments and commissioning of services other than cancer (e.g.: funding, location and sustainability of other services and organisations, use of healthcare resources, impact on ancillary services, equipment and other operating capacity)
- To consider and challenge recommendations from Cancer Pathway Boards and subgroups or work-streams (including evidence, impacts and mitigations)
- To make specific recommendations on behalf of *London Cancer* to commissioners for potential changes to cancer services and pathways
- To hold providers of cancer care accountable on an ongoing basis for their behaviours and commitment to the delivery of the overall goals of *London Cancer*
- To maintain an ongoing focus on the needs of local cancer patients and the population, ensuring *London Cancer* is constantly innovating and embedding its work in evidence to improve outcomes for patients and healthcare value
- To report recommendations and progress to UCLP Executive Group
- To review on a periodic basis a defined set of pathway metrics / outcome measures and agree any remedial steps as required (including the potential for exclusion of a partner from London Cancer)
- To require and review bench-marking (national and international) of evidence to demonstrate progress against agreed goals and the effectiveness or otherwise of changed models of cancer care
- To review, oversee the consultation on and update outcome focused compliance measures for cancer services
- To work in partnership with commissioners to develop and agree effective incentives (including to ensure GP engagement) designed to promote and support improvements in cancer services
- To oversee London Cancer's influencing and communication strategy (including publication of information and data) including, but not limited to, the development of national strategies for value based healthcare in the NHS

- Horizon scanning to provide advance notice of selected new and emerging technologies and practices that might require evaluation, consideration of clinical and cost impacts, or modification of clinical guidance prior to launch in the NHS
- To ensure effective engagement with and involvement of stakeholders on an ongoing basis
- To approve appointments of Cancer Pathway Directors
- To receive notification of membership of Cancer Pathway Boards to ensure proper representation
- To consider on an ad hoc basis solutions to specific and significant cancer-related challenges
- To ensure that momentum is maintained in the pace of work of *London Cancer*, and ensure that good and proper process does not delay progress in achieving the desired outcomes

### Membership (and skills):

- The Board will include an independent Non-executive Chair
- The Chief Medical Officer, which will be an executive role, will be on the Board
- The Board will in addition have 6 independent Non-executive Directors, who will with the Chair and the Chief Medical Officer bring together the following skills and knowledge:
  - Cancer pathways and quality outcomes
  - Leadership of service transformation
  - Workforce development across partners
  - Strategy and financial governance
  - Clinical expertise in cancer
  - Patient and population focus
  - Public health priorities for cancer
  - Commissioning and value based healthcare
  - Primary care

#### Authority:

- To make recommendations and then agree with commissioners the appropriate incentives and any sanctions necessary to drive the prioritised recommendations from Cancer Pathway Boards on behalf of *London Cancer*
- To report recommendations to UCLP Executive Group
- To receive recommendations from Cancer Pathway Boards, subgroups and work-streams
- To commission further review, analysis or information gathering as necessary to support recommendations
- To recommend appointments to London Cancer Board (subject to the approval of UCLP Executive Group)
- To approve:
  - Changes in cancer metrics and outcome measures at the system level
  - Publications and other public announcements on behalf of London Cancer

• Appointment of Cancer Pathway Directors

# Appointments to London Cancer Board:

- Initial appointments to be made by UCLP Executive Group
- Subsequent appointments to be made by London Cancer Board and approved by UCLP Executive Group

# Support:

- Board support / administration through a London Cancer Board Secretary
- Communications support
- Cancer Pathway Boards
- Subgroups and work-streams

# Meeting frequency:

Monthly

# **Document 2: Generic Pathway Board Terms of Reference**



# XXX Pathway Board

# Terms of Reference

Board title	xxx Pathway Board
Pathway Director	
Ratified by	London Cancer Board
Date agreed	May 2012
Review date	May 2013

The terms of reference have been agreed by:

Pathway Director	Chief Medical Officer for London Cancer, on
	behalf of the <i>London Cancer</i> Board
Name: Sam Janes	Name: Kathy Pritchard-Jones
Date agreed:	Date agreed:

# London Cancer Board

London Cancer is an integrated cancer system covering a resident population of approximately 3.2 million people in North Central London, North East London and West Essex.

The *London Cancer* Board is independent of the *London Cancer* providers and is supported by high quality information and recommendations from cancer Pathway Boards. The *London Cancer* Board takes account of clinical evidence, population, value and potential impacts in other pathways and treatments when making decisions. It has a focus on bringing about real change that delivers significant benefits for patients.

# Constitution of the Pathway Board

The xxx Pathway Board is a group that reports into and is ultimately governed by the *London Cancer* Board. The xxx Pathway Board is a cancer care specific board with responsibility to improve cancer outcomes and patient experience for local people within *London Cancer*. The Pathway Board is led by a Cancer Pathway Director and will have notable membership and active participation from primary care and from patients.

# Aims and Purpose of the Pathway Board

The overall purpose of the Pathway Board is to improve cancer care for patients accessing the *London Cancer* lung pathway. Specifically, the board aims to save more lives, put patients at the centre of care services, and improve patient experience. The Board will represent the interests of local people with cancer, respecting their wider needs and concerns. The Pathway Board is a primary source of clinical opinion on this pathway for the *London Cancer* Board.

The Board will gain a robust understanding of the key opportunities to improve outcomes and experience by gathering and reviewing intelligence about their pathway. It will ensure that

objectives are set, with a supporting work programme which drives improvements in clinical care and patient experience.

This Board will contribute outside the specific tumour type to share best practices as well as engaging with cross-cutting work streams such as survivorship and early diagnosis.

The Board will communicate its recommended annual work programme and progress at an annual community engagement event for staff and patients across *London Cancer*, as well as using its expertise to provide an annual educational event for primary and community care colleagues.

The Pathway Board also has a duty to promote equality of access, choice and quality of care for all patients within *London Cancer*, irrespective of their individual circumstances. The Board will also work with cancer commissioners to provide expert opinion on the design of any commissioning pathways, metrics and specifications.

# Key Roles and Functions of the Pathway Board

The role and aims of xxx Pathway Board are to:

- 1. Represent the *London Cancer* professional and patient community for xxx cancer, and the Board has a duty to consult all *London Cancer* partner organisations on its plans and their implementation. The Board must be able to demonstrate that this engagement is active and meaningful.
- 2. Identify specific opportunities for improving outcomes and patient experience and convert these into agreed objectives and a prioritised programme of work.
- 3. Gain approval from the *London Cancer* Board for the plan of work, and provide regular reporting to the Board on its progress.
- 4. Assess all recommendations for service change for their impact on providers, workforce, communities and patients using the agreed *London Cancer* tools, as well as an equalities assessment.
- 5. Ensure operational plans and actions are in place for delivery of the work programme; this may include authorizing working groups or projects across *London Cancer* to progress specific items of work.
  - The Board must ensure that processes and information technology are in place to meet mandatory requirements for the pathway, such as Peer Review and mandatory dataset collection (cancer waiting times, cancer registry, national audits, COSD dataset).
- 6. Ensure that clinical, imaging and pathology guidelines are agreed by provider trusts, followed, and are annually reviewed
- 7. Ensure that all providers working within the pathway collect the pathway dataset measures to a high standard of data quality and that this data is shared transparently amongst the Pathway Board and beyond; all partners will be expected to share data openly to drive up quality of care and demonstrate that outcomes are improving for patients.
- 8. Promote and develop research and innovation in the pathway, and to have agreed objectives in this area for the Board.
- 9. Monitor performance and improvements in outcomes and patient experience via the pathway scorecard, understanding deviations and assessing variation to identify unexpected or undesirable areas for action.
- 10. Ensure that appropriate communication occurs through the processes outlined in the *London Cancer* governance framework when performance degrades or improves.

- 11. Escalate any clinical concerns through provider Trusts using the processes outlined in the *London Cancer* governance framework.
- 12. Highlight any key issues that cannot be resolved within the Pathway Board itself, to the *London Cancer* central team for assistance, and if necessary referral to the *London Cancer* Board governance process.
- 13. Ensure work plans, scorecards, programmes of work and decisions involve clearly demonstrable patient participation.
- 14. Share best practices with other boards within *London Cancer*
- 15. Design and implement new services for patients where these progress the objectives of *London Cancer*, can be resourced and have been shown to provide improvements in outcomes that matter to patients.
- 16. Contribute to cross-cutting initiatives (e.g. work streams in survivorship, early diagnosis)
- 17. Discuss opportunities for improved education and training related to the pathway and implement new educational initiatives.

# Membership

# Core executive members:

Primary role		Additional role	
1	Pathway Director (Chair)		
2	Deputy Pathway Director	Also to represent own provider trust	
3	Clinical Lead for Clinical Oncology	Also to represent own provider trust	
4	Clinical Lead for Medical Oncology	Also to represent own provider trust	
5	Clinical Lead for Thoracic Surgery	Also to represent own provider trust	
6	Lead for Earlier Diagnosis	Also to represent own provider trust, may be a primary care professional	
7	Lead for Primary Care Interface	Also to represent own provider trust, may be a primary care professional	
8	Clinical Lead for Specialist Nursing	Also to represent own provider trust	
9	Lead for Radiology	Also to represent own provider trust	
10	Lead for Histopathology	Also to represent own provider trust	
11	Clinical Lead for AHPs	If from a trust, to act as organisational representative if required	
12	Lead of Survivorship or Psychological Support	If from a trust, to act as organisational representative if required	
13	Lead for Research	·	
14	Lead for Education	Also to represent own provider trust	
15	Patient Advocate		
16	User Representative (at least one)		
17	Pathway Manager	If from a trust, to act as organisational representative if required	
18	Organisational representative (where this is required for provider trusts not already represented) to ensure all providers have representation		

Extended membership will be determined by the Board, but the above encompasses all the necessary roles for the Board and all voting members of the executive will be within this group.

# Frequency of Meetings

The Pathway Board will meet monthly in the first instance, and for at least its first six months. Following this the Board will meet at least bi-monthly. Members will be expected to attend the meetings in person. A register of attendance will be kept.

# Quorum

To be agreed for each pathway by the Pathway Director but to include as a minimum: Pathway Director or nominated deputy, at least one each of medical and one nursing/AHP members, a patient representative or patient advocate, and two others.

# Dissemination of the Board's Work

The Pathway Board design, organise and host at least two open meetings per year to communicate to the *London Cancer* community and local people the progress of the Board against its annual plan, and to provide an educational opportunity for local xxx cancer staff and generalists:

- a) The Board will hold at least one annual engagement event open to the whole of *London Cancer* and beyond, including the public to account for its progress against the work programme objectives, and to help obtain input and feedback from the local professional and public community.
- b) The Board will also hold at least one annual educational event for the wider pathway professionals and interested others to allow new developments and learning from the Board to be disseminated across the system.

The invitees to these meetings will represent all sections of the *London Cancer* professional body and geography, as well as patients and voluntary sector partners.

The minutes, agendas and work programmes of the Pathway Board, as well as copies of papers from educational and engagement events will be made available for viewing by the local community through the *London Cancer* website.

# Administrative support

Administrative support will be provided by the Senior Coordinator, London Cancer.

# Document 3: London Cancer Joint Development Group Terms of Reference

Draft document. London Health Programmes, NHS London. February 2012.





# **London Cancer Joint Development Group 15<sup>th</sup> February 2012**

Title:	London Cancer Joint Development Group Terms of Reference.		
Agenda item:	3	Paper:	2
Action requested:	JDG is asked to approve the revised Terms of Reference		
Executive summary:	This draft of the Terms of Reference was amended to reflect discussions held at the December JDG.		
Summary of recommendations:	n/a		
Reference to other docs:	London Cancer action plan		
Date paper completed:	London Cancer service plan		
Other forums that have considered this paper:	December JDG		
Author name and title:	Nick Lawrance, Deve	elopment l	Lead, LHP





# London Cancer Joint Development Group Draft Terms of Reference

# 1. Introduction

There is a strong consensus that cancer outcomes and experience for the population of London are poor. Both commissioners and providers recognise the need for fundamental change. This led to the integrated cancer system designation process for London to bring providers together in governed systems to focus on earlier diagnosis, reduced fragmentation of care for patients, and improved patient experience.

Two groups of cancer care providers made submissions against the integrated cancer system specification on 30<sup>th</sup> June 2011. *London Cancer* developed its proposals for governance with involvement from all acute providers in NCL and NEL and presented these to LHP through verbal and written submissions. The plans were subject to an assurance process during July and August. The evaluation panel that led this assurance process concluded that the proposed integrated system should be authorised subject to an agreed action plan, and identified areas that should be addressed prior to full authorisation in April 2012. The recommendation of the evaluation panel was approved by the NHS London Delivery Group (5<sup>th</sup> September) and the Cancer Implementation Board (13<sup>th</sup> September).

London Cancer has developed an action plan to address the areas prioritised by the evaluation panel. The NHS London Delivery Group committed London's commissioners to funding a substantial portion of the set-up costs in 2011/12, post the August processes described above. These action plans therefore included a clear indication of the resources that will be required to deliver the proposals, within the current financial year.

Alongside the development of integrated cancer systems work is in hand to improve the commissioning arrangements for cancer care and specifically to develop a pathway approach to commissioning to ensure a focus on patient experience, delivery of best practice, consistent and co-ordinated care, improved quality and outcomes and better value for money.

To oversee these changes, designed to bring about a step change in cancer care in the capital, Joint Development Groups are to be established for each integrated cancer system. These are to allow a collaborative approach to the development of implementation plans for both the integrated cancer system and the commissioning arrangements. These Joint Development Groups will be in place by December 2011. They will provide a forum in which the integrated cancer system and commissioners come together to ensure timely decision making and co-ordination of activity and will provide the strategic context for contractual discussions between commissioners and *London Cancer* or individual trusts.

London Cancer and the commissioners will need their own governance arrangements to which members of the group will relate.

# 2. Purpose

The role of the Joint Development Group is to support provider and commissioner collaboration and co-development of the new arrangements for cancer care. The focus will be on the

- development of the integrated cancer systems, in the short term this will focus
  on London Cancer meeting the system specification and addressing differences
  in view that may arise about how to achieve this with respect to timing, direction
  or approach. The Joint Development Group will also address the longer term
  funding and trajectory for the ICS.
- implementation of the agreed model of care, specifically to discuss and agree
   London Cancer's Service Plan and to agree respective actions of
   commissioners and providers in taking forward the significant service changes
   within it.
- development of the commissioning arrangements; commissioners wish to develop a pathway approach to commission and hold providers to account collectively for the delivery of the pathway through the ICS. There is much work to do on the development of this approach, the Joint Development Group will provide an opportunity to develop, test and agree a strategic approach and its implementation

These Joint Development Groups will replace the current Cancer Network Boards, or Cancer Programme Board, where they continue to meet.

# 3. Terms of Reference

# **London Cancer's Development**

- 1. To receive reports on the implementation of the agreed action plan relating to the development of *London Cancer* as an integrated cancer system
- 2. To discuss and agree any alternative approach to meeting the overall vision and specification for an integrated cancer system
- 3. To provide assurance to the commissioners that the Integrated Cancer System service specification published in May 2011has been met
- 4. To agree a resourced plan and sources of funding for the further development of London Cancer in 2012/13
- 5. To agree the ongoing development trajectory for *London Cancer*.
- 6. To develop proposals to include in the membership or ways of working, providers of cancer care along the whole pathway, for example primary and community services providers.

#### **Service Plans**

- 7. To ensure that there is agreement across providers and commissioners to the priority changes in cancer care
- 8. To agree London Cancer's Service Plan to implement the agreed model of care
- 9. To identify those service changes that require action by providers and commissioners and agree respective actions
- 10. To identify and agree the resource consequences of the planning, consultation and implementation process and any subsequent service changes

# **Commissioning Development**

- 11. To agree the implementation process for the use of best practice pathways in commissioning cancer care, which are expected to be specified once for London, and implemented by each integrated cancer system, this will include the best practice description, metrics and possible approaches to pathway tariffs.
- 12. To support the development of pathway tariffs through the agreement to the design, monitoring and modelling arrangements and any subsequent implementation.
- 13. To discuss and agree a the role of the London Cancer Board with respect to the constituent trusts and/or a lead contractor model so that commissioners can hold providers to account collectively for the delivery of care along whole pathways and to populations.
- 14. To support the development of cancer-specific CQUINs and other incentives to be used by commissioners or *London Cancer* to improve quality and outcomes in cancer care.
- 15. To ensure that the smooth transition of commissioning arrangements to those responsible post April 2013, and arrangements to ensure commissioners are coordinated and take a whole pathway approach.

# 4. Members

The membership of the group will be made up of the commissioners and proposed ICS providers and be chaired by a Cluster Chief Executive. The commissioner membership will change over time to reflect the transition of commissioning responsibilities to CCGs and the NHS CB. For the transition period – 2011/12 and 2012/13 the cancer implementation SRO and clinical director from LHP will be additional members. CCG representation and patient representation are imperative and no significant recommendations should be considered unless these key constituents are present.

The group will proceed through consensus rather than a voting procedure.

Cluster Chief Executive (Chair) – Alwen Williams

- Patient and public representatives (2) initially to drawn from the current network patient panels.
- ICS clinical and managerial leads (up to 6) London Cancer Board members once appointed, Kathy Pritchard Jones, Charlotte Williams
- Commissioning representatives (up to 6) to be drawn from collective commissioning arrangements and to include clinical commissioning group representatives (x2) lead contractor from CSO and London specialised commissioning group representative – Alex Berry. Until these arrangements are in place, also Cancer Network Directors – Bob Park and Lallita Carballo
- Cancer implementation SRO and clinical director Rachel Tyndall and Chris Harrison
- NHS London representation Hannah Farrar and Rachel Bartlett

London Health Programmes will support and service the group.

# 5. Accountabilities

This group is accountable to the respective commissioning and provider Boards.

# 6. Conduct of meetings

Meetings will initially be monthly and will last for 1.5 hours, with additional meetings arranged as necessary.

# 7. Evaluation

The terms of reference will be evaluated in March 2012.

# Document 4: A model of care for cancer services – Clinical paper

NHS Commissioning. August 2010.



**Commissioning Support for London** 

# A model of care for cancer services

Clinical paper

August 2010

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# Foreword from the project board

In some way, cancer will likely touch the lives of every person in London. With around 13,600 deaths from cancer in the capital each year and the number of new cases expected to rise, London needs world-class cancer services to meet this major challenge.

The case for change provides a compelling set of arguments for the need to improve cancer services in London. This model of care has been developed by London's cancer community and proposes robust, clinically-led solutions to enable improvements to be made in the capital's cancer services. If adopted by London's commissioners, its recommendations would help earlier diagnoses to be made, improve inpatient care and reduce inequalities in access to and uptake of services, all with the ultimate aims of improving patient experiences and outcomes.

The proposed model of care recommends that high quality care should be delivered by provider networks to allow the sharing of best practice and drive improvements in cancer services. Commissioners should commission services from provider networks and not necessarily from individual organisations, ensuring that pathways and best practice are standardised. Professor Sir Mike Richards CBE, National Cancer Director said:

"I commend all those who have been involved in the London Cancer Services Review. The model of care sets out a forward looking approach to the early diagnosis, treatment and aftercare of Londoners with cancer. Collaborative working should be encouraged through the proposed new arrangements for provider networks. Implementation of this model of care would enable London to acquire the world class services it deserves."

Ensuring the future availability of world-class cancer services for all Londoners is at the heart of the proposed model of care. If it were adopted by commissioners then its implementation will most certainly contribute to improving survival rates to meet the best in Europe and could translate into saving 1,000 Londoners' lives per year. Achieving earlier diagnosis has the greatest potential for improving outcomes and survival for cancer patients in London and so is deserving of particular attention.

We would like to thank the many individuals and organisations that helped us develop the model of care for London's cancer services through our work with primary and secondary care professionals, service users, and independent and third sector partners.

Bill Gillespie

Chief Executive, Sutton and Merton Primary Care Trust and Senior Responsible Officer

**Professor John Toy** 

Professor of Cancer Medicine at Queen Mary, University of London and Clinical Lead



# Foreword from the patient panel

The patient panel was formed of patients, carers, relatives and researchers. Its two co-chairs were members of the project board, representing patients' and carers' views and championing their interests. The panel worked to ensure that the overarching issues and principles that dominated their discussions informed the cancer project board when producing the case for change and model of care documents.

Londoners expect the best quality of care. Despite areas of excellence in cancer care across London, the capital still has poorer survival outcomes than most European countries. The cancer case for change and model of care documents have shown that London scores poorly in clinical outcomes and survivorship data compared to other areas of Britain and countries in Europe.

Londoners expect an increased emphasis on public awareness about cancer symptoms and problems associated with delays in early diagnosis. Social marketing and further research should be used to analyse the best methods for engaging patients early in the diagnostic pathway or in screening programmes to improve outcomes.

To help achieve better outcomes, we acknowledge that it will be necessary to consolidate some cancer care in fewer specialist centres. This will increase travelling times for some patients, but it will improve patient care and cancer treatment outcomes. We understand that the ultimate goal is to deliver high quality of care and quality of life.

While we think that the people of London will acknowledge the need to travel further for the best specialist care, they will expect to have transport needs considered. Certain treatments make patients unwell and immunologically compromised and attempts to alleviate problems encountered due to public transport would be invaluable.

Londoners expect to have a joined up pathway of care throughout their treatment, with care to be delivered closer to their home, where appropriate. Patients should be transferred back for ongoing or follow-up care in local providers or the community as soon as is practicable following care at the specialist centres.

Patients should be informed of all treatment options and outcomes at every stage of their journey to ensure that they are involved in shared and informed decision making.

The people of London expect a holistic approach to their care and for their carers to be acknowledged as partners in their care and to be appropriately supported with communication, information and professional help as needed.

Londoners also expect to have a designated keyworker throughout their journey. Keyworkers, often clinical nurse specialists, are crucial to achieving seamless care for patients, both in the acute setting and importantly when they return home. They prevent feelings of abandonment and act as a contact for advice and reassurance.



The members of the panel consider the invitation to contribute this foreword as an indication of the close working partnership that we have had with the cancer project board and the clinical expert groups. We thank the expert reference groups and the cancer project board members for the opportunity to engage and inform from a patient and public perspective.

We are pleased that a number of our suggestions have led to significant changes in the documents and hope that such input will have a positive impact on the patient experience. We look forward to improvements in cancer treatment and survival for all in London.

Natalie Teich and Virginia Gorna Co-chairs of the cancer patient panel

August 2010



# 1. Proposing a model of care

At its meeting of July 2009, the London Commissioning Group asked Commissioning Support for London to bring together London's cancer community to propose changes to services in the capital. The project was charged with the creation of two substantial documents. First, a thorough case for change and, if this case was accepted, a proposed model of care. The *case for change* was approved by the London Commissioning Group in December 2009 and has now been published. The proposed model of care is laid out in the following pages.

The process has been clinically led. A clinical lead, Professor John Toy, was appointed by Commissioning Support for London's Medical Director, along with a Senior Responsible Officer, Bill Gillespie, Chief Executive of Sutton and Merton Primary Care Trust.

Applications for involvement in the process were sought from London's cancer community. Three expert reference groups were formed, one for each of the three workstreams involved: early diagnosis, common cancers and general care, and rarer cancers and specialist care. Each group consisted of 15-18 individuals from a range of professions and joint chairs were chosen from among its members. The groups met at monthly intervals and commented frequently in between times, both individually and as a group, providing further evidence and clinical input to the development of the documents.

An overarching expert reference panel was also formed from the six co-chairs of the expert reference groups along with the clinical lead and other senior figures from London's cancer community. This group met monthly following the expert reference group meetings to review progress and ensure that the work of the three groups was closely aligned. A group of clinical experts from outside of the Greater London area were also asked to comment on the draft case for change and model of care at intervals throughout the process.

A cancer patient panel was formed from members of Commissioning Support for London's patient and public advisory group and service user representatives from London's five cancer networks. The patient panel also met on a monthly basis and provided invaluable feedback on and input into the two documents and supporting papers. The two co-chairs of the patient panel also sat on the cancer project board.

A stakeholder engagement event was held in November 2009 to share and seek feedback on the draft case for change and emerging model of care. The event was attended by over 120 people, including patients, a range of clinicians, and third sector organisations. The feedback received from the event was written up and fed into the development of the project documents, including this model of care.

In addition, telephone interviews were held with senior representatives of four leading cancer centres in the USA. The purpose was to gain insights into their cancer care models, to compare them with the proposals made in this document and to consider whether anything more could be helpfully proposed for London.

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<sup>&</sup>lt;sup>1</sup> NHS Commissioning Support for London, Cancer services: case for change, 2010

# 2. Key themes from the case for change

The case for changing cancer services in London was published in March 2010.<sup>2</sup> The overarching theme in the *case for change* is that the lack of progress in implementing coordinated cancer services across London means that, although services are excellent in some instances, they are not so everywhere and so provide patients with fragmented care. Survival outcomes for Londoners suggest that about 1,000 more lives a year are lost compared with the best outcomes in Europe.

# **General themes**

- The incidence of cancer is predicted to increase and there are specific aspects of cancer services in London that argue for a case for change.
- Strong commissioning ensures that coordinated services are based on best practice.
- There are barriers to improving cancer services to the same level for all Londoners.
- High quality research is necessary to drive improvement and should be strongly supported.

# **Early diagnosis**

- There is a need to diagnose cancer earlier in London in order to improve survival outcomes the most.
- Some delay in diagnosis is associated with the behaviour or personal situation of Londoners.
- Some delay in diagnosis is attributable to clinical and organisational practice.
- Some delay in diagnosis is attributable to insufficient or inappropriate infrastructure.

# **Common cancers and general care**

- Differences in clinical and organisational practice cause variation in the quality of services offered to cancer patients across London.
- Available evidence indicates that improvements can be made in certain areas of cancer care; these should be implemented across London.
- Cancer services should be localised where possible and centralised where necessary. Strong clinical governance will ensure the delivery of high quality and safe services.
- The development of recommended treatment plans through multidisciplinary teams is best for patients. These teams can operate more efficiently and effectively.

<sup>&</sup>lt;sup>2</sup> NHS Commissioning Support for London, Cancer services: case for change, 2010

- In London there are unnecessary follow-up attendances and these can be in nonoptimal settings.
- Supportive care and palliation services should be brought in line with National Institute for Health and Clinical Excellence (NICE) guidelines.

# Rarer cancers and specialist care

- The centralisation of specialist services has benefits for both patients and the services themselves.
- Some of London's rarer cancer services should be further centralised.
- Some of London's rarer cancer services are appropriately configured, but improvements to these services are still possible.
- Specific arrangements should be made for providing highly specialist services associated with rarer cancers.



### 3. Introduction

Around 13,600 people die from cancer in London each year and more than half of them are under 75 years of age.<sup>3</sup> The case for changing the way that cancer services are delivered in London has been presented.<sup>4</sup> The case is compelling: it shows that not all Londoners have access to the high quality care that they deserve. If UK cancer survival equalled Europe's best, there would be an estimated 11,000 fewer deaths each year.<sup>5</sup> Getting the future model of care right would therefore allow London's NHS to save roughly 1,000 more lives from cancer every year.

Ensuring high quality care for people with cancer has been a focal point for the NHS for some years. The Department of Health's *NHS Cancer Plan*<sup>6</sup> and *Cancer Reform Strategy*<sup>7</sup> highlighted that the quality and safety of patient care across the country could be improved. Over the last decade good progress has been made in cancer care and there are areas of excellence in London. However, there is still much more to be done to ensure that cancer outcomes across all of London become among the best in the world.

This model of care is presented to commissioners by London's cancer community as a proposal for how services should be delivered in the future. It will be for commissioners to determine how and from whom they wish to commission services on behalf of their patients.

One of the themes of the *Cancer Reform Strategy* was that routine healthcare should take place as close to home as possible while more complex care should be centralised:

"New models of care can bring considerable advantages to patients. [There are] a range of ways in which service models for cancer could be improved, based on two key principles: first that care should be delivered locally wherever possible to maximise patient convenience; and second that services should be centralised where necessary to improve outcomes." 8

This model of cancer care for London proposes that use is made of the full range of care settings. Cancer patient pathways cross organisational boundaries: these boundaries should not be allowed to stand in the way of developing a high quality seamless clinical model. Provider networks should therefore be developed that span organisational boundaries. These provider networks should be clearly managed so that services are provided to the required standard in all settings.

Making these improvements and sustaining them will depend on improving the quality and comparability of the outcomes data that London's cancer services collect and publish to inform patient choice and commissioning.

<sup>&</sup>lt;sup>3</sup> Coupland VH, Okello C, Davies EA, Bray F, Møller H, 'The future burden of cancer in London compared with England', *Journal of Public Health*, 2009

<sup>&</sup>lt;sup>4</sup> NHS Commissioning Support for London, Cancer services: case for change, 2010

<sup>&</sup>lt;sup>5</sup> Cancer Research UK, Tackling cancer delays will boost British survival, 2008

<sup>&</sup>lt;a href="http://info.cancerresearchuk.org/news/archive/pressreleases/2008/november/tackling-cancer-delays">http://info.cancerresearchuk.org/news/archive/pressreleases/2008/november/tackling-cancer-delays></a>

<sup>&</sup>lt;sup>6</sup> Department of Health, *The NHS Cancer plan: a plan for investment, a plan for reform*, 2000

Department of Health, Cancer Reform Strategy, 2007

<sup>&</sup>lt;sup>8</sup> Department of Health, Cancer Reform Strategy, 2007

## 4. Guiding principles of this model of care

The model of care is underpinned by the following ten guiding principles:

- Services should provide informed choice, quality outcomes and a high quality experience for cancer patients
- Patients should be at the centre of services, which should be based on patient pathways and should be commissioned to meet their needs
- Services should aim to exceed national, regional, and local care and quality standards, such as the NICE Improving Outcomes Guidance, and national policies including the Cancer Reform Strategy<sup>9</sup>
- 4. Health services should be delivered locally where this is clinically appropriate and delivers value for money
- Healthcare should be delivered close to home and in ambulatory care settings where possible, avoiding or reducing the need for patients to attend or be admitted to hospital
- 6. Services should be centralised where clinically appropriate
- Tertiary, secondary, and primary care services should work closely together, with partners such as local authorities, to provide more cohesive and better care for cancer patients
- 8. Services should deliver improved outcomes for cancer patients while being productive and providing value for money for taxpayers
- Services should meet the needs of the populations they serve and be innovative and continually evolving
- Cancer research, both basic and clinical, should be strongly supported and fostered.

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<sup>&</sup>lt;sup>9</sup> Department of Health, Cancer Reform Strategy, 2007

### 5. Networks

"We can foresee a better NHS that is less insular and fragmented, and works much better across boundaries, including between hospitals and practices"

## **Equity and excellence: liberating the NHS**

South east

Organisational boundaries should not be allowed to stand in the way of developing a high quality seamless clinical model for cancer services in London. The development of networks that place patients and clinical staff at the heart of pathways creates a major opportunity to reduce the impact of organisational barriers. Cancer networks are already in existence but the way they work in London should be redefined to address the issues raised in the *case for change*.<sup>10</sup>

## 5.1 Current cancer network arrangements

Cancer networks in their current form were set up following the publication of the *NHS Cancer Plan* in 2000.<sup>11</sup> The networks were established with the aim of facilitating seamless care across organisational boundaries. There are currently five London cancer networks: north west, north, north east, south east and south west. The north London network also includes West Essex PCT.

North (including West Essex PCT)

North west

South west

Figure 1: Current cancer networks

The current cancer networks consist of the acute trusts, primary care trusts, voluntary sector organisations, and patient and user representatives in the network area. These

11 Department of Health, *The NHS Cancer plan: a plan for investment, a plan for reform*, 2000

<sup>&</sup>lt;sup>10</sup> NHS Commissioning Support for London, Cancer services: case for change, 2010

groups are represented on the network board, which directs and oversees the work of the network. There is also a London Cancer Networks Board, formed from representatives of the five boards, through which the individual networks collaborate and lead on matters that require a pan-London approach.

Each network has a core management team as defined by the *Manual for Cancer Services*. <sup>12</sup> Cancer network management teams provide expert support to cancer commissioners, act as agents to secure clinical engagement, and work alongside providers to secure development and innovation.

Each network has developed local arrangements to respond to the demands of their populations and environment. The nature of the relationships formed may vary both between network areas and also in individual networks.

Each network has a number of network site specific groups (NSSGs) for services relating to specific tumour sites. The role of these groups is to agree evidence-based, clinically effective care pathways that build on best practice in service and workforce redesign, together with clinical guidelines. They monitor compliance through agreed audit metrics and peer review measures with the key aim of assuring consistency of care across the network.

The programme of peer review, a quality assurance programme for NHS cancer services involving both self-assessment and external reviews conducted by professional peers, allows the existing networks to monitor services. Notwithstanding this, the current cancer networks are based more on shared commitment than the ability to regulate the work of network members.

The London Specialised Commissioning Group (SCG) exists to commission specialised services collaboratively using a variety of contracting and financial risk-sharing arrangements. It coordinates the planning and delivery of rarer cancer services in collaboration with cancer networks across the whole population of London. The London SCG also works collaboratively with adjacent SCGs reflecting the significant inflows of users of specialist cancer services into London.

While significant progress has been made since 2000, the *case for change* illustrates that considerable variation still exists in cancer services across London. Despite the efforts of the existing cancer networks (and the PCTs with which they work), the constraints of the system in which they operate have prevented them from eliminating this variation.

The future direction of clinical networks was identified in *London: Commissioning for Health*, which outlined proposals for the development of a model to deliver a world class commissioning process across London.<sup>13</sup> The report concluded that:

"Networks have developed considerable commissioning expertise essential to establishing the PCT collaborative commissioning arrangements. However,

<sup>&</sup>lt;sup>12</sup> Department of Health, *Manual for Cancer Services*, 2004

<sup>&</sup>lt;sup>13</sup> Londonwide PCTs, London: Commissioning for Health - Developing world class commissioning to improve the health of Londoners, 2006

arrangements vary between networks and the staff working for these networks is spread between commissioning and providing organisations."

It was felt that commissioners should commission clinical networks to deliver on agreed objectives.

"[This] approach would ensure that there is a clear commissioning rather than provider development role for clinical networks; and the provider network role itself will need to be clarified, with providers themselves taking this responsibility."

The Cancer Reform Strategy endorsed this approach and identified strong commissioning as a key tool for delivering its recommendations. 14 The strategy also supported the need to review the role of cancer networks, stating that the role of network teams should be redefined to 'act as agents of commissioners' and that networks should be advisors to commissioning.

## 5.2 Appraisal of the current cancer networks

Cancer networks have been instrumental in making considerable improvements in cancer care over the last decade through delivery of the NHS Cancer Plan. 15 However, there are still areas that need further improvement to ensure London's cancer services are among the best in the world. An assessment of the networks' strengths and weaknesses is shown below.

### 5.2.1 Strengths

The networks have:

- Led implementation of NICE Improving Outcomes Guidance (IOG) standards and improvement of relationships between organisations
- Had a key role in supporting the general development of the infrastructure for cancer services
- Played a positive role in developing clinical engagement
- Defined and developed network-wide care pathways and clinical guidelines
- Developed meaningful user engagements processes, with each having a user partnership group and various other local user engagement forums
- Widely promoted the use of service improvement methodology to develop and redesign patient pathways
- Led London-wide drugs prioritisation, national pathways exercises and nursing workforce censuses.

<sup>15</sup> Department of Health, *The NHS Cancer plan: a plan for investment, a plan for reform,* 2000

<sup>&</sup>lt;sup>14</sup> Department of Health, Cancer Reform Strategy, 2007

#### 5.2.2 Weaknesses

The networks now need to:

- Achieve a greater balance between working on provider development and cancer prevention, screening, and awareness and early diagnosis
- Place more emphasis on early cancer detection and the working arrangements to address both the commissioning and provider dimensions of this issue
- Strengthen the alignment between the network team and commissioners to better enable strategic plans to be operationalised through the contracting process
- Have clearly defined responsibilities, giving clarity on what they need to do support both commissioners and providers
- Support commissioners in monitoring cancer services through annual service reviews, application of the Cancer Commissioning Toolkit, and introduction of performance metrics
- Place more emphasis on auditing standards to improve clinical outcomes while reducing the cost of services
- Ensure decisions are consistently taken and implemented on the basis of evidence of best practice rather than organisational considerations.

In addition, the affordability of the current network arrangements needs to be considered in the light of the current and future financial position of the NHS and balanced against the benefits that can be delivered.

The strengths of the cancer networks should be consolidated and embedded in commissioning structures. Their weaknesses must be addressed to tackle the issues identified in the *case for change*. This will require a re-definition of the way that they work to address three critical issues:

- The clarity of the commissioning role and how it is discharged in a way that drives high standards and value for money
- The ability of both commissioners and providers to respond to the agenda for cancer services, as set out in the case for change
- The need to avoid parochialism and work in a way that is more collaborative from an NHS perspective and more coherent from a patient perspective.

To address these critical issues, London's cancer services should move to a model of clearly delineated commissioning arrangements and provider networks.

### 5.3 Proposed model

The aim of the proposed model is to create consistent high quality clinical practice across whole care pathways. London should foster distributed excellence as well maintaining its centres of excellence for the treatment of specific

tumours. Professionals must be enabled to function effectively across a network of services that reflects the patient pathway.

Figures 2 and 3 below outline the transition from the current network arrangements to the proposed model. There are two main features of this transition:

- 1. The incorporation of commissioning activities and associated staff of the current cancer network management teams into commissioning arrangements
- The establishment of new provider networks incorporating the provider development functions of the current cancer network management teams

Figure 2: Current network arrangements

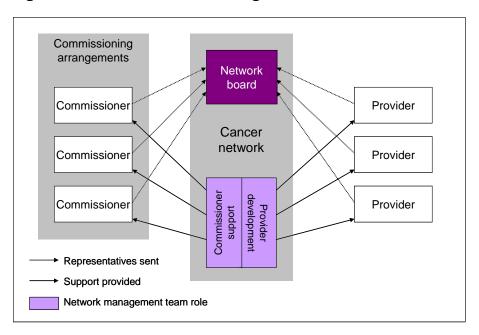
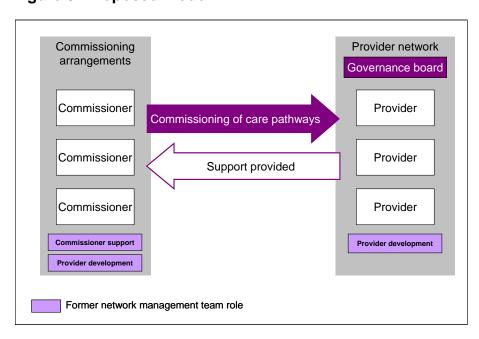


Figure 3: Proposed model





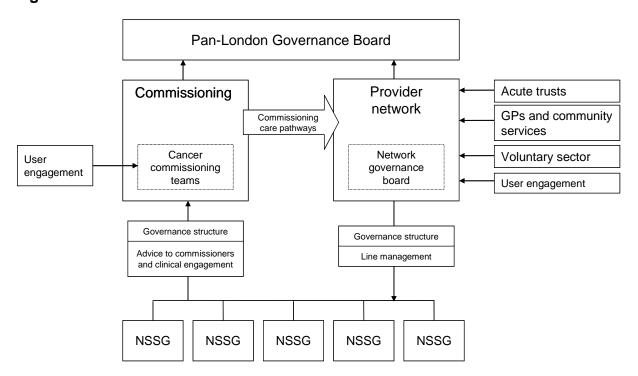
It is not possible to completely separate the concepts of commissioning support and provider development. The transition would involve the incorporation of the current network management teams with the explicit function of provider development within the provider network. Commissioners would retain the responsibility for supporting provider networks to meet their specifications.

NSSGs would continue to function and would have a key responsibility for supporting the development of care pathways. They would continue to ensure the spread of good practice, set and audit standards, and be responsible for clinical governance of specific pathways.

NSSGs would be managed by provider networks and their role would be formalised and standardised across London. They would be formally engaged by commissioners to provide clinical advice for the commissioning process.

Figure 4, below, gives an overview of the proposed model.

Figure 4: Overview of model



### 5.4 Commissioning

Strong commissioning is vital to delivering world-class cancer services in London. Commissioning should be on the basis of whole pathways of care.

The expertise of current network management teams should not, and must not, be lost. Instead, their role should be refocused to provide commissioners with support to commission cancer services of the highest quality. To this end, the commissioning activities and associated staff of the current cancer networks should be incorporated into commissioning arrangements as 'cancer commissioning networks'.



This is in line with the emerging commissioning picture outlined in the Department of Health's commissioning consultation document, published in the wake of *Liberating the NHS*, which states that:<sup>16</sup>

"The NHS Commissioning Board will provide a framework to support GP consortia in commissioning services, including: where appropriate and by agreement with consortia, hosting some commissioning networks, for example for cancer."

To maintain the local knowledge and relationships that have been developed since the publication of the *NHS Cancer Plan*, a cancer commissioning network should initially serve each of the existing five network areas. They should be embedded in commissioning arrangements to ensure a strong link between this local cancer expertise and the commissioning process. The commissioning networks should retain their strong links with commissioners and the London SCG and continue to advise and support commissioning at these levels, in particular in terms of awareness and early detection. Future opportunities for them to gain improvements advantageous to patients through closer working or consolidation should be sought.

The London SCG should continue to drive the commissioning of the rarer cancer services that need to be planned and organised across the whole population. Where necessary, these five regional commissioning networks should come together to work with the London SCG to inform pan-London commissioning processes.

Commissioning networks should work closely alongside clinicians and managers of the proposed provider networks, as set out in the *Cancer Reform Strategy*:

"Network teams should act as agents for commissioners, supporting them to coordinate their activities and providing shared expertise, maintaining the dialogue with clinical teams and users, agreeing clinical guidelines and pathways and driving forward innovative, high quality care." <sup>17</sup>

To address the problems of fragmentation highlighted in the *case for change*, commissioners should move towards cancer commissioning on the basis of patient pathways rather than individual organisations. The effectiveness of the model requires commissioners to embrace the concept of commissioning in this way as well as the existence of a strong interface between commissioners and provider networks.

The onus should be on providers to work collaboratively to provide seamless care pathways by sharing knowledge and best practice. Service delivery should be monitored by cancer commissioning networks using increasingly sophisticated quality and outcome measures as they are developed. Sanctions should be made available for commissioners to use should the commissioned specifications not be met.

Representatives of the cancer commissioning networks should sit on the governance boards of provider networks, providing a feedback loop from providers into the commissioning process.

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<sup>&</sup>lt;sup>16</sup> Department of Health, *Liberating the NHS: Commissioning for patients, a consultation on proposals*, 2010

<sup>&</sup>lt;sup>17</sup> Department of Health, Cancer Reform Strategy, 2007

Cancer commissioning networks should continue the work of the current cancer networks, gaining an insight into patient experience by engaging meaningfully with patients and carers. The role of current NSSGs should be retained. Although managed by provider networks, these groups should have a formal responsibility to provide expert advice to commissioners on the delivery of services and be a focus for clinical engagement.

Patient and public involvement must be fundamental to the process of commissioning cancer services to meet local need. The National Cancer Action Team (NCAT) has published guidelines, with involvement from existing London cancer networks, on involving service users in commissioning. Key recommendations include providing a designated lead to support continuing patient involvement in commissioning services and direct participation of service users in decision making.

Consideration should be given to centralising commissioning of radiotherapy and some rarer services and specialist treatments. This would ensure that a pan-London approach is taken to the planning and delivery of these services.

#### 5.5 Provider networks

Success in commissioning comprehensive patient pathways will be dependent on the coordinated and managed delivery of services across different types of providers. The proposed model of care for cancer services in London is therefore based on provider networks. Provider networks are defined as groups of providers commissioned collectively to provide a comprehensive cancer service.

Provider networks would allow the development of services that focus on the principle of 'right person, right time, right place'. Provider networks would enable acute trusts, voluntary sector, social care, and community providers to maintain agreed standards and implement commissioned care pathways. They would also allow clinicians to apply their skills in the most appropriate setting for patients.

Provider networks would provide high quality, seamless services, collaboratively working across organisational boundaries, sharing best practice, and creating flexible staffing arrangements such as joint posts. Provider network governance boards would centrally ensure quality and safety. Boards would also ensure that provider networks link with high quality cancer research institutions including, where appropriate, Academic Health Science Centres (AHSCs).

Provider networks would be established with at least one cancer centre as an integral part. Cancer centres would provide organisational development input to support the development of the provider network arrangements.

### 5.5.1 Features of provider networks

Provider networks should be clinically led. They should have executive responsibility for delivering the specified care pathways for different tumour sites developed by cancer commissioning networks and NSSGs.



Provider networks should encompass services for all tumour sites in their catchment area and should have responsibility for governing and delivering services across the network.

Provider networks should be integrated to include providers at each step of the pathway, including the community. The proposed model is not prescriptive about how this integration is achieved. Some of the options available to provider networks for achieving integration are outlined in section 10.7. Ensuring that all of the elements of the pathway are integrated will be a challenge for both commissioners and provider networks.

The voluntary sector should also be represented on the governance board to ensure that it is fully involved in decisions about the delivery of care pathways. The role of the voluntary sector in making decisions should be addressed in developing proposals for the functioning of the provider network as outlined above.

Commissioners should no longer commission services from NHS providers that are not part of a provider network so membership would be compulsory for all accredited providers. The provider network should be given outcomes to deliver by commissioners, who should hold the provider network to account for performance, based on the care pathway contracts that are let.

### 5.5.2 Number of provider networks

This model of care does not propose an optimum number of provider networks for the capital. There is no compelling argument for how large provider networks should be. The configuration of provider networks should be determined as the recommendations of the model of care are implemented, particularly those regarding the further consolidation of specialist surgical services. The configuration would therefore be for London's commissioners to determine. These decisions should be based on a number of factors, including those below and is likely to result in fewer provider networks than the current five cancer networks.

Population and coverage: The coverage of each provider network and the cancer services provided within it should match the population requirements. The current population coverage of each of the existing five London cancer networks ranges between 1.51 million to 1.85 million. In comparison, the Yorkshire network serves a population of 2.64 million (roughly a third of London's population) and has one cancer centre. The largest cancer network in England is Greater Manchester and Cheshire, which covers a population of 3.24 million and also has one cancer centre. It is considered locally that a larger sized network provides overall patient benefits through central efficiency gains, easier service developments and introduction of new treatments, an increased number of patients entered into clinical trials and easier internal benchmarking of clinical performance.

**Cancer activity:** Fewer, larger provider networks, covering a larger geographical area and population, would allow a higher proportion of London's cancer patients to receive their cancer care within a single network. This should be expected to result in more consistent high quality care for more patients across a larger set of community types as a higher proportion of cancer services would be managed and delivered by a single



provider network. Fewer, larger provider networks would afford the opportunity of an increased managerial oversight of patient outcomes and could also lead to management efficiency savings.

**Cancer centres:** The concentration of cancer care into fewer specialist centres would fit with a reduction in the number of provider networks, with each containing at least one such centre as well as at least one cancer centre as an essential component. If a provider network contained more than one cancer centre then this would result in more competition within the network than is now the case.

**Innovation, research and education:** Alignment with research institutions, education and innovation should be considered when configuring provider networks to enhance their abilities to drive improvements in clinical care.

Health Innovation and Education Clusters (HIECs) are formal partnerships between NHS organisations, leading medical education institutes, industry and academia. Their purpose is to promote innovation, quality and productivity in the NHS through the training and education of healthcare staff and to share best practice across the capital. London has three HIECs, focusing specifically on developing a high-performing and innovative workforce, and spreading skills and proven innovations across NHS organisations to deliver more integrated care closer to where people live.

Alignment of provider networks with HIECs and research active institutions will bring many benefits to a provider network. As well as providing clinical leadership they will operate in a collaborative model, fostering mature relationships. They will enhance the provider network's ability to translate research, innovation and education into improved clinical care.

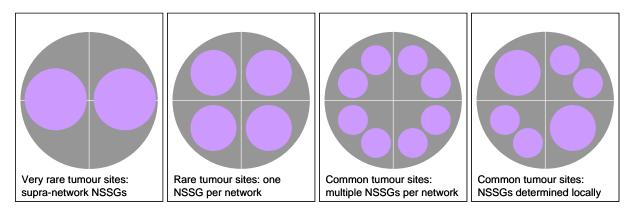
### 5.5.3 Network site specific groups (NSSGs)

NSSGs should continue to take responsibility for implementing the care pathways for their tumour site. Their role should be formalised and standardised across the provider network. NSSGs should continue to ensure the spread of good practice, setting and auditing standards, and for clinical governance. Groups should continue to be informed by strong service user engagement.

Each of the current cancer networks has an NSSG for each tumour site. Under the proposed model, groups should be consolidated where appropriate so that each provider network contains one group for each tumour site or service. For some tumour sites, particularly common tumours such as breast and colorectal, consolidated NSSGs may become too large and unwieldy. In such cases, provider networks may contain multiple groups as determined by local factors, such as patient flows, as illustrated in figure 5. The direct line management of NSSGs by provider networks would ensure that the operations of the groups are standardised.



Figure 5: Options for the configuration of NSSGs in provider networks



## 5.6 Provider network governance

The governance structure of the proposed provider networks would ensure that they work collaboratively rather than hierarchically. Each provider network should function as an integrated, actively managed, single entity, taking responsibility for governance of all cancer patients in the network. Provider networks should be led by a governance board that should be comprised of representatives from each of the providers in the network and representatives from the cancer commissioning networks.

The governance boards would be responsible for agreeing the governance and operational arrangements to address issues such as:

- The process for decision-making in the provider network
- How the provider network functions to meet the requirements of commissioners
- The way in which contracts, performance, risk and clinical governance will be managed when pathways cross constituent organisations
- How resources will be allocated and accounted for
- How GPs and the voluntary sector will be integrated into the provider network, based on advice from these providers
- Ensuring that all patients requiring care in the provider network have access to an integrated clinical service that meets all of their needs
- Ensuring that systems are in place for patient information to be shared across the provider network to facilitate seamless care
- Establishing clear clinical care pathways and ensuring that these are efficiently, effectively and consistently delivered
- Publically reporting on the quality of clinical care across the whole provider network



- Ensuring that the provider network offers a comprehensive range of training opportunities for its clinical and non-clinical workforce
- Working with academic institutions in London to encourage the development of related clinical research programmes and translation of research findings into clinical practice.

### 5.7 Pan-London governance board

A pan-London governance board should be formed in place of the existing London Cancer Networks Board. The board should have representatives from both commissioning groups and provider networks and should have the formal role of providing leadership on matters requiring a supra-network approach. The pan-London board would oversee performance across the whole city to ensure that the activities of commissioners and provider networks across the capital are aligned with one another. It would also interrogate relative performance metrics of London provider networks and collectively against international comparator countries.

#### 5.8 Benefits

The proposed structure would have a number of important benefits that will directly enhance the performance of current cancer network arrangements.

Responsibilities would be clear:

- The clear distinction of roles for the commissioners and providers would address the previous lack of clarity about responsibilities
- Clinical engagement by commissioners would remain of central importance and the good practice already developed can be sustained in the structures
- All constituent organisations that deliver cancer services would be included in the provider network
- The provider network would provide the platform for commissioning on the basis of pathways and outcomes, which would be the expressed intent of commissioners.

### **Key recommendations:**

London should shift to a model of clear commissioning arrangements and provider networks.

The role of the existing network management teams should be redefined as cancer commissioning networks and focus on supporting the commissioning of high quality services.

There should initially be five cancer commissioning networks embedded within



commissioning arrangements.

The configuration of provider networks should be determined as the recommendations of the model of care are implemented, particularly those regarding the further consolidation of specialist surgical services.

A pan-London board should oversee performance across the whole city.



## 6. Patient experience

"Patient experience is only as good as the weakest point in the patient pathway."

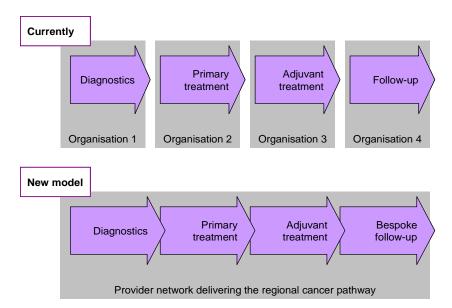
### Cancer patient panel

### 6.1 The patient pathway

Patients with cancer should not notice their transition between organisations in the provider network. They should not feel that they have been abandoned when their care is transferred from a specialist centre to their local hospital or primary care.

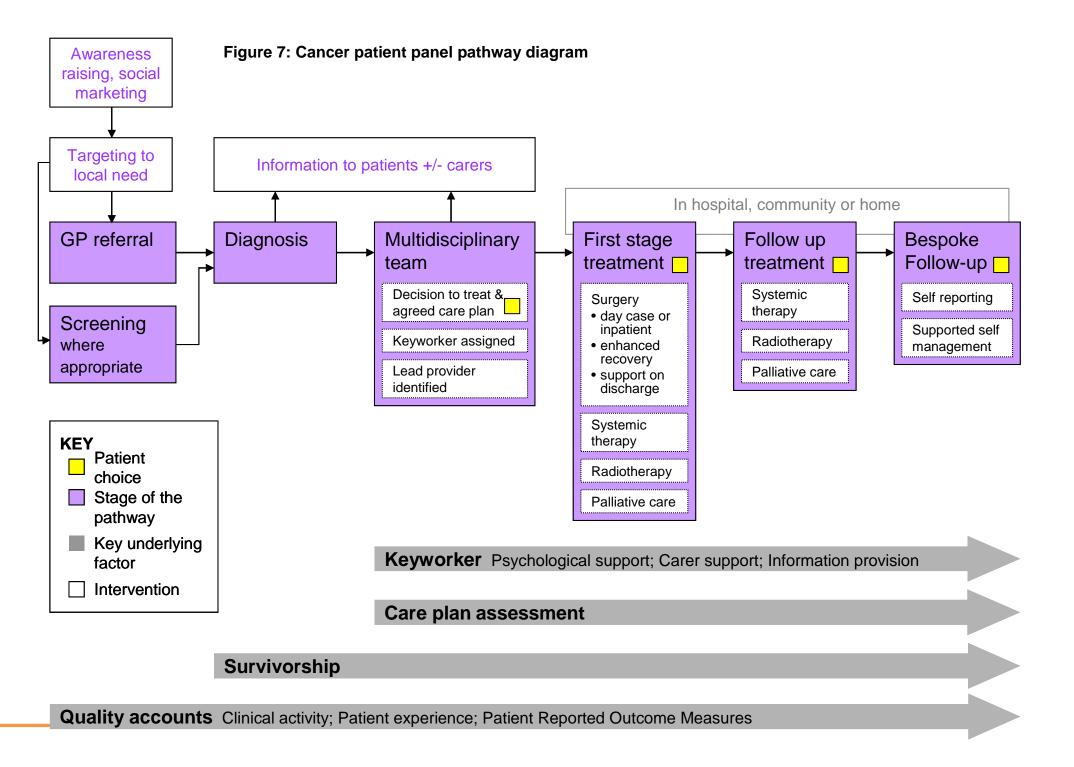
Cancer patients should instead find themselves on the regional cancer pathway. The patient may attend different settings but these should be the appropriate setting for each part of the pathway. Care would not always be delivered where the decision-making process occurs. Patients should not notice the transition between organisations and there should no longer be gaps in the system through which they can fall. Patients should instead know that one entity has the accountability and responsibility for their experience across the entirety of the pathway.

Figure 6: Delivering pathways – from organisations to provider networks



The cancer patient panel proved invaluable to ensuring that the patient experience was kept central to model of care's development. This proposed model of care is largely a clinical document and may not therefore be wholly accessible to patients and the public. The panel developed a generic patient pathway diagram to summarise some of its key recommendations in an accessible way. This care pathway diagram is found at figure 7, below. As well as setting out the various parts of the pathway it identifies the points in the pathway at which the patient panel felt it important that patients and carers should be able to exercise choice.





### 6.2 Key themes from the patient panel

Figure 7 outlines some of the key themes that the patient panel discussed: the centrality of the keyworker and carer support, patient choice the survivorship agenda, and care planning. These themes are incorporated throughout this document and are summarised below.

The cancer patient panel felt strongly that the people of London expect:

- The best quality of care. Despite areas of excellence in cancer care across London, the capital still has poorer survival outcomes than most European countries. Work must be undertaken to identify and eliminate the causes of these poor outcomes. Quality of life and patient choice should be the guiding principles in decision-making.
- Public awareness of cancer related symptoms and problems associated with delays in early diagnosis to be raised. These delays may be attributable to language, literacy, religion, cultural traditions, communication and accessibility issues. Social marketing should analyse the best methods for engaging patients early in the diagnostic pathway or in screening programmes to improve outcomes.
- Care closer to home where appropriate. They acknowledge the need to travel further for best specialist care, but expect transfer back to local providers or the community as soon as is practicable for ongoing or follow-up care.
- To have their transport needs taken into consideration, particularly when they are expected to travel some distance to access specialist services. As certain treatments make patients unwell and/or immunologically compromised, attempts to alleviate problems encountered due to public transport would be invaluable.
- To have a designated keyworker throughout their cancer journey. Keyworkers should be part of the multidisciplinary team and are crucial to achieving seamless care for patients, both within the acute setting and most importantly when they return home. Keyworkers prevent feelings of abandonment and act as a contact for advice and reassurance.
- To be informed of all possible treatment options and outcomes at all stages of their cancer journey to ensure shared informed decision-making.
- To have a joined up pathway of care throughout their treatment including input from rehabilitation and social services when appropriate.
- A holistic approach to be taken to their care. Cancer does not define the whole, the total experience matters before, during and after treatment. Special considerations are also needed to address the care of those with co-morbidities, such as long term conditions or mental illness.
- Carers (professional, relatives and friends) to be acknowledged as partners in their care and to be appropriately communicated with and supported with information and professional help as needed. It is important to ensure, rather than assume, that these people are willing and

able to help. There is also a need to understand that the psychological needs of patients and carers may change with time and to provide the appropriate support when changes develop.

- Patients to be involved in decision making about their care with clear high quality outcome information to inform these choices at every step. The information provided should always be at a level and in a format appropriate to the patient's and carer's understanding.
- Improved communication with patients. Clinical staff must ensure that patients, families and carers really do understand the condition, nature, potential benefits and risks of proposed treatment and future lifestyle requirements and limitations.
- Special considerations of social and age demographics to identify those
  populations with greater or specific needs, such as the elderly, many of whom will
  not have family members or other carers, and the socially deprived who might
  have poorer health literacy. Short hospital stays are unlikely to be appropriate for
  these populations and alternative support may therefore be necessary.
  Community nursing services and social care services are particularly important
  because of the focus on day surgery and early discharge.
- Clear guidance on reducing the risk of cancer recurring in addition to initial prevention campaigns.
- Patient reported outcome measures (PROMs) to be designed in partnership with patients, carers and health professionals. A greater focus on the experience of cancer care for patients and their carers along the whole pathway should be included in annual quality accounts.



## 7. Early diagnosis

### 7.1 Introduction

The earlier a cancer is diagnosed and treated, the greater the prospect of survival and improved quality of life. Achieving earlier diagnosis has the greatest potential for improving outcomes and survival for cancer patients in London. The *case for change* notes that raising survival rates in England to match the best in Europe could save approximately 1,000 lives per year in London. This area requires urgent attention and further action is needed to achieve earlier diagnoses of cancer.<sup>18</sup>

Early diagnosis is essential to improving outcomes for cancer patients. The *case for change* for London's cancer services notes that early diagnosis could be improved by:

- Increasing early recognition of signs and symptoms among both the public and in primary care and ensuring that advice is sought at the earliest opportunity
- Ensuring prompt referral and access to diagnostics in both primary and secondary care
- Increasing understanding of the potential benefits of screening to increase uptake rates
- Designing, agreeing and implementing locally agreed, clinically effective pathways for early diagnosis
- Understanding the differences in population groups in both the awareness of cancer signs and symptoms and in their perceived barriers to care.

Professor Sir Mike Richards CBE, National Cancer Director, has stated that:

"efforts now need to be directed at promoting early diagnosis for the very large number (over 90%) of cancer patients who are diagnosed as a result of their symptoms, rather than by screening." 19

To improve early diagnosis of cancer, the proposed model of care offers guidance to commissioners in four key areas:

- Population awareness and understanding
- Referrals and accessibility of diagnostics
- Effective screening programmes
- Understanding and addressing inequalities.

<sup>&</sup>lt;sup>18</sup> Department of Health, Cancer Reform Strategy: achieving local implementation – second annual

<sup>&</sup>lt;sup>19</sup> Richards, M., 'The size of the prize for earlier diagnosis of cancer in England', *British Journal of Cancer*, 2009:101, S125–S129

This guidance is intended both to support and drive London commissioners of services to ensure that improved early diagnoses of cancer are being made where possible, thereby improving survival and patient outcomes.

## 7.2 Population awareness and understanding

### 7.2.1 Raising awareness and understanding

In England, the awareness levels of the early signs and symptoms of cancer are poor.<sup>20</sup> Improving public awareness may help improve early presentation and therefore early diagnosis.

Public awareness initiatives and campaigns should be focused on:

- Cancer signs and symptoms
- The importance of screening, including the benefits of early detection
- How to access cancer services.

The National Awareness and Early Diagnosis Initiative (NAEDI), jointly led by the National Cancer Action Team (NCAT) and Cancer Research UK is a programme of activity to support local initiatives to raise public awareness of the signs and symptoms of early cancer and encourage people to seek help sooner.

To help improve early diagnosis of cancer, commissioners should ensure that the initiatives of NAEDI are implemented locally across London. These should include:

- Measuring the awareness of cancer symptoms and introducing regular assessment surveys
- Interventions to promote early presentation, focusing on evaluation and dissemination
- Interventions in primary care and understanding the nature of primary care delay.

The Cancer Awareness Measure (CAM) (commissioned by NAEDI) is a survey tool designed to assess local levels of awareness of the signs and symptoms of cancer and to identify perceived barriers to care.

Through piloting this tool, some early adopter primary care trusts (PCTs), along with current cancer networks, are currently undertaking baseline assessments of local need to establish variations in awareness at PCT and network levels. The use of this tool over time by commissioners would enable local needs to be understood and would provide a basis for targeted interventions and an opportunity for sharing best practice.

<sup>&</sup>lt;sup>20</sup> Robb, K., 'Public awareness of cancer in Britain: a population-based survey of adults' *British Journal of Cancer*, 2009:101, S18– S23

Following baseline assessment, targeted interventions to increase awareness and understanding should be developed through engagement and collaboration with local government, local communities and the third sector.

This could be done using social marketing techniques.<sup>21</sup> Commissioners should ensure that an evaluation of the impact of these interventions is undertaken, following which the interventions should be modified as necessary.

As part of the NAEDI, the Department of Health has developed an online tool to provide guidance and support on social marketing techniques to increase awareness levels of the signs and symptoms of cancer and encourage early presentation. The tool is available to commissioners and includes social marketing initiatives as well as economic modelling to help commissioners plan and deliver the service.

Health professionals in all settings have a role to play in increasing public awareness of the signs and symptoms of cancer. Primary care professionals such as dentists and pharmacists are ideally placed to provide opportunistic public health information, encouraging people to see their GP earlier when experiencing symptoms suggestive of cancer. Additionally, Macmillan Cancer Support has recently entered into partnership with a national high street chemist to ensure that information on cancer is available in every store across the country.

# Evidence of outcomes: raising cancer awareness through providing targeted information in pharmacies

Information leaflets on the signs and symptoms of certain cancer types were made available in pharmacies, a health setting that some people are likely to visit more frequently than their GP. The pilot ran during April 2006, with two Lambeth pharmacies and GP surgeries actively involved to test if the approach was acceptable to the general public and practical to implement. This information encouraged those most at risk to seek advice from their GP sooner than they might have otherwise done. The pilot proved successful and has subsequently become part of the pharmacy contract across all the south east London PCTs.

Educational information for patients of the signs and symptoms of cancer and the benefits of early diagnosis should be provided in a variety of formats to suit different audiences. Engagement with the London population at local levels would need to take place to provide translated materials to suit the needs of local communities.

### 7.2.2 Increasing early presentation

Greater efforts to encourage patients to present earlier are needed. Implementing the workstreams of NAEDI to improve the understanding and awareness of cancer

<sup>&</sup>lt;sup>21</sup> Social marketing is a systematic approach used to achieve and sustain behaviour goals on a range of social issues. Its primary aim is to achieve social good (rather than commercial benefit), with clearly defined behavioural goals. In the case of health-related social marketing, the 'social good' can be articulated in terms of achieving specific, achievable and manageable behaviour goals for improving health and reducing health inequalities.

signs and symptoms would go some way to reduce late presentation amongst Londoners.

## **Evidence of outcomes: increasing awareness through targeted interventions**

The Doncaster Cough Campaign<sup>22</sup> used social marketing with the aim of addressing the town's problem of late presentation with lung cancer. Men aged 50 to 60 who were current or ex-smokers (and their families) from the most deprived parts of Doncaster were targeted. The campaign proved to be successful with an increase in awareness by the target audience and a change in the stage of presentation for people with newly diagnosed cancers (from 11% to 19% stage I or II).

Commissioners should consider developing similar campaigns for colorectal cancer and the early detection of breast cancer in older women.

The Cancer Commissioning Guidance highlights a number of areas that commissioners can explore to determine whether late presentation is a problem in their local population.<sup>23</sup> These include:

- Low one year survival rates
- Screening uptake
- Two-week referral rates by general practice per 10,000 population
- The number of cancers diagnosed through non-urgent routes
- Emergency hospital admissions where cancer is diagnosed.

Additionally, in partnership with NHS London, commissioners should give consideration to improving access to symptom screening questionnaires. These should be in a variety of formats such as leaflets or web-based tools for patients concerned about new symptoms, for example, an unexplained cough and weight loss or a testicular lump. Advice to seek medical attention should be given, where appropriate. Improving access to such information could lead to a higher proportion of patients presenting earlier with symptoms suggestive of cancer and initiate earlier referrals if necessary.

## 7.2.3 Awareness and understanding in primary care

PCT medical directors and Professional Executive Committee (PEC) chairs have a key role to play in raising the awareness and understanding of the signs and symptoms of cancer in primary care. The *Cancer Reform Strategy* proposed that a

<sup>&</sup>lt;sup>22</sup> National Cancer Action Team and National Cancer Equality Initiative (NCEI), *We Can. Reducing Inequalities in Commissioning Cancer Services*, 2009

Department of Health and the National Cancer Action Team, Cancer Commissioning Guidance, second edition, 2009

national audit in primary care of newly-diagnosed cancers be undertaken. It is recommended that commissioners in London carry out this audit in conjunction with GP cancer leads. The RCGP-NCAT Cancer Diagnosis Audit Tool (CDAT)<sup>24</sup> is now available to support primary care audit. The results would need to be associated with significant event audit (SEA) in order to gain a deeper understanding of any prediagnostic delays that take place. Results from this audit should be used to make decisions about how to provide more support to primary care professionals to ensure early diagnosis of cancer. Additionally, commissioners should consider setting out requirements for better data collection at primary care level, including undertaking and sharing of SEA on all diagnostic delays and specific quality outcomes to be achieved in line with local need.<sup>25</sup>

In 2008, 32 out of the 52 GP practices in Lambeth PCT piloted an audit of cancer diagnostic pathways and details of 370 new cancer cases were returned. Analysis of the length of time taken to complete a number of steps in the diagnostic pathway was undertaken. The results of the audit suggest that there are significant variations between practices both in terms of the time taken for patients to present from first symptoms and the time between presentation and referral. There also appeared to be significant variation in the time taken to negotiate stages of the diagnostic pathway according to cancer type. The sample was self-selected and the quality of the returns was variable. However, the results are useful to begin to understand the role of primary care in cancer diagnosis.

Lessons learned from primary care cancer audits should be shared and used to inform the education and training of healthcare practitioners in all settings and to streamline pathways where appropriate.

Macmillan Cancer Support is currently working with the north west London cancer network to develop educational packages for GPs to address early diagnosis. Initially the work is focusing on a DVD educational resource providing GP experiences. It also uses a captured patient experience of primary care, for example GP consultations when patients initially present with symptoms that are suggestive of cancer. The aim of this educational tool is to improve early diagnosis.

As highlighted in the *case for change*, knowing the positive predictive value<sup>26</sup> of symptoms and combinations of symptoms could help to improve the diagnosis of early stage cancer.<sup>27</sup> As part of the Healthy Communities Collaborative, the Improvement Foundation<sup>28</sup> developed a pilot which gives cumulative positive predictive values for the symptoms suggestive of certain types of cancer with the aim

The positive predictive value, or precision rate, or post-test probability of disease, is the proportion of patients with positive test results who are correctly diagnosed. It is the most important measure of a diagnostic method as it reflects the probability that a positive test reflects the underlying condition being tested for. Its value does however depend on the prevalence of the disease, which may vary. Hamilton, W., 'Five misconceptions in cancer diagnosis', *British Journal of General Practice*, 2009 The Improvement Foundation carries out service improvement work across the public sector in the UK and overseas. The organisation works in partnership with frontline staff and service users to

deliver large-scale improvements in health, education and service outcomes, and provide leadership and quality improvement skills training.

<sup>&</sup>lt;sup>24</sup> The RCGP-NCAT CDAT has been developed by the Royal College of General Practitioners and the National Cancer Action Team to provide a template for GPs carrying out the primary care audit to use to record their data

<sup>&</sup>lt;sup>25</sup> National Patient Safety Agency, *Delayed diagnosis of cancer*, 2010

of enhancing early diagnosis. This is a potentially useful predictive tool for GPs and if the pilot proves it to be successful, consideration should be given to wider use, in association with clinically effective pathways.

Additionally, a study has been undertaken to specify the symptoms of ovarian cancer which would lead to the development of a symptom index tool and guidance for GPs which is due to be published in the next year.<sup>29</sup>

Consideration should be given to developing an easily accessible advice service for GPs from specialists in secondary care, via telephone or email. This would enable GPs to obtain a specialist opinion on patients who present with diffuse symptoms and refer the patient onto the correct pathway to minimise diagnostic delays. The National Clinical Director for Cancer has announced plans to introduce a computerassisted cancer risk assessment to help GPs estimate whether a patient's symptoms could indicate the presence of a cancer and decide whether they needed to refer them for urgent diagnostic investigations. Work is currently being undertaken with by the National Patient Safety Agency (NPSA) with partners such as the Royal College of General Practitioners and the NCAT.<sup>30</sup>

## **Key recommendations:**

Commissioners should use the CAM to assess awareness levels of the signs and symptoms of cancer in their local population.

Commissioners should have clear strategies for improving awareness levels of the signs and symptoms of cancer amongst the public and reducing late presentation.

GPs should participate in the primary care national audit of newly-diagnosed cancers to gain an understanding of any pre-diagnostic delays that take place.

### 7.3 Referrals and accessibility of diagnostics

### 7.3.1 Access to diagnostics from primary care

Rapid access to diagnostics is essential to make an early diagnosis and reduce delays for patients. There should be ease of access to general diagnostics from primary care in line with the NICE guidelines for all patients suspected of cancer.31 GPs may want to exclude a diagnosis of cancer for a patient presenting with clinically vague symptoms and in November 2009, plans were announced to offer all patients in England who are not referred on the urgent two-week referral pathway, access to diagnostics tests and results which can confirm or exclude cancer, within one week.32

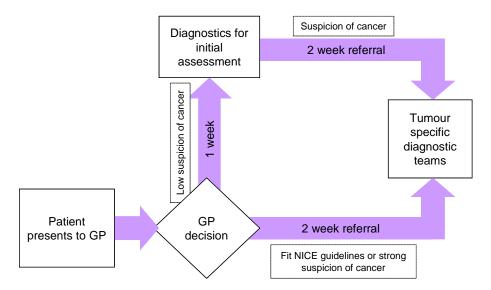
<sup>&</sup>lt;sup>29</sup> Hamilton, W., 'Risk of ovarian cancer in women with symptoms in primary care: population based case-control study', *British Medical Journal*, 2009

30 National Patient Safety Agency, *Delayed diagnosis of cancer*, 2010

NICE, Referral guidelines for suspected cancer, 2005

<sup>&</sup>lt;sup>32</sup> Department of Health, The NHS Constitution: A consultation on new patient rights, 2009

Figure 8: Access to diagnostics



In line with this, it is recommended that direct access to x-ray, non-obstetric ultrasound and flexible sigmoidoscopy for initial assessment should be granted across London.

To ensure diagnostic services can be accessed rapidly, directly from primary care and closer to home, they should be available in primary care where appropriate and possible. Services should be developed, based on local need and supported by outreach programmes from acute hospitals where appropriate. Access to these investigations in primary care would allow efficient and accurate follow-up of patients to occur in the community.

# Evidence of outcomes: improving early diagnosis through access to diagnostics

The introduction of community-based flexible sigmoidoscopy in north east England has improved GP access to diagnostic tests and greatly reduced referrals to specialist colorectal clinics, while improving early diagnosis of colorectal cancer. Evidence has shown that flexible sigmoidoscopy accompanied by a full blood count and abdominal examination is an adequate initial diagnostic work-up for patients with new lower gastrointestinal symptoms and can identify 95% of new cases of colorectal cancer.<sup>33</sup>

Recent evidence strongly supports flexible sigmoidoscopy as the investigation of choice in patients with colorectal symptoms with a change in bowel habit and/or rectal bleeding. Flexible sigmoidoscopy should be substituted for total colonoscopy

<sup>&</sup>lt;sup>33</sup> Thompson, MR. et al., 'Flexible sigmoidoscopy and whole colonic imaging in the diagnosis of cancer in patients with colorectal symptoms', *British Journal of Surgery* 2008, 95:9

as appropriate. This would allow more procedures to be carried out at a lesser cost, with subsequent financial savings.34

To improve consistency of access to initial assessment diagnostics from primary care, it is recommended that commonly agreed local and network-wide referral pathways are in place from primary care to diagnostic services that eliminate unnecessary delays. In line with national plans, results should be returned and communicated to the patient within one week. This configuration of services and greater access to tests would help GPs to save lives by diagnosing cancer earlier and to rule out suspected cases of cancer, providing faster reassurance to patients.

Methods should be developed and introduced for empowering patients on a cancer diagnostic pathway. The aim would be to help patients ensure that they are kept informed, can ask for a second opinion if they wish, and are enabled to follow up test results relating to their own care.35

### 7.3.2 Improving the accuracy of referrals

Urgent patient referrals are essential in ensuring suspected cancer patients are seen as soon as possible. However, the large number of urgent referrals, most of whom do not have cancer, can perversely cause delays for patients who are referred nonurgently but who turn out to have cancer.

The second annual report of the Cancer Reform Strategy highlighted wide variation across the country in the number of cancers referred and the proportion of cancers diagnosed in this way. 36 To obtain full insight into referral patterns, it is important that commissioners review referral patterns from primary to secondary care to ensure the best use of the urgent referral route for their local populations. This should include compliance with the NICE guidelines, participation in the Primary Care Audit and other assessments to inform programmes where improvement is required. Additionally, organisations should review the systems that their cancer multidisciplinary teams have in place to identify, report and investigate delays in appropriate referrals.<sup>37</sup>

In addition, when reviewing referral patterns, care should be taken to balance the need to reduce the proportion of referrals of patients who turn out not to have cancer, with the need to ensure that patients who do have cancer are identified and their treatment is not delayed. Feedback from secondary care on referrals received would enable primary care to gain an insight on their accuracy. Consideration should be given to formal provider network mechanisms to allow feedback from secondary care clinicians to GPs on the quality of referrals. Commissioners could audit GP feedback returns to gain insight into individual GP practice performance.

It is important to ensure that the urgent referral route is only used for patients who fit the NICE guidelines criteria for suspected cancer or, if not, for whom the GP

<sup>&</sup>lt;sup>34</sup> Kent, A.J. et al., 'The use of symptoms to predict colorectal cancer site. Can we reduce the pressure on our endoscopy services?' *Colorectal Disease*, 2010: 12(2)

National Patient Safety Agency, Delayed diagnosis of cancer, 2010

<sup>&</sup>lt;sup>36</sup> Department of Health, Cancer Reform Strategy: achieving local implementation – second annual report, 2009

National Patient Safety Agency, Delayed diagnosis of cancer, 2010

nevertheless has a strong suspicion of cancer. However, there is an emerging issue about the 'appropriateness' of the guidelines themselves. The NICE guidelines are due to be reviewed in summer 2010, and any changes in referral criteria resulting from this review should be adopted and adhered to.

## 7.3.3 Referrals to secondary care and specialist services

Commissioning clinically effective and standardised diagnostic pathways for all patients with a suspicion of cancer across London would ensure that they are treated within the national cancer waiting times and make an important step to reduce inequalities. Furthermore, from January 2010, all patients with any breast symptoms are referred for specialist opinion within two weeks.<sup>38</sup> GPs must ensure that the importance and urgency of referrals are communicated to the patient, and ensure that all relevant information is provided. Failure to convey the urgency of the referral can lead to a patient unwittingly delaying their appointment.

For patients who present with diffuse, non-specific symptoms, access to the necessary diagnostics to exclude or confirm a diagnosis of cancer should be available within the two-week referral timeframe. If results are negative for the particular type of cancer, results should be reported back to the requester and the patient should be referred onto the relevant clinical team for further investigations.

As highlighted in the *case for change*, the majority of newly diagnosed cancers do not arise through the two-week referral route and therefore there is a need for appropriate and clear protocols for diagnosticians to act on the receipt of abnormal results when patients have little or no suspicion of cancer. Consultant to consultant direct rapid referrals should be made if cancer is suspected.

Secondary care clinicians across London should also follow these guidelines when symptoms suggestive of cancer are identified in other care pathways and upgrade referrals in line with *Going further on cancer waits*. This would ensure an early referral to cancer specialists is made once cancer is suspected, thus avoiding potential delays in establishing a definitive diagnosis by non-oncologists. Two-week referral offices should ensure that upgraded referrals are treated with the same rigour as those sent in by a GP. Clear frameworks for communicating with patients' GPs following such referrals should be developed and adopted across all provider networks. Additionally, results negative for cancer should also be communicated back to the requester.

### 7.3.4 Specialist cancer diagnostic teams

A central theme of the *Cancer Reform Strategy*<sup>40</sup> is that care should be provided as close to home as possible. However, most cancer patients recognise that they may have to travel to see a specialist team to receive the highest possible quality of care, especially for complex investigations or treatments.<sup>41</sup> For example, in some

<sup>&</sup>lt;sup>38</sup> NHS Improvement, Breakthrough Breast Cancer, National Cancer Action Team. *Going further on cancer waits: The symptomatic breast two week wait standard, a guide to support implementation,* 2009.

<sup>&</sup>lt;sup>39</sup> Department of Health, Going further on cancer waits, 2008

Department of Health, Cancer Reform Strategy, 2007

<sup>&</sup>lt;sup>41</sup> Department of Health, Cancer Reform Strategy, 2007

instances GPs may strongly suspect cancer and therefore it is important that patients have rapid access (two-week referral) to specialist diagnostic services and teams.

Whilst specialist cancer diagnostic teams are an integral part of a multidisciplinary therapeutic team, they are more than the routine team in place for seeing a standard new patient referral. Organised by tumour type, they have the expertise to diagnose cancer accurately and rapidly. Specialist cancer diagnostic teams should operate to the same standards across London provider networks. Where possible, and where necessary, these teams should integrate seamlessly with general diagnostic activity, providing all the necessary investigations in one visit and results on the same day.

There is a need for specialist diagnostic teams to be established across London to expedite an accurate diagnosis and any subsequent referral to the most appropriate team. The specialist cancer diagnostic team must appreciate all of the different imaging technologies to accurately interpret findings and recommend the optimal immediate diagnostic and staging pathway. Specialist cancer diagnostic teams should be able to engage other imaging modalities without patients having to return to a GP for these investigations to be ordered. These teams can seamlessly place patients onto a fast-track pathway which has the potential of reducing the time to treatment.

### 7.3.5 Service provision

Access to high quality diagnostics is essential at all stages of the patient pathway and all diagnostics should be commissioned to defined, common standards across London and quality assured. This should also include those commissioned from private providers. Service provision would require expert commissioning advice provided by cancer commissioning networks coupled with the spread of best practice and enabled by joint governance.

Whatever the route of referral, there should be rapid access to diagnostic teams in the provider network linked to multidisciplinary teams, and mapped to clinically effective patient pathways which cross current organisational boundaries. A networked diagnostic team approach is recommended and GPs should be involved. For example, the *Report of the Second Phase of the Independent Review of NHS Pathology Services in England* recommends that pathology networks should be developed and that each consolidated network should have a single integrated management structure. Putting these recommendations into action would significantly improve pathology services for cancer patients.

There is a need for rapid access to specialist diagnostics and staging investigations, for example PET-CT scanning (see section 9.10). Timely access should be standardised across London. Additionally, it is anticipated that the role of molecular diagnostics, which detects abnormalities within genes, gene expression and protein markers will expand rapidly. Therefore rapid access from diagnostics to molecular marker teams would be required.

<sup>&</sup>lt;sup>42</sup> Department of Health, Report of the Second Phase of the Independent Review of NHS Pathology Services in England, Chaired by Lord Carter of Coles, 2008

Provider networks should establish protocols to reduce the number of unnecessary repeated tests in secondary care, which occur as a result of variations in quality, as these can delay diagnosis and treatment for patients, simultaneously increasing costs and putting pressure on diagnostic services.

A stable and secure mechanism for rapid sharing of data, images and results across a better coordinated provider network is important for a timely diagnosis and reduced duplication of tests. Consideration should be given to the use of electronic referrals, particularly from secondary to tertiary care, as these can reduce the missing information on referrals and lessen delays along the pathway. Good practice in the process of ordering, managing and tracking tests and test results should be identified and reviewed in primary and secondary care.<sup>43</sup>

## **Key recommendations:**

London GPs should have rapid access to diagnostics for initial assessment to exclude or confirm a diagnosis of cancer. Investigations and the return of results should be within one week.

The accuracy of referrals to secondary care should be improved and clear protocols for acting on the receipt of abnormal results in secondary care should be established to reduce delays.

Specialist cancer diagnostic teams should be strengthened to expedite an accurate diagnosis.

Compatible IT and imaging systems with data sharing capabilities are important to provide a timely diagnosis.

### 7.4 Effective screening programmes

To obtain good population coverage and high uptake of screening programmes it is essential that there is:

- High awareness and understanding of the national screening programmes
- Improved access and effectiveness of national screening programmes
- A robust call and recall system(s) to coordinate the programmes.

### 7.4.1 Awareness and understanding of screening

There should be a London-wide approach to improving uptake rates of screening programmes and addressing inequalities in uptake must remain a priority. It is also necessary to use targeted interventions, especially for those groups that are currently least likely to take-up invitations for screening tests. This could be achieved by providing good quality, reliable information on screening services tailored to suit the needs of the local community.

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<sup>&</sup>lt;sup>43</sup> National Patient Safety Agency, *Delayed diagnosis of cancer*, 2010

It is important that awareness and understanding of all aspects of screening programmes are raised through engaging with local communities and it is essential to ensure that information on screening programmes is kept up-to-date. With reference to breast screening, a recent review found that screening may result in some women getting a cancer diagnosis even though their cancer would not have led to death or sickness. 44 However, a recent study found that the benefits of the breast screening programme do outweigh the harms and a substantial and significant reduction in breast cancer mortality was associated with the screening programme in England. 45

## Evidence of outcomes: increasing breast screening coverage through tailored information

A project was undertaken at Central and East London Breast Screening Service (CELBSS) in conjunction with Tower Hamlets PCT to increase breast screening uptake rates amongst British and Bangladeshi women aged between 50 and 70. Communication that was clear, personal and positive was developed to target each group of women to explain the importance of screening. The local community was engaged through media campaigns and a free bus service was provided to take women to and from their screening appointments. The project resulted in an increased coverage rate from 54% to just under 64%.

There is a lack of data on the characteristics of those people who do not attend screening programmes and until these are known it would be difficult to greatly increase uptake. The London Social Marketing Unit (LSMU) has undertaken a cancer screening audience identification and insight programme across London to understand the reasons why different audiences fail to respond to an invitation for cancer screening. Commissioners should use the programme's results to develop interventions to increase uptake of invitations to screening and implement these across London in accordance with the results of local equity audits.

The NHS London Screening Improvement Team is currently working with PCTs across London to develop action plans to help improve uptake rates of breast cancer screening. Assessment templates have been developed for PCTs to obtain an understanding of the demand and capacity of the breast screening service in their area and of how they meet best practice standards in the following areas:

- Data flows and quality
- Management of the breast cancer screening service
- Active promotion of screening of eligible women

<sup>&</sup>lt;sup>44</sup> Gøtzsche, PC, and Nielsen, M, 'Screening for breast cancer with mammography', *Cochrane Database of Systematic Reviews*, 2009

<sup>&</sup>lt;sup>45</sup> Duffy, S, et al. 'Absolute numbers of lives saved and overdiagnosis in breast cancer screening, from a randomised trial and the Breast Screening Programme in England', *Journal of Medical Screening*, 2010; 17: 25-30

### Reporting requirements.

These assessments should be transformed into robust action plans for commissioners. It is important that they are completed and that they meet the performance management requirements defined by NHS London. Additionally, commissioners should work with the NHS London Improvement Team to develop a best practice examples database that can be shared across London.

### 7.4.2 Improving access and existing screening facilities

Screening facilities should be in accessible locations with extended opening hours, flexible in agreeing and changing appointments, and situated in the community where possible and where appropriate. Consideration should be given to providing mammographic breast cancer screening and post-treatment follow-up and surveillance in a community setting. This would allow women to access mammography at a screening service of their choice at any one of the multiple sites across London while maintaining all of the NHS Breast Screening Programme standards for mammography and image reading. In addition, improving travel plans<sup>46</sup> for existing screening facilities could go some way to increase the uptake of programmes.

The London Specialised Commissioning Group (SCG) has undertaken a review of breast screening services across London and recommended that the call and recall offices of the Breast Screening Programme are consolidated into a smaller number. This would enable flexible appointments for women and go some way to increasing access. It would also combat the problems of GP catchment areas causing patients to be missed or called to screening services in the wrong borough. This consolidation should be implemented by the London SCG.

There is also a need to improve the call and recall systems for the cervical cancer screening programme and it is recommended these also be consolidated from the current number of 11. Consideration should be given to providing a central booking service for community clinic sessions. This may attract the younger female London population and increase uptake. Similarly, with the challenge of ensuring a 14-day turnaround time for results, laboratories could be consolidated, again bringing about cost-effectiveness improvements for commissioners. This also has the advantage of greater standardisation of reporting for women and preparing the capital for likely developments in the next few years for example, the inclusion of human papillomavirus testing into the programme.

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<sup>&</sup>lt;sup>46</sup> A travel plan is a package of measures to encourage the use of alternatives to single-occupancy car-use. Plans can include a commitment to improve cycling facilities or a dedicated bus service. Travel plans can offer real benefits such as relieving local parking or congestion problems or improving public transport connections across the area.

### 7.4.3 Introduction of new technology

New technologies should be used where appropriate for efficient screening tests and quick turnaround times. Currently, all six breast screening services have plans in place for screening through digital mammography in line with the *Cancer Reform Strategy*'s commitment. The second annual report of the strategy highlighted that the target implementation date for this was 2010 in preparation for the age extension to begin; this should now be a high priority. This would provide commissioners with the opportunity to look at the infrastructure of the screening programme and consider where suitable imaging services may have spare capacity that could potentially be available for screening. This would bring high quality screening services closer to women as well as the having advantage of collocation with symptomatic services. Digital mammography can improve the accuracy of test results and allow the transfer of images between clinicians across providers. It is also cost effective with reduced chemical usage, film and printing. The use of digital mammography would benefit all screened women, not just those who are symptomatic.

The introduction of liquid based cytology has led to a reduction in the number of repeat cervical screening tests for women and a quicker return of results. The recent ten-site pilot (which included two sites in London) working to ensure that results are returned to women within 14 days of being screened has been successful.

Achieving a 14-day turnaround time for results of cervical screening is a Vital Sign (VSA15) in the *NHS Operating Framework* and is to be achieved by 2010.<sup>48,49</sup> The Department of Health and the NHS Cervical Screening Programme have published guidance to help commissioners review their service and achieve this target.<sup>50</sup> In particular commissioners should consider:

- Better use of technology
- More advanced biomedical scientist practitioners in cervical cytology
- Posting results letters by first class mail
- Reconfiguring laboratories to make them more efficient
- Using larger call and recall offices to reduce variation in local practices, cut turnaround times and allow better facilities.

### 7.4.4 Improving the accuracy of patient lists

Many London boroughs have high levels of population mobility. A high proportion of the London population moves in the three year interval between screens and often people do not register with a new general practice. List cleaning should be made an

<sup>&</sup>lt;sup>47</sup> Department of Health, Cancer Reform Strategy, achieving local implementation – second annual report, 2009

Department of Health, Cancer Reform Strategy, achieving local implementation – second annual report, 2009

<sup>&</sup>lt;sup>49</sup> Department of Health, *The NHS Operating Framework for England 2010/11*, 2008

<sup>&</sup>lt;sup>50</sup> Department of Health and NHS Cervical Screening Programme, *NHS Cervical Screening Programme: Achieving a 14 day turnaround time for results by 2010*, 2008

ongoing priority with PCTs and GPs. Sufficient resources would be needed to be identified so that GP lists can be validated and kept up-to-date in order for the correct population to be called. Exeter database systems, which provide lists of people to be called to screening services, should be linked across regions in order for patients to be tracked in screening programmes.<sup>51</sup> This would also enable people accessing care to be monitored.

General improvements in data and data systems are required. A standard IT system or systems able to communicate with each other to support call and recall centres are needed to replace the range of systems that provide different lists of patients to be screened. A standard IT system would also help to overcome challenges such as high turnover of GP patient lists due to London's mobile population. Additionally, evidence from the diabetic retinopathy screening programme suggests that the use of electronic validation greatly improves the accuracy of patient lists.<sup>52</sup>

### 7.4.5 Expansion of screening programmes

Expansion of screening programmes would increase the proportion of the London population who are eligible to be screened. The Cancer Reform Strategy has committed to increasing breast screening to nine screening rounds for women between 47 and 73 years with a round length (interval between screens) of three years and a guarantee that women would have their first screening before the age of 50. This has been reiterated as a Vital Sign (VSA09) in the NHS Operating Framework.<sup>53</sup> Full implementation is expected by the end of 2012.

Bowel screening is currently offered to men and women aged 60 to 69, with a test kit being sent out to participants every two years. This will be expanded from 2010 to include men and women aged 70 to 75, with people over 75 being able to request a kit every two years. By the end of 2010, a decision will be made on whether to extend the offer to people in their fifties.<sup>54</sup>

As a result of the recent Advisory Committee on Cervical Screening (ACCS) review, the starting age of screening for cervical cancer will not be lowered. However, guidelines have recently been published for primary care on young women who present with persistent gynaecological symptoms. 55 Commissioners across London should comply with and implement this national guidance.

Although there is no national programme for prostate screening, men may be tested through the Prostate Cancer Risk Management programme. Commissioners should ensure that GPs are aware of and are making use of the information provided by this programme and should ensure that laboratories providing tests are to the national standard.

<sup>&</sup>lt;sup>51</sup> The Exeter system is a database of all patients registered with an NHS GP in England and which

also provides the patients listed to be called for NHS screening programmes.

52 English National Screening Programme for Diabetic Retinopathy, *Guidance on Failsafe in the* Diabetic Retinopathy Screening Programme, 2008

53 Department of Health, The NHS Operating Framework for England 2010/11, 2008

<sup>&</sup>lt;sup>54</sup> Department of Health, Cancer Reform Strategy, 2007

<sup>&</sup>lt;sup>55</sup> Department of Health, Clinical Practice Guidelines for the assessment of young women aged 20-24 with abnormal vaginal bleeding, 2010

Expanding screening programmes, population growth and improved uptake and coverage of screening will put increasing pressure on screening facilities. Forecasting should take place and efforts should be made to understand increasing demand to ensure that services can meet it. It is recommended that service provision be extended to help with the potential increase in demand. Operating hours could be extended, for example, but this would have both financial and workforce implications.

### 7.4.6 Targeted screening and enhanced surveillance

Guidelines published by the National Institute for Health and Clinical Excellence (NICE) and the National Collaborating Centre for Primary Care (NCCPC) clearly set out how health professionals should identify and care for women who are at high risk of developing breast cancer because of a history of the condition in their family (familial breast cancer).<sup>56</sup>

Work is currently being carried out nationally by a working party of the Advisory Committee on Breast Cancer Screening (ACBCS). It is due to report its findings in Summer 2010 and final recommendations for screening higher-risk groups under the NHS Breast Screening Programme (NHS BSP) will be made by the ACBCS. NHS BSP screening units in London and across England should therefore expect to receive guidance on appropriate screening for women at an increased risk of breast cancer.

The London Specialised Commissioning Group (SCG) is currently undertaking work to develop a pathway for higher risk women and it is recommended that this is commissioned across London.

Some data suggest that certain population groups might have a genetically increased risk of developing specific cancers. For example, some black African women have a higher risk of developing more aggressive types of breast cancer and at a younger age than the age of entry for the NHS screening programme. There is a need to explore the potential benefits of offering enhanced surveillance to these groups at an earlier age to assess whether earlier detection would lead to better outcomes. If benefits can be highlighted, protocols for identifying patients who have a high genetic risk of developing certain cancers with referral pathways to appropriate screening units should be in place to improve consistency across London.

## Evidence of outcomes: increasing public understanding through tailored information

At an African and Caribbean information day, Breast Cancer Care used a range of sources to highlight breast cancer in black and minority ethnic (BME) women and the significantly poorer outcomes experienced by this group. Information on the benefits of screening and early diagnosis was successfully communicated to African and Caribbean women in London and the south east

<sup>&</sup>lt;sup>56</sup> NICE and NCCPC, Familial breast cancer. The classification and care of women at risk of familial breast cancer in primary, secondary and tertiary care, 2006

region which resulted in an increased level of understanding amongst this group of women.

Targeted screening, or surveillance, might have a useful role to play in conditions known to be pre-cancerous, such as Barrett's oesophagus, at-risk groups for hepatocellular carcinoma, or in people with certain genetic predispositions to cancer, such as Lynch syndrome.

### **Key recommendations:**

Commissioners should ensure that their local population, and individual groups in the population, are aware of and understand the benefits of cancer screening programmes.

Access to screening programmes and the accuracy of patient lists should be greatly improved.

Screening programmes should be expanded and new technology introduced where appropriate and necessary.

Consideration should be given to targeted screening of some discrete populations.

## 7.5 Understanding and addressing health inequalities

The National Cancer Action Team has pledged to continue to reduce inequalities in cancer care through the National Cancer Equality Initiative (NCEI).<sup>57</sup> To address health inequalities and in particular, inequalities in accessing care and the early diagnosis of cancer, focused action would need to be taken by primary care professionals to improve uptake of services at the beginning of the care pathway. The National Cancer Equality Initiative has recently published guidance to promote greater equality, identifying a range of activity to be taken forward nationally as well as activity to be considered locally.<sup>58</sup>

The methods described in this health inequalities section are to be used when planning all types of service delivery described in this chapter. The methods described aim to help commissioners to plan and deliver a service that understands and meets local need.

### 7.5.1 Understanding local need

Understanding the demography of local populations, the characteristics of different groups and their healthcare needs at both regional and local levels is crucial when

<sup>57</sup> National Cancer Action Team, *National Cancer Equality Initiative: Principles and Practical Guidance in Good Equality Working*, 2009

Department of Health, Reducing cancer inequality: evidence, progress and making it happen: a report by the National Cancer Equality Initiative, 2010

planning, commissioning and delivering all healthcare services. This information will inform service developments at regional and local levels that appropriately respond to local needs. This message has been reinforced by national policies and strategies, such as:

- Joint Strategic Needs Assessments (JSNA), which seek to identify the health and wellbeing needs of a local population. The issues identified by a JSNA would inform the priorities and targets set by the Local Area Agreement and the delivery agreement for the Sustainable Community Strategy.
- The Commissioning Framework for Health and Wellbeing which identifies eight steps to effective commissioning, including understanding the needs of populations and individuals.

For commissioners, the systems, tools and processes are in place to take this work forward.

**Optimising data collection:** It is necessary to optimise data collection to enhance the understanding of existing inequalities. Through analysis of data, commissioners may gain an understanding of:

- Who lives in the local area.
- Future forecasts and how the population will change in the next five to ten years
- Where people live in the local area and the population flows
- Patterns of deprivation, along with a breakdown of the local population groups who reside in those areas
- Which cancer services are being used locally
- Uptake of local screening services.

It is important that the above data are understood in terms of distribution of age, gender and ethnicity in the local area.

**Knowledge of local area:** By drawing on knowledge of the local area and further engagement with key community groups it is important to assess the particular challenges each population or group might face, in awareness of the signs and symptoms of cancer and access to services.

**Clinical evidence:** Commissioners should consider clinical evidence to understand whether:

- Any of the groups living in the local area have a higher incidence rate of developing cancer
- Those with a genetic risk of developing cancer have been identified
- A clinically effective pathway is in place for them.



## 7.5.2 Raising awareness

The case for change highlights that people living in deprived areas have lower awareness of cancer signs and symptoms and lower expectations of positive health outcomes. This can lead to later presentation to primary care and lower uptake of screening opportunities. In developing communication campaigns to raise awareness, PCTs have the opportunity to tailor and target messages in deprived areas to reach these people.

## Evidence of outcomes: improving early presentation with cancer symptoms in disadvantaged communities<sup>59</sup>

The Improvement Foundation used the Healthy Communities approach to tackling health inequalities in the Earlier Presentation of Cancer Symptoms National Improvement Programme commissioned by the Department of Health. The programme focused on earlier presentation of breast, lung and bowel cancers in 19 deprived communities in England through engagement with the local community in a variety of venues, including bingo halls, mosques and temples. Games, songs, plays and poems were used to encourage community members to present early with symptoms suggestive of cancer. Clinicians in primary care were encouraged to see their patients quickly and refer them speedily and appropriately.

Results include an increase in the number of urgent two-week referrals and an increase in the proportion of new cancer cases diagnosed through the urgent two week referral route (from 43% to 51%) for bowel, lung and breast.

The results demonstrate that the public can understand and react to possible symptoms of cancer when the methods of communication are designed to fit local culture and norms and that general practice can respond quickly.

Improving health literacy by ensuring that information is tailored to the needs of the local community has been identified as an important part of tackling health inequalities. This needs to be coupled with ensuring that services are based on a thorough understanding of what people, especially the most disadvantaged, want, and that when they reach out to people this is done in a way which is appealing and feels relevant. 60 For example, the Beating Bowel Cancer national charity works to highlight awareness of signs and symptoms, promote early diagnosis and encourage open access to treatment for those affected by bowel cancer. Campaigns include 'Don't sit on your symptoms' and the annual 'Loud Tie Campaign'. 61



<sup>&</sup>lt;sup>59</sup> Lyon, D. et al., 'Improving the early presentation of cancer symptoms in disadvantaged communities: putting local people in control, *British Journal of Cancer* 2009;101, 549-554 <sup>60</sup> Department of Health, *Health Inequalities: Progress and Next* Steps, 2008

<sup>&</sup>lt;sup>61</sup> See <www.beatingbowelcancer.org>

# Evidence of outcomes: increasing uptake of screening by assisting those with low literacy or unfamiliarity with English

Tower Hamlets PCT developed talking invitations for women who cannot read or use a spoken-only dialect such as Sylheti. A pilot was implemented in two GP practices to call women before they receive their invitations and encourage them to attend their screening appointments, helping those who cannot read to make an informed choice about attendance. Support and translation is also provided through the Tower Hamlets PCT health advocates service at the static breast screening unit. Tower Hamlets has seen a considerable improvement in its screening uptake rates.

Information leaflets and other materials from the NHS breast, bowel and cervical screening programmes have been produced in various languages. It is important that these are available to local populations. These should be used as parts of a targeted outreach programme working with key communities to raise awareness of the signs and symptoms of these types of cancer. Working with existing community and voluntary groups is often a good way to establish good relationships with communities.

Many areas in the past have assumed that a local cancer service will address inequalities. This model of care recommends that only targeted action focusing on a particular community can yield positive results.

## 7.5.3 Reducing inequalities in access to services

There should be equitable access to services for all population groups. *High Quality Care For All* pledged to tackle inequalities in primary care by establishing new GP practices in the areas of the country with the fewest primary care clinicians and the greatest health needs. *Liberating the NHS* has pledged that the Department of Health will incentivise ways of improving access to primary care in disadvantaged areas.<sup>63</sup>

Engagement with key community groups that are known not to access services can help commissioners to further understand access issues. This can be key to reducing late presentation and transforming uptake rates of screening programmes. For those areas that have a large number of residents who have English as a second language, information materials should be culturally appropriate and translated into the main community languages.

For those people who have difficulty reading, or who have visual impairment, written information materials should be available in large print format or Braille. Information resources to support this recommendation are already available at a national level and would be free and immediately available to commissioners and providers in London. This includes material for women with learning disabilities and their carers. Additionally, use should be made of audio CDs and community radio stations.

63 Department of Health, Equity and excellence: Liberating the NHS, 2010



<sup>62</sup> Department of Health, Cancer Reform Strategy Equality Impact Assessment, 2007

Access to services for hard-to-reach groups, such as those in secure establishments and those who do not regularly receive invitations should be improved. The National Cancer Screening Programmes Team and representatives from commissioning, mental health and prison health organisations have developed a model for those in secure establishments, such as prisons and secure mental health hospitals. The model takes a pragmatic approach to screening the target populations in an efficient and effective way without compromising integrity and safety. The Bowel Cancer Screening Programme is currently piloting this model with some prisons in London to ensure that those eligible still have access to this service. If the pilot proves to be successful, plans should be developed to implement this across London.

## 7.5.4 Ensuring that cancer services meet local needs

Knowledge of the local population is important to ensure that services commissioned meet local needs. For example, evidence shows that women with learning disabilities have a low uptake rate of some cancer screening programmes. <sup>64</sup> There should be guidelines in place to enforce information sharing between GPs and other primary care colleagues to raise their awareness when working with this client group. This information can then be used to inform screening services.

# Evidence of outcomes: increasing access to breast screening for women with learning disabilities

In partnership with the Department of Health's Pacesetters programme, Walsall Integrated Learning Disabilities Service has successfully addressed the historically low take up of breast screening by women with learning disabilities.

Through a combination of user engagement and raising staff awareness of the needs of this group, it has improved screening rates from 62% to 100% for those women who are able to be screened. When the project began in August 2006, only 17 learning disabled women had attended breast screening in recent months. By August 2009, this had risen to more than 140 women who attended screening as part of a rolling programme.

The programme was a positive experience for the women involved. It was also rewarding for radiographers, who had found it difficult to work with people with learning disabilities. Their successful collaboration with nurses for those with learning disabilities, and the other strategies used in the breast screening pilot, have been extended to increase the uptake of cervical screening and the bowel cancer screening programme for the over 60 learning disabled population.

To prevent the inequalities gap widening, rapid progress needs to be made. The Department of Health's *Health Equity Audit: a guide for the NHS* is aimed at PCT chief executives, directors of commissioning and public health, and SHA directors of

<sup>&</sup>lt;sup>64</sup> Hall, P. et al., 'Cervical screening for women with learning disability', *British Medical Journal*, 1999; 318: 536.

public health and performance.<sup>65</sup> It provides guidance to support achievement of the Priorities and Planning Framework requirement to conduct Health Equity Audits to inform NHS service planning and commissioning.

Commissioners should make use of the Department of Health's self-assessment tool and undertake Health Equity Audits to identify how fairly services are distributed in relation to the health needs of different groups and areas, and provide services relative to need. The overall aim is not to distribute resources relative to health need rather than equally, otherwise inequities occur that lead to health inequalities.

## 7.5.5 Evaluations and targets for improvement

The health inequalities gap between the most deprived groups and the general population remains significant and more needs to be done. To support the further improvement on reducing cancer inequalities, a series of equality metrics have been suggested by the NCEI Advisory Group. 66 It is recommended that commissioners monitor implementation of targeted interventions by using these quality metrics to measure the impact on cancer inequalities.

# **Key recommendations:**

Commissioners should understand the different factors that contribute to health inequalities in their local area.

Commissioners should routinely collect patient data by age, gender, ethnicity and disability to understand the uptake of cancer services. This data should be used by commissioners to identify health inequalities that should be addressed locally.

Plans to reduce health inequalities should be developed by taking focused action and using targeted interventions.

Data collection on one year survival rates would act as a measure for success in this area.

<sup>66</sup> Department of Health, Reducing cancer inequality: evidence, progress and making it happen: a report by the National Cancer Equality Initiative, 2010

<sup>&</sup>lt;sup>65</sup> Department of Health, *Health Equity Audit: a guide for the NHS*, 2003

# 8. Common cancers and general care

#### 8.1 Introduction

This chapter considers common cancer surgery (breast, lung, colorectal, bladder and prostate), the issues specific to haematological and skin cancers, the non-surgical treatments for these and rarer tumour sites and other general areas relating to all cancers. There are specific issues relating to specialist multidisciplinary teams and specialist radiotherapy provision that are addressed in the proposed model of care for rarer cancers (chapter 9).

The case for change highlights that variation in practice across London is leading to variation in the quality of services offered to patients. This variation is in the use of surgical techniques, average lengths of hospital stay and the use of the day case setting where clinically appropriate.

The model of care proposes the provision of care outside of hospital settings where possible, but recognises the case to provide complex investigations and treatments in only a few centralised settings. This would ensure that services are high quality and as safe as possible.

To enable implementation of this model and ensure services meet patient needs and expectations, processes should be in place to ensure efficient access to hospital services when necessary.

All non-hospital based services should be integrated with other services in the provider network and appropriate communication systems should be in place to support this. Patients should have easy access to support, information and advice at every stage of their pathway to enable self-management and care outside of hospital where possible. Where services are centralised, consideration needs to be given to access for patients so that centralisation neither puts unnecessary strain on patients, nor increases inequalities.

## 8.2 Common cancer surgery

The case for change highlights a significant number of low volume providers of common cancer surgical services. For tumour types where there are low volume providers, commissioners should consolidate surgical services. This is based not merely on the relationship between volumes and outcomes, but on the wider ambition to provide, and continuously improve, high quality services to all Londoners. In developing the proposed model of care for common cancer surgery, the following principles have therefore been taken into account:

- 1. It is the ambition of London's NHS to provide consistent world-class services.
- 2. The integration of research with clinical care is essential for the continuous improvement in the provision of high quality services. Consolidation of services would improve the research environment.



- Consolidating services reduces duplication of effort and equipment and dilution of expertise.
- 4. NICE Improving Outcomes Guidance (IOGs) recommends minimum volumes for a variety of services. Where services have been rationalised, London should aim to go beyond the minimum volumes laid out in NICE IOGs.
- 5. London has a younger population than the national average and should therefore aspire to exceed recommended national minimum volumes.
- The population served by London's NHS is swelled beyond the eight million people resident within the metropolitan area by inflows of patients from outside the capital.

Where recommended surgical volumes are found in the following sections they are based on expert clinical advice, which has taken into consideration all of these factors.

#### 8.2.1 Breast cancer

Breast cancer affects a significant number of women over the age of 70. There is increasing evidence that poorer survival rates in English breast cancer patients compared to their European counterparts are due to less aggressive treatment for patients in this age bracket.<sup>67</sup>

The age of the patient should not be a deciding factor for the treatment plan by the clinical team. The fitness of the patient and the presence or otherwise of comorbidities is of far greater importance when making treatment recommendations. The issues of patient fitness and co-morbidities should become a routine part of the multidisciplinary team discussion.

Breast cancer produces high volumes of surgery. Low complexity breast surgery should be available locally to patients, as a day case where clinically appropriate. Low complexity breast cancer surgery should take place in elective surgery settings, either in dedicated centres or acute hospitals.

# Evidence of outcomes: increasing day case breast cancer surgery rates

King's College Hospital changed its breast cancer surgery service over two years, increasing its rate of day surgery to over 90% of cases. This has been achieved through implementing system changes and changes in surgical practice. The latter include ceasing drain usage and seroma aspiration, using advanced suturing techniques and applying aggressive management of wound problems.

System changes include carrying out robust pre-assessment checks, promoting enhanced working between the breast team and day surgery, and

<sup>&</sup>lt;sup>67</sup> Møller, H. et al, 'Breast cancer survival in England, Norway and Sweden: a population-based comparison', *Int J Cancer*, 2010 (epublication ahead of print)

conducting formalised telephone questionnaires post surgery. The patient experience has improved, and is validated through externally administered focus groups rather than satisfaction surveys.

The 23-hour stay model for mastectomy without reconstruction described above has become the norm in other parts of the UK. The model was adopted by one Birmingham trust following shared learning with King's College Hospital. Following successful early testing the model has been rolled-out across the pan-Birmingham cancer network. The patient's personal circumstances must be taken into account when planning surgical interventions on the 23-hour model. It must be ensured that appropriate support arrangements are fully in place prior to discharge.

The breast IOG states a recommended minimum volume of 30 procedures per surgeon per year. 68 As multidisciplinary teams should not rely solely on one surgeon, each multidisciplinary team should be advising at least 60 procedures a year.

The IOG states that multidisciplinary teams should see in excess of 100 new cases a year. The reasons for this are:

- Research evidence of benefit from specialised multidisciplinary care.
- Research evidence of benefit from a surgical caseload above 30 per surgeon.
- The belief that this level of workload is operationally cost-effective for the
  deployment of a suitable group of specialists which functions as a team. It is likely
  to be neither feasible nor cost-effective for a group of specialists to meet weekly
  and invest time and resources coordinating care if the number of new breast
  cancer patients falls below two per week.
- The belief that this level of workload is necessary to sustain the collective expertise of the team.
- Professional consensus in the Association of Breast Surgery at BASO (British Association of Surgical Oncology) clinical guidelines of the desirability of such a minimum figure.

The IOG recommends a minimum catchment population of 200,000. The demography and geography of the capital mean that London providers should serve populations of more than 300,000. This model of care does not propose an optimum number of providers for low complexity breast cancer surgery. Instead, providers should be subject to an accreditation scheme (see section 10.5). The need to gain accreditation would encourage low volume providers to grow or exit the market and in this way the optimal level of providers would be achieved. Low volume providers are likely to be the units that are not involved with breast screening. Screening units generally have the expertise in radiology, pathology and surgery that is essential for modern diagnosis and treatment.

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<sup>&</sup>lt;sup>68</sup> NICE, Improving outcomes in breast cancer: manual update, 2002

All patients undergoing mastectomy should have the opportunity to discuss their breast reconstruction options and have immediate breast reconstruction if appropriate. <sup>69</sup> The *case for change* reveals that there is variation in immediate reconstruction practice across London. Inclusion of an oncoplastic surgeon in the breast surgery team improves availability of immediate reconstruction within waiting time targets but this is reliant on the team's operating capacity.

Not all immediate breast reconstructive surgery can be offered by a surgeon trained in oncoplastics. Complex immediate breast reconstructive surgery, specifically free flap surgery, should be undertaken in specialist centres with dedicated plastic surgery and rehabilitation teams. Rapid-access pathways must be in place across provider networks between providers offering reconstructive surgery and those who do not provide the full range of breast cancer surgery options.

Sentinel node biopsy should be offered to all women who are eligible. A combination of patent blue dye and technetium colloid should be used to maximise the likelihood of identification of the sentinel node. Technological advances, such as intra-operative sentinel node assessment, should be adopted across the capital as soon as they are shown to be worthwhile and affordable.

# Evidence of outcomes: reducing bed days with sentinel lymph node assessment<sup>70</sup>

This technology tests metastatic spread of breast cancer cells to the sentinel lymph nodes intra-operatively, with results available within 30-45 minutes. If metastases have occurred, surgery can be continued to remove the remaining lymph nodes. Traditionally, histopathological results are not available until after surgery, and if positive, patients have to be readmitted for completion of lymph node removal during a second surgical procedure.

Initial findings suggest the potential to avoid approximately 8,000 second surgical procedures with hospital lengths of stay of one to six days. This would equate to a saving of between 8,000 and 48,000 bed days in the UK a year as well as improving the patient experience by them avoiding a second operation.

### **Key recommendations:**

A 23-hour stay model for mastectomy without reconstruction should be available locally to patients, where appropriate. This should take place in dedicated elective surgery settings.

Providers should become subject to an accreditation scheme to encourage low

<sup>&</sup>lt;sup>69</sup> Association of Breast Surgery at BASO, *Surgical guidelines for the management of breast cancer*, 2009

<sup>&</sup>lt;sup>70</sup> Stollar, H. and Cawthorn, S., *Breast Lymph Node Assay Project: Rapid Intra-Operative Lymph Node Analysis for Breast Cancer Patients*, NHS Technology Adoption Centre, presentation, 2009

volume providers to grow or exit the market.

Intra-operative sentinel node assessment should be considered for all women and adopted as soon as the techniques are shown to be worthwhile and affordable.

All patients undergoing mastectomy should have the opportunity to discuss their breast reconstruction options and have immediate breast reconstruction if appropriate.

## 8.2.2 Lung cancer

Lung cancer is a common cancer treated infrequently with surgery because it is only performed on patients diagnosed with early stage disease. Despite decreasing lung cancer incidence rates in London, the procedure should become more common as early presentation and diagnosis improves.

One observational study cited in the lung IOG suggests that patients are more likely to survive if they undergo surgery in hospitals where more than 24 lung resections a year are carried out.<sup>71</sup> Evidence published since the IOG is that the best outcomes are achieved in centres performing more than 60 lung cancer resections per year. In those performing fewer than 60 it has been shown that outcomes are still significantly better if more than 20 lung cancer resections are performed a year.<sup>72</sup>

Part of the workload of a thoracic surgeon working with lung cancer is also to perform diagnostic and palliative procedures. Lung resection is complex surgery with high mortality and morbidity rates and providers should not rely on one surgeon alone. Providers should therefore perform at least 60 resections per year including diagnostic and therapeutic lung cancer surgery.

In 2007/08, two out of the total of seven providers in London performed fewer than 60 procedures. While there is no clear evidence for the minimum volume that providers should be treating, concentrating services is likely to provide a clinical environment that delivers best practice.

London commissioners should consolidate lung cancer surgery to five providers, each serving a population of more than two million. These five providers should be specialist centres. There is also an observed association between improved outcomes in thoracic surgical centres aligned to teaching facilities.<sup>73</sup>

Evidence from the national lung cancer audit suggests that rates of lung cancer surgery are lower in providers where multidisciplinary teams have limited input from

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<sup>&</sup>lt;sup>71</sup> NHS Executive, *Improving outcomes in lung cancer: The Manual*, 1998

<sup>&</sup>lt;sup>72</sup> Cheung, MC. et al., 'Impact of teaching facility status and high-volume centers on outcomes for lung cancer resection: an examination of 13,469 surgical patients', *Ann Surg Oncol.* 2009;16(1):3-13 
<sup>73</sup> Cheung, MC. et al., 'Impact of teaching facility status and high-volume centers on outcomes for lung cancer resection: an examination of 13,469 surgical patients', *Ann Surg Oncol.* 2009;16(1):3-13

thoracic surgeons.<sup>74</sup> Thoracic surgery should therefore provide input to all lung multidisciplinary team management recommendations in London.

## **Key recommendations:**

London providers should perform at least 60 resections a year including diagnostic and therapeutic lung cancer surgery.

London commissioners should consolidate lung cancer surgery to five providers, each serving a population in excess of two million. These five providers should be specialist centres.

Thoracic surgeons should provide input to all lung multidisciplinary team management recommendations in London.

## 8.2.3 Colorectal cancer

Non-complex colorectal cancer surgery should be available locally to patients. As with breast cancer, it should be provided in dedicated elective surgery settings. Patients should be offered the choice of surgery using laparoscopic techniques, where appropriate, and from October 2010 all colorectal multidisciplinary teams nationally must ensure that every patient suitable for laparoscopic resection is given this choice of treatment. If laparoscopic surgery is not available suitable onward referral arrangements would need to be in place.

All colorectal multidisciplinary teams in London should include at least one fully trained laparoscopic surgeon and should aspire to a minimum of two. This would prevent the overreliance on one individual when providing this choice of treatment to patients. Further training of some colorectal surgeons in London would be required to achieve this and there would be a lead time while surgeons are trained where robust clinical governance would be necessary.

The colorectal IOG recommends that surgeons should carry out a minimum of 20 procedures with curative intent each year. The IOG does not set volume requirements beyond the statement that a notional district general hospital with a catchment of 200,000 should expect to see 120 new cases a year.

As with breast cancer, the model of care does not propose an optimum number of providers for low complexity colorectal cancer surgery. Instead, providers should be subject to an accreditation scheme (see section 10.5). The need to gain accreditation would encourage low volume providers to grow or exit the market and in this way the optimal level of providers would be achieved.

Recent evidence strongly supports flexible sigmoidoscopy as the investigation of choice in patients with colorectal symptoms of a change in bowel habit and/or rectal

<sup>75</sup> NICE, Improving outcomes in colorectal cancer: manual update, 2004



<sup>&</sup>lt;sup>74</sup> The NHS Information Centre, *National Lung Cancer Audit 2009*, 2009

bleeding and no other symptoms, risk factors or anaemia. Flexible sigmoidoscopy should be substituted for total colonoscopy as appropriate. This would allow more procedures to be carried out at a lesser cost, with subsequent financial savings.<sup>76</sup>

The *case for change* outlines the apparent variation in the use of abdominoperineal excision (APE) and anterior resection for treatment of low rectal cancers. It is therefore essential that the appropriate surgery should be undertaken for low rectal cancers. Such surgery is facilitated by the use of preoperative MRI scanning, improved surgical techniques and greater use of preoperative downstaging radiochemotherapy.<sup>77,78</sup> All Londoners with low rectal cancer should have access to MRI directed surgery and preoperative downstaging therapy.

Every effort should be made to ensure that the appropriate surgery is undertaken for all patients with low rectal cancer. Where APE is deemed to be the appropriate operation, surgery must include that part of the levator muscles that envelopes the distal mesorectum plus the anal sphincter complex. It is also desirable that surgeons should learn to recognise the nerves that subserve erectile function during the perineal phase of the operation.

Management of locally recurrent colorectal cancers should be concentrated in fewer surgical hands. Each provider network should contain one specialist colorectal cancer centre for recurrent local surgery. There is a need in these centres for expert urology, neurosurgery, plastic surgery and occasionally orthopaedic surgery.

Some early rectal cancers may be best treated by trans-anal endoscopic microsurgery (TEMS). Demand for TEMS is low in London at present; however, the roll-out of the bowel cancer screening programme is likely to identify more patients with early cancers, and therefore the demand for TEMS is likely to increase.

"TEMS requires specially designed equipment which until recently had a high cost. TEMS also requires a surgeon who possesses advanced laparoscopic skills since it is essentially a form of laparoscopic surgery performed in a much more confined space [...]. The technique is therefore demanding and one of the problems is that the learning curve is steep because the number of cases is (or has been so far) rather small for surgeons to acquire technical expertise. Concentration of cases in certain centres would allow for easier accumulation of experience with the technique." <sup>79</sup>

The equipment for carrying out TEMS is expensive at around £60,000. Due to the high cost of equipment, and the need for accumulation of surgical expertise, TEMS services should initially be concentrated in the specialist colorectal cancer centres outlined above. Expertise in trans-rectal ultrasound is also a necessity for appropriate selection of cases for TEMS. As demand for TEMS increases, provider

<sup>&</sup>lt;sup>76</sup> Kent, A.J. et al., 'The use of symptoms to predict colorectal cancer site. Can we reduce the pressure on our endoscopy services?' *Colorectal Disease*, 2010: 12(2)

Mercury Study Group, Diagnostic accuracy of preoperative magnetic resonance imaging in predicting curative resection of rectal cancer: prospective observational study', *BMJ* 2006; 333: 779 Nagtegaal I. et al., 'Low rectal cancer: a call for a change of approach in abdominoperineal resection', *J Clin Oncol* 2005; 23 (36); 9257–9264

<sup>&</sup>lt;sup>79</sup> Papagrigoriadis S., 'Transanal endoscopic micro-surgery (TEMS) for the management of large or sessile rectal adenomas: a review of the technique and indications', *Int Semin Surg Oncol* 2006;3:13

networks should work with commissioners to determine what the best configuration of services is for their populations.

Enhanced recovery after surgery programmes should be adopted by all surgical and anaesthetic teams treating patients with colorectal cancer to improve care and reduce hospital length of stay (see section 8.7). The patient's personal circumstances must be taken into account when planning earlier discharge and it must be ensured that appropriate support arrangements are fully in place prior to their departure from hospital.

## **Key recommendations:**

Non-complex colorectal cancer surgery should be available locally to patients in dedicated elective surgery settings.

Patients should be offered surgery using laparoscopic techniques, where appropriate. All colorectal multidisciplinary teams should include at least one fully trained laparoscopic surgeon.

Providers should become subject to an accreditation scheme. The need to gain accreditation would encourage low volume providers to grow or exit the market.

All patients with low rectal cancer should have access to MRI directed surgery and preoperative downstaging therapy. The appropriate surgery should be undertaken for all Londoners.

Each provider network should contain one specialist colorectal cancer centre for recurrent local surgery.

Enhanced recovery after surgery programmes should be adopted by all surgical and anaesthetic teams treating patients with colorectal cancer.

## 8.2.4 Bladder and prostate cancers

The IOG for urological cancers states that patients with newly diagnosed, non-complex, bladder tumours should be treated by complete trans-urethral resection (TUR), which should be carried out by designated urologists in local units.<sup>80</sup>

Radical bladder and prostate operations are however complex surgical procedures. The IOG for urological cancers states that radical surgery should be provided by teams typically serving populations of one million or more, carrying out a cumulative total of at least 50 radical bladder and prostate procedures a year.

The case for change shows that in 2007/08 there was a significant number of low volume providers of prostatectomy and cystectomy. The case for change also shows that there is evidence of a relationship between surgical volumes and outcomes across all complex surgery, including complex urological procedures. While the optimal surgical volume for complex urological procedures is not known, there is

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<sup>&</sup>lt;sup>80</sup> NICE, Improving outcomes in urological cancers: the manual, 2002

evidence that the more concentrated the activity, the greater the benefit.<sup>81</sup> The general view among UK urologists is that minimum surgical thresholds should be set.<sup>82</sup> There will be a volume above which the benefits will be marginal and will be offset by logistical issues but there is no evidence of where this optimal point lies. Most clinical opinion and evidence would favour moving the median number of cases upward, which would necessitate concentrating services.

Given this evidence, and the principles outlined at the beginning of this section, complex bladder and prostate surgery should be commissioned from five providers for London, with each serving a population of at least two million. These providers should be specialist centres.

The treatment options available for men with newly diagnosed prostate cancer are much broader than they were previously. For example, NICE guidelines state that men with Gleason 3+3 disease should be offered active surveillance as a reasonable therapeutic option. There are also other treatment options that may be available and patients should be made aware of these options even if they are treated in a centre where they are not offered.

Clinical engagement has confirmed that the clinical consensus has shifted away from radical surgery for prostate cancer, making this procedure less common than previously. As such, services should be commissioned from providers seeking to carry out a minimum cumulative total of 100 radical procedures for bladder and prostate cancer each year.

Robotic-assisted laparoscopic prostatectomy needs a sizeable catchment population to make it cost effective. Equipment is expensive and there is currently no robust evidence showing that outcomes are better than those achieved by other procedures. Patients are, however, increasingly demanding robotic surgery. This is due, in part, to the perception that it is superior to other techniques. The current evidence suggests otherwise, with functional outcomes worse from robotic and laparoscopic surgery at present.<sup>83</sup> This variation may be ascribed to a surgeon learning curve, which would be lessened by concentrating services.

One London provider is currently setting up a robotic service linked to a research programme to measure outcomes. London's NHS should await at least the outcome of this trial before investing further in this area.

### **Key recommendations:**

Complex bladder and prostate surgery should be commissioned from five providers for London, with each serving a population of at least two million. These providers should be specialist centres.

Providers should seek to carry out a minimum cumulative total of 100 radical

Nuttall, M. et al., 'A systematic review and critique of the literature relating hospital or surgeon volume to health outcomes for 3 urological cancer procedures', *BJU Int.* 2004, 172(6 Pt 1):2145-52
 Nuttall, M. et al., 'Threshold volumes for urological cancer surgery: a survey of UK urologists', *J Urol.* 2004, 94(7):1010-3

<sup>&</sup>lt;sup>83</sup> Hu, J. et al., 'Comparative effectiveness of minimally invasive vs open radical prostatectomy', *JAMA* 2009, 14;302(14):1557-64

procedures for bladder and prostate cancer a year.

London's NHS should await the outcome of trials of robotic-assisted laparoscopic prostatectomy before investing further in this area.

## 8.3 Haematological and skin cancers

### 8.3.1 Haematological cancers

There have been numerous important national developments in the provision of care for patients with haematological malignancies in recent years. These initiatives provide for a detailed specification of the standards that need to be met for the care of patients with haematological cancers.

The NICE IOG states that:84

- All patients with haematological cancer should be managed by multidisciplinary haemato-oncology teams which serve populations of 500,000 or more
- Every diagnosis of possible haematological malignancy should be reviewed and interpreted by experts who work with local haemato-oncology multidisciplinary teams and provide a specialised service at network level. This is most easily achieved by locating all specialist haemato-pathology diagnostic services in a single laboratory.

The British Society for Haematology (BSH) has produced an updated guideline for use both by providers of this clinical care and by those who commission it.<sup>85</sup> The BSH approach has been to define levels of care that reflect the facilities and resources required to treat patients with haematological malignancies according to:

- The complexity of the treatment delivered
- The duration of anticipated neutropenia following chemotherapy
- In some instances, the rarity of the disease subtype.

The levels range from level 1, where chemotherapy should be delivered in an outpatient setting, through levels 2a and 2b, where treatment should be delivered as a day case and inpatient, respectively, to level 3, where complex chemotherapy should be delivered as an inpatient. Although these levels of care are described as distinct entities, provision of care should be flexible so that any patient can have access to appropriate components of the services across different levels when necessary. Providers of care for haematological cancers in London should adopt all of the recommendations made by the BSH.

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<sup>&</sup>lt;sup>84</sup> NICE, *Improving Outcomes in Haematological Cancers*, 2003

<sup>&</sup>lt;sup>85</sup> British Society for Haematology, Facilities for the Treatment of Adults with Haematological Malignancies – 'Levels of Care', 2009

## **Key recommendation:**

Providers of care for haematological cancers in London should adopt all of the recommendations made by the BSH in *Levels of Care*.

#### 8.3.2 Skin cancers

The skin cancer IOG states that patients with invasive skin cancer associated with a greater risk or rarity, such as malignant melanoma, should be managed by a skin multidisciplinary team. In London, these are usually based in major cancer centres with plastic surgery and other specialist tertiary services of relevance to skin cancer and should provide a service for a minimum population of 750,000.

The results of peer review will reveal the extent to which London centres comply with this guidance. Clinical engagement has revealed that while some specialist multidisciplinary teams are likely to be compliant, others might not be. Where services are non-compliant they should be consolidated. Melanoma services should be collocated with the delivery of systemic anti-cancer therapies to enable ongoing research into future treatments.

Commissioners and provider networks should address the issue of some GPs undertaking diagnosis and management of low-risk basal cell carcinomas when they are not adequately trained to do so. GPs should continue to be encouraged to develop an interest in managing these patients but should be appropriately trained to do so. Services should not be commissioned from GPs who have not been appraised and assessed. Provider networks should ensure that those GPs with an interest have access to training. Pathology alert systems should be considered to allow the identification of unaccredited GPs submitting samples for analysis.

In May 2010 NICE issued a partial update to the improving outcomes guidance relating to the management of low-risk basal cell carcinomas in the community.<sup>87</sup> Provider networks should ensure that all services are compliant with this renewed guidance.

## **Key recommendations:**

Services for invasive skin cancer associated with a greater risk or rarity, such as malignant melanoma, should be consolidated where they are not IOG compliant.

All GPs undertaking the management of basal cell carcinomas should be appropriately trained and accredited to do so.

<sup>86</sup> NICE, Improving Outcomes for People with Skin Tumours including Melanoma: the Manual, 2006 NICE, Improving outcomes for people with skin tumours including melanoma (update): the management of low-risk basal cell carcinomas in the community (2010 partial guidance update), 2010

## 8.4 Systemic anti-cancer therapy

## 8.4.1 Quality and safety

The National Confidential Enquiry into Patient Outcome and Death (NCEPOD) report raised concerns about the quality and safety of systemic anti-cancer therapy (SACT). The model of acute oncology has been proposed in response to these concerns.

The 2009 National Chemotherapy Advisory Group (NCAG) report identified a need to extend the availability of emergency assessment and treatment for cancer patients suffering side effects from systemic treatments.88 The NCAG report concluded that all hospitals with emergency departments should establish an acute oncology service to bring together the necessary expertise from emergency medicine, general medicine and oncology.

Policies and protocols should be in place for the oncological assessment of cancer patients who present at accident and emergency (A&E) with the symptoms of their disease or the side effects of SACT. These protocols should be readily accessible and cover managing complications seen in the emergency department (for example neutropenic sepsis), training senior and junior doctors from medical specialties in acute oncology, and processes for ensuring rapid referral and assessment (including treat-and-transfer, where appropriate) by an oncologist and other members of the acute oncology team. Each acute oncology team should have named permanent members of the rehabilitation professions and good links with palliative care.

Medicines to control the adverse symptoms of chemotherapy are now much improved. The use of symptom control, combined with better patient education about symptoms and 24-hour access to advice, should make emergency admissions due to side effects of treatment a rare event. The establishment of proactive telephone support to identify possible problems before they become serious should be considered. Patients with known cancer should have access to advice 24 hours a day. If problems arise, the aim should be for the acute oncology team to manage patients in an ambulatory care setting without the need for admission.

Acute oncology services in hospitals with an A&E service would be ideal settings to provide 24-hour acute oncology telephone advice lines and ambulatory care settings where adverse side effects of SACT can be treated. As acute oncology services would have 24-hour cover by the in-house oncology team and access to inpatient cancer beds when necessary; this model would provide high quality, safe care.

The Department of Health's Manual for Cancer Services states that the chemotherapy group in each current network should agree a list of acceptable chemotherapy regimens for the network, which should be updated annually.89 This is to prevent individual practitioners having non-standard practice that does not correspond to that used across the network. London's provider networks should comply with this requirement and agree lists of regimens that have been

<sup>&</sup>lt;sup>88</sup> National Chemotherapy Advisory Group, Chemotherapy Services in England: Ensuring quality and safety, 2009

Department of Health, Manual for Cancer Services, 2004

commissioned for use in the tumour site and disease stage, and for which funding has been agreed.

## 8.4.2 Service delivery

The 2009 NCAG report also recommended that inpatient delivery of SACT should be minimised and that services should be provided closer to a patient's home, where clinically appropriate. 90 Care close to home reduces travel times for patients at a time when they often feel unwell, leading to improved patient experience. It could also make them more prepared to accept the treatments recommended.

Advances in drug therapies mean that many cancer patients no longer have to stay in hospital as inpatients. With the exception of complex haematological treatments, almost all chemotherapy treatments could be delivered in an ambulatory care setting and some patients can even take oral medication at home.<sup>91</sup>

Delivering treatment closer to home must be a clinical decision based on a risk assessment. The risk should be assessed as a combination of the complexity of delivery and the status of the patient. It is likely that a simple regimen may sometimes need to be administered at a specialist centre if the patient requires other medical support or complex supportive care.

To provide high quality care close to home, satellite services should be set up and linked to a central unit in the provider network. The provider network as a whole should ensure governance of quality and safety. The provider network should ensure that protocols and pathways are in place to enable standardised care and smooth transfers across settings. This will include protocols for the transfer of patients to a networked acute oncology service in the event of an acute situation arising. Provider networks will also allow flexible working of clinical staff across community and central settings as well as the establishment of appropriate communication systems (in real time) to support this model.

Satellite services could include outreach teams to enable treatment at home. NHS Bristol is currently piloting a scheme providing nurse-administered chemotherapy at patients' homes as part of their drive to give people more choice about where they receive their treatment. Strong consideration should be given to whether providing treatment at home is an efficient use of resources. In this instance, the community setting would allow provider networks to provide high quality care closer to home while using resources efficiently.

The availability of clinical information is critical to localising SACT delivery. It will be essential that all points in the pathway have the relevant information available in real time, 24 hours a day. This information should include multidisciplinary team outcomes, e-prescribing (at sites where chemotherapy is not given a view only access would still be needed), records of administration (including presence or not of central line access), the patient's clinical management plan, and the availability of

<sup>&</sup>lt;sup>90</sup> National Chemotherapy Advisory Group, Chemotherapy Services in England: Ensuring quality and safety, 2009

Department of Health, Cancer Reform Strategy, 2007

diagnostic imaging through PACS (picture archiving and communication system) wherever the patient is treated.

It is also important that data relating to chemotherapy are collected systematically. A minimum dataset for chemotherapy is being developed (likely to be implemented in 2012) so that all areas where SACT is prescribed, dispensed or administered would need to have systems in place to collect and submit the data.

## 8.4.3 New drugs

Londoners should have equal access to clinically appropriate and cost-effective treatments that cancer clinicians are able to prescribe. To achieve this, the role of the London Cancer New Drugs Group should be strengthened to ensure that its recommendations are adopted by commissioners.

The London Cancer New Drugs Group would be supported by the work of the newly formed pan-London new medicines and treatment project in Commissioning Support for London, the organisation set up to provide clinical and business support to NHS commissioners across London. The project will identify and evaluate options for a London-wide approach to horizon-scanning and prioritisation, supporting PCTs to manage Individual Funding Requests (IFRs). The project will also identify processes to support medicines and treatments disinvestment and decommissioning and promoting prescribing cost-effective medicines and treatments in primary care and acute trusts.

The expected benefits of the work of the project include:

- Less variation to minimise costs and complaints
- High quality and timely decisions to reduce IFR pressures
- Centralised monitoring, learning and horizon scanning
- The potential for decommissioning with more funding available for genuine innovation.



### **Key recommendations:**

All hospitals with emergency departments should establish an acute oncology service to ensure the appropriate early assessment of cancer patients presenting as an emergency.

Inpatient delivery of SACT should be minimised. Satellite services should be set up and linked to a central unit in the provider network to provide treatment closer to home where clinically appropriate.

The community setting should be considered by provider networks to provide high quality care closer to home.

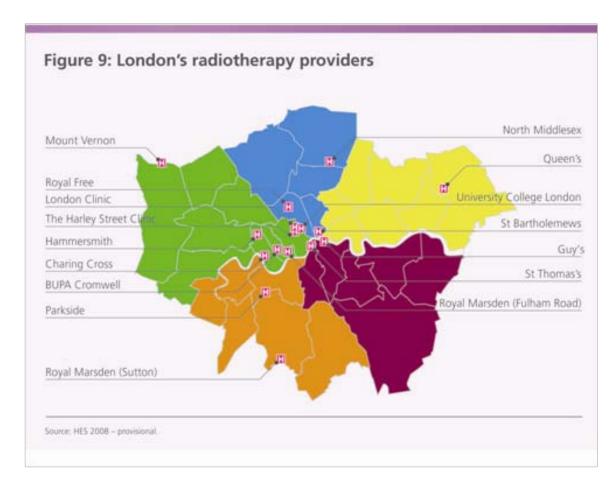
The role of the London Cancer New Drugs Group should be strengthened to ensure that its recommendations are adopted by commissioners.

## 8.5 Radiotherapy

Radiotherapy is estimated to contribute to around 40% of cases where a cancer is cured (either on its own or in combination with other treatments). 92 It is vital that London has a world-class radiotherapy service and radiotherapy treatment is fully delivered to all suitable patients.

Radiotherapy is delivered at eight NHS trusts in London, and treatment is also delivered for Londoners at Mount Vernon Cancer Centre in Hertfordshire. There are also three private providers of radiotherapy in London. Private providers are not routinely commissioned to provide radiotherapy for NHS patients. London's radiotherapy providers are set out in figure 9.

<sup>&</sup>lt;sup>92</sup> National Radiotherapy Advisory Group, Radiotherapy: Developing a world-class service for England, 2007



The National Radiotherapy Advisory Group (NRAG) was asked to advise the Department of Health on the position of radiotherapy services in England. Its report, published in 2007, outlines how to ensure that current resources are deployed to best effect and how to plan for a world-class service in the longer term. The London Cancer Network Board comprehensively assessed the implications of the NRAG report for London in its 2009 report. London's cancer community should implement the recommendations of these two reports.

London providers have enough linear accelerators (linacs) to be able to deliver appropriate treatment for all patients requiring radiotherapy if they are staffed adequately and used efficiently. The London Cancer Network Board (LCNB) identified issues that need to be addressed to ensure this can be achieved, including the need to address variation in services and for a pan-London strategic view of radiotherapy. The *case for change* outlines that there are London specific factors exacerbating national workforce issues, including problems retaining staff due to the cost of living. Radiotherapy recruitment and retention, including staff education and training should be made a priority by provider networks.

The LCNB identified the need for agreement across London on referral for radiotherapy treatment, including treatment with palliative intent, to combat the

<sup>&</sup>lt;sup>93</sup> National Radiotherapy Advisory Group, *Radiotherapy: Developing a world-class service for England*, 2007

<sup>&</sup>lt;sup>94</sup> London Cancer Networks Board (on behalf of London Commissioning Group), *NRAG* Recommendations: A review of the implications for London, A baseline assessment of London Radiotherapy Services, 2009

variation in the proportion of patients receiving radiotherapy. In addition, fractionation regimens and maximum waiting times should be standardised.

Centralised commissioning of radiotherapy should be considered to ensure that patient flows are managed more efficiently across London and to maintain high safety and quality standards. When planning decommissioning of radiotherapy services, configuration should be considered to improve equality of access across London. In particular, the plans to develop a satellite service to improve access to radiotherapy for the population of south east London should be expedited.

## **Key recommendations:**

Agreement should be reached across London on referrals for radiotherapy treatments, fractionation regimens and maximum waiting times.

Centralised commissioning of radiotherapy should be considered to ensure that patient flows are managed more efficiently across London and to maintain high safety and quality standards.

# 8.6 Multidisciplinary teams

Multidisciplinary teams are now well established as the core model for cancer service delivery in hospitals. These teams bring together all the relevant experts to plan and coordinate treatment.

The case for change highlights variability across London in structure, function, roles and compliance with IOG requirements of multidisciplinary teams. There is concern that multidisciplinary team meetings do not always make efficient use of clinical time and are not well supported. Multidisciplinary teams must be structured and must function at the highest levels to ensure that patient care plans are designed to the best possible standard and, with the agreement of the patient, are carried out. Multidisciplinary teams should be standardised across provider networks. Meetings should be planned and organised to ensure their effective and efficient functioning and the optimum use of clinical time.

The coordinator role is essential to the efficient and smooth running of multidisciplinary teams. The role should be better defined and standardised across the provider network. Cases discussed at multidisciplinary teams should be scheduled to enable non-core members to attend only for the discussion of patients that requires their input.

The multidisciplinary team plays a pivotal role in generating high quality data for auditing outcomes. The team serves to focus attention on outcomes as well as processes and is the forum for receipt of local action plans based on these audits.

The establishment of larger multidisciplinary teams can strengthen team membership. This should eliminate gaps in core membership, ensure consistent levels of expertise and avoid reliance on a single clinical nurse specialist for a range of multidisciplinary teams. This would also ensure both rehabilitation and palliative care input into all multidisciplinary teams. Surgical

representation should include experts in various best practice techniques and technologies as appropriate. Lung multidisciplinary teams should include input from thoracic surgeons.

The role of the keyworker, often a clinical nurse specialist, is vital to providing coordinated care for patients. The keyworker acts as a point of contact for patients, ensuring that they have access to information and support services as well as ensuring that ongoing holistic assessments are consistently carried out. The keyworker contributes to increased patient satisfaction and empowerment. Multidisciplinary teams should ensure that all patients have a designated keyworker. <sup>95</sup>

Keyworkers should have protected time to carry out the responsibilities of this role. Provider networks should consider a dedicated multidisciplinary team member to fulfil all the administrative and coordination responsibilities currently often fulfilled by clinical nurse specialists. They would then be able to focus on their role as keyworker and multidisciplinary team interface with the patient.

Multidisciplinary teams should be embedded in provider networks to ensure they are appropriately supported and to promote collaborative working. Provider networks should ensure that access to a keyworker is available consistently throughout the network.

To ensure effective collaborative working across boundaries and efficient running of meetings, appropriate communication technologies (for example, videoconferencing and effective image sharing) should be available. Provider networks should explore innovative ways of conducting meetings such as virtual online multidisciplinary team meetings. Multidisciplinary team recommendations should be electronically recorded in real time to ensure that minimum datasets are captured. This would drive therapeutic decisions as well as audit and research.

### **Key recommendations:**

Multidisciplinary teams should be standardised across provider networks. Meetings should be appropriately planned and organised to ensure their effective and efficient functioning and the appropriate use of clinical time.

The establishment of larger multidisciplinary teams in some instances would eliminate gaps in core membership and ensure consistent levels of expertise.

Provider networks should ensure that patient access to a keyworker is available consistently throughout the network.



<sup>&</sup>lt;sup>95</sup> Department of Health, *Manual for Cancer Services*, 2004

## 8.7 Bed days

#### 8.7.1 Elective

Standardised surgical techniques and consistent implementation of improvement programmes would reduce elective bed days, leading to reductions in inpatient care costs, and improved clinical quality and patient experience.

Enhanced recovery is a novel approach to elective surgery, which ensures that patients are in the optimal condition for treatment, have different care during their operation, and experience optimal pre- and post-operative rehabilitation. It should be used across all elective cancer surgery.

# Evidence of outcomes: reducing length of stay through enhanced recovery after surgery<sup>96</sup>

Queen Mary's Hospital, Sidcup, worked with NHS Improvement to improve the quality of patient care and reduce the length of stay for colorectal cancer patients by introducing an Enhanced Recovery after Surgery (ERAS) integrated care pathway.

Alterations in clinical practice were required throughout pre-operative and post-operative patient care, nursing, anaesthetics, surgical techniques and allied health professional involvement. Training included visual and verbal presentations by the project team, covering a summary of the philosophy of ERAS and the individual aspects of the program.

The ERAS pathway project served to reduce the provider's average length of stay by more than half during the pilot period.

Implementing enhanced recovery would require a more integrated rehabilitation approach as well as the professional belief of nurses in the clinical management process offered by enhanced recovery.

If patients are to be discharged sooner their personal circumstances must be taken into account and appropriate support arrangements must be in place before their departure from hospital. This would necessitate pre-surgical communication with patients and carers and possible self-management programmes for patients and carers after surgery. Effective discharge planning would also require close links between provider networks and local social services.

Less invasive surgical techniques, such as laparoscopic colorectal surgery, should be consistently used where clinically appropriate to speed recovery.

Patients undergoing day surgery may need more support close to home. Patients should know what to expect after their day surgery. Patients and carers should be informed about possible post-operative signs and symptoms, who to contact

<sup>&</sup>lt;sup>96</sup> NHS Improvement, Enhanced Recovery After Surgery Program – Improving Patient Outcomes for Colorectal Surgical Patients, 2008

(including out of hours) and have clear access routes to their keyworker and acute oncology services. Ensuring these patients have access to support and advice in the community can help avoid presentation at A&E and further non-elective bed days.

#### 8.7.2 Non-elective

Emergency cancer admissions currently make a significant contribution to avoidable bed days.

The NCAG report recommends that acute oncology services should be established in every hospital with an A&E department and acute admissions ward. <sup>97</sup> An acute oncology service should deal with all cancer emergencies (both related to disease and treatment) and emergencies related to previously undiagnosed cancers.

A cancer of unknown primary pathway should be incorporated into the work of the acute oncology team to improve the services offered to these patients. The service should include 24/7 access to telephone advice from a consultant oncologist, as set out in the NCAG report. Acute oncology teams should work closely with rehabilitation and supportive and palliative care services to ensure that patients presenting as an emergency are promptly assessed.

Cancer centres and sites that provide chemotherapy treatment without an A&E department on site should develop defined pathways of care for patients to access and receive emergency assessment and treatment on another site in the provider network at any time and without delay.

# Evidence of outcomes: reducing emergency bed days through acute oncology services<sup>98</sup>

The Whittington Hospital has an acute oncology service that provides urgent review (within 24 hours, Monday to Friday) for known cancer patients. The service uses an electronic alert system to notify the oncology team when a known cancer patient is admitted to the hospital. For emergency admissions suspected but not previously known to have cancer, admitting teams can request early oncology advice either on an inpatient basis or via a fast-track clinic within a week.

During the first six months of the service, the service demonstrated an average 3.7 days reduced length of stay for patients with known cancer. For patients with previously undiagnosed cancers it demonstrated an almost 50% reduction in length of stay and a one third reduction in the cost of the admission.

<sup>98</sup> NHS Improvement, *Transforming care for cancer inpatients: spreading the winning principles and good practice*, 2009

<sup>&</sup>lt;sup>97</sup> National Chemotherapy Advisory Group, Chemotherapy Services in England: Ensuring quality and safety, 2009

The acute oncology service should have an IT system that includes a recurring admission patient alert system to automatically and rapidly notify the acute oncology team when a known cancer patient is seen in A&E or admitted via acute services.

# Evidence of outcomes: supporting reduced bed days with recurring admission patient alert (RAPA)<sup>99</sup>

RAPA is a process that supports coordination and timely care for patients admitted as an emergency, alerting members of the clinical teams when their previously diagnosed cancer patients are being re-admitted to the acute hospital.

The alert allows the assessment of patients before admission rather than their admission to allow assessment. The pilot site of Sherwood Forest Hospitals NHS Foundation Trust has shown a reduction in the number of unnecessary diagnostic tests and reduced non-elective length of stay.

The provision of acute oncology services in every hospital with an A&E department and acute admission wards would mean that the local hospital will become the main focus of care for treatment complications.<sup>100</sup>

# **Key recommendations:**

Enhanced recovery programmes should be implemented across all elective cancer surgery.

Appropriate support arrangements should be fully in place prior to a patient's departure from hospital.

Less invasive surgical techniques such as laparoscopic colorectal surgery should be consistently used where clinically appropriate to speed recovery.

Acute oncology services should be established in every hospital with an A&E department to reduce emergency admissions and to improve pathways for cancers of unknown primary.

### 8.8 Follow-up

Where clinical guidance exists that covers the follow-up care of cancer patients, such as the recent NICE guidance on the diagnosis and treatment of early and locally advanced breast cancer,<sup>101</sup> this must be adhered to. There is no evidence that traditional follow-up of regular appointments in secondary or tertiary care always

<sup>&</sup>lt;sup>99</sup> NHS Improvement, *Transforming care for cancer inpatients: spreading the winning principles and good practice*, 2009

good practice, 2009

100 National Chemotherapy Advisory Group, *Chemotherapy Services in England: Ensuring quality and safety*, 2009

<sup>&</sup>lt;sup>101</sup> NICE, Early and locally advanced breast cancer: diagnosis and treatment, 2009

provides the most effective care. There is broad consensus that some of the follow-up carried out by London's cancer clinicians is unnecessary. Most cancer recurrences are picked up as a result of referrals between planned appointments. There is low awareness and poor understanding of the consequences of cancer and cancer treatment amongst both patients and some non-specialist clinicians. These issues lead to a considerable number of avoidable NHS visits with associated costs and poorer quality of care for patients.

In addition, people are now living longer with their cancer, more people survive cancer, and more people live with 'chronic cancer'. These factors mean that more people are now also experiencing long-term side effects of cancer treatment. To address these issues, traditional follow-up services should be reviewed to ensure that they are evidence-based and, where necessary or desirable, replaced with bespoke aftercare services based on the emerging vision of the National Cancer Survivorship Initiative (NCSI). 102

The NCSI has identified the need for five shifts in the approach to care and support for people living with and beyond cancer:

- a cultural shift to a greater focus on recovery, health and wellbeing after cancer treatment
- a shift towards assessment, information provision and personalised care planning, away from a one size fits all approach
- 3. a shift towards support for self-management, away from a clinically led approach
- 4. a shift from a single model of clinical follow-up to tailored support that enables early recognition of and preparation for the consequences of treatment and signs and symptoms of further disease
- 5. a shift from an emphasis on measuring clinical activity to a new emphasis on measuring experience and outcomes through routine use of patient reported outcome measures (PROMs).

A cultural shift is needed in the approach to care and support for people affected by cancer. Aftercare with a greater focus on recovery, health and wellbeing after cancer treatment would replace the single model of clinical follow-up, where appropriate.

Aftercare links specialist, primary care, palliative care, rehabilitation and support services (including social care and third sector providers) with a dedicated case manager or 'supporter'. These services should work within the framework for supported self-management centred on individual care plans that have been developed together with the patient. This would lead to the provision of tailored support, enabling early recognition of and preparation for consequences of treatment and early recognition of signs and symptoms of further disease.

The cancer survivorship vision recommends that cancer patients should be assessed following initial treatment and then be assigned a level of risk of

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<sup>&</sup>lt;sup>102</sup> Department of Health, Macmillan Cancer Support & NHS Improvement, *The National Cancer Survivorship Initiative Vision*, 2010

developing consequences of treatment or further disease. An individual care plan would then be drawn up addressing the whole range of needs an individual might have after treatment with the aim of minimising risks and supporting the patient to manage ongoing conditions.

Figure 10 outlines the proportion of patients that would fall into three broad levels of need as estimated in by the NCSI. Commissioners must be aware that, while the majority of survivors should be supported to self-manage, others would continue to require varying levels of secondary care input and there may be unmet need for the type intensive follow-up required at level 3.

Figure 10: Survivorship levels of need

Level of need	Estimated number of patients involved (percentages will vary according to cancer)
<b>Level 1</b> – supported self-care with quick access back into the system if and when needed to improve early detection and management.	ca. 70%
Level 2 – level of requirement requiring low levels of secondary and/or primary care input after specialist assessment, diagnosis and care planning.	ca. 25%
<b>Level 3</b> – highly complex consequences of treatment requiring case management by an assigned keyworker (often a clinical nurse specialist) with multidisciplinary support.	ca. 5%

Patients should be given the appropriate information to make an informed choice on their preferred method of follow-up. Some patients are likely, initially at least, to prefer regular follow-up in secondary care to supported self-management. This option should be discussed with patients and their choice respected. A seamless transition to end of life care should be made when necessary.

It is imperative that any change in follow-up does not impair the capture of outcome data to maintain first class services. Patient reported outcome measures (PROMs) should be used routinely to measure the experience and outcomes of aftercare services by cancer survivors.

Personalised care plans should address psychological, rehabilitation, and information needs, including what signs of recurrent or progressive disease to look for and what to do if they occur. They should also include support for getting back to work, identification and management of short, medium and long-term consequences of cancer treatment, and rapid re-entry to specialist services.

Where there is evidence that follow-up screening (such as mammography and blood tests) is effective in identifying recurrence,

this should be undertaken in primary care where possible. Provider networks should ensure that protocols and pathways are in place for rapid access to secondary care from settings of screening follow-up.

# Evidence of outcomes: increasing value for money by proving follow-up in the community

Prostate patients in south west London have historically been followed-up in secondary care. The pilot of a new pathway sees some patients being followed-up in GP surgeries with external supervision from specialist consultant urological surgeons and oncologists.

Clear protocols have been developed describing the pathway to ensure that patients are seen in the appropriate setting.

To ensure prompt consultant support and leadership the PCT pays one consultant session to staff what is effectively a Prostate Cancer Hotline. This allows GPs to ask for specialist advice without sending the patient to hospital with the inherent delays and costs to the patient and the NHS.

Current estimates are that the partially implemented scheme saves the PCT around £100,000 a year.

The survivorship model is dependent on improved education and support for patients, carers and healthcare professionals to promote supported self-management and personalised care planning. Patient information should be made available in appropriate formats. This model should improve patients' quality of life and experience of cancer care. Data collection and information exchange systems need to be in place to enable measurement of patient experience and outcomes. Implementing this model would require initial investment, but savings would be seen in the longer term through a reduction of unnecessary follow-up in secondary care. This reduction would free up consultant time, which can be used to reduce waiting times for new referrals.

Providing follow-up and survivorship services for rarer cancers needs to be balanced to ensure both sufficient patient volume for clinical expertise and local access for patient experience are provided. New follow-up systems should be monitored and assessed to ensure they improve outcomes and quality of life for patients.

The National Cancer Survivorship Initiative is undertaking further work to improve care for people living with and beyond cancer. The vision document was published early in 2010. This represents only the starting point of this work and commissioners and provider networks should monitor further outputs from the National Cancer Survivorship Initiative to identify how to turn the vision into reality.



## **Key recommendations:**

Follow-up services should be reviewed to ensure that they are evidence-based and, where necessary or desirable, they should be replaced with bespoke aftercare services based on the emerging survivorship model.

Patients should be given the appropriate information to make an informed choice on their preferred method of follow-up.

A patient's level of risk should be assessed following initial treatment. An individual care plan should then be drawn up addressing the patient's whole range of needs.

Patient information should be made available in appropriate formats to promote supported self-management.

New follow-up systems should be monitored and assessed to ensure they improve the quality of life for patients while maintaining good outcomes.

## 8.9 Supportive and palliative care

Providing holistic and integrated supportive and palliative care are key to improving patients' experiences of cancer services, enabling self care and improving patients' quality of life. The NICE guidance on supportive and palliative care should be implemented across London.<sup>103</sup>

Supportive care includes psychological, social, rehabilitation and spiritual support services for patients and their carers.

Patients should be holistically assessed to determine which supportive and palliative care services they need. Holistic assessments should be embedded in the patient pathway and take place at key stages from diagnosis onwards. Patients should be involved in the decision-making process following their assessment. They should receive information and communication in appropriate formats so they understand the risks and benefits of supportive and palliative care, and are able to make an informed decision.

Psychological care has been identified by patients as an area of need. Staff in every setting play a vital role in the psychological support of patients and should be equipped with the skills and knowledge to assess and prevent psychological distress. The involvement of specialist social workers, counsellors, clinical psychologists and liaison psychiatry may be required for some cancer patients. While these specialist staff may have direct contact with a limited number of patients, their knowledge should influence the majority of staff. They should therefore be embedded in clinical teams to ensure that all levels of psychological need are met appropriately. Equitable access to psychological support services should be explicitly commissioned and managed in the provider network.

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<sup>&</sup>lt;sup>103</sup> NICE, Improving Supportive and Palliative Care for Adults with Cancer, 2004

Engagement with service users has also shown that the lack of support for carers is a gap in current services. Holistic patient care should include assessments of the support requirements of carers, and keyworkers should work closely with social services to ensure that these needs are met. Palliative care, support, and rehabilitation should form part of a patient's personalised follow-up care plan.

All staff should be trained in providing generalist palliative care and recognising when to refer patients for specialist palliative care. Clinicians working in palliative care feel that some patients may prefer to opt out of any or further non-curative care when long survival prospects are improbable in favour of a shorter but, what they consider to be, better quality of life. Clinicians should be alert to the early recognition of this possibility.

Commissioners should ensure that there is provision of general and specialist palliative care close to home and at home as described in the End of Life Care Strategy. 104 Where they do not exist already, commissioners should ensure that alternative provision of general palliative care advice, such as telephone advice lines, is available to patients.

## Evidence of outcomes: reducing admissions by providing telephone advice<sup>105</sup>

Hull and East Yorkshire NHS Trust's 24-hour palliative care advice line was set up to provide support to patients in their own homes where possible and to present a detailed strategy of working which would address the chronic inequalities within the healthcare service. The helpline was manned by staff possessing the knowledge and skills to give sound evidence-based advice to any caller requiring palliative care advice. Staff training was essential in implementing the advice line.

Implementation of the advice line led to reduced emergency admissions and bed days. An assessment of 119 calls received between January and December 2005 revealed that just 11% resulted in patients being admitted to hospital. It was estimated that this saved 47 hospital admissions and 72 bed days.

Healthcare professionals, patients and carers who used the advice line found it invaluable. In addition, anecdotal evidence suggested that patients who did not use the line found it reassuring to know that it was available whenever they might need it.

Rehabilitation should be explicitly managed and commissioned across the patient pathway in the provider network model. National rehabilitation pathways should be used to guide the development of an appropriate rehabilitation model for each

<sup>&</sup>lt;sup>104</sup> Department of Health, End of Life Care Strategy: promoting high quality care for all adults at the end of life, 2008

<sup>&</sup>lt;sup>105</sup> NHS Improvement, *Transforming care for cancer inpatients: spreading the winning principles and* good practice, 2009

tumour site including palliative care. <sup>106</sup> Patients should be consulted on developing a rehabilitation care plan before treatment as appropriate. Inequalities in access to rehabilitation professionals should be addressed through benchmarking against the national evidence on rehabilitation workforce requirements in relation to throughput for cancer treatment services.

Rehabilitation should be provided in a variety of settings and as close to patients' homes as possible. Wherever rehabilitation is provided, it should be integrated with supportive and palliative care services. All patients should have access to allied health professionals providing supportive care and rehabilitation in all settings, and at all disease stages, to ensure maximum retention of function and rehabilitation potential. This would require explicit pathways to ensure that patients reach the right professionals with the right level of expertise.

To ensure that psychological support, palliative care and rehabilitation are integrated in a patient's care (from diagnosis through to follow-up care), palliative care and rehabilitation specialists should be part of all multidisciplinary teams. The initial focus of the multidisciplinary team is the patient's primary treatment. It is for provider networks to decide locally whether, and how, patient cases should be reconsidered beyond this point (taking into account any relevant recommendations by NICE). Multidisciplinary teams can focus only on the diagnosis and treatment elements of the patient pathway. Provider networks should ensure that criteria for patient review at multidisciplinary team meetings are developed and standardised across the network. This would ensure that patients are reviewed by multidisciplinary teams at any part of the pathway where complex and difficult decisions need to be made. The requirement for the meetings to look beyond the treatment phase may have significant time implications for some multidisciplinary teams, providing a further driver for consolidating and organising multidisciplinary teams meetings efficiently and effectively.

The representation of palliative care, support and rehabilitation on multidisciplinary teams is monitored by peer review. The peer review programme should consider extending the measures used to assess whether multidisciplinary teams consider the patient pathways beyond diagnosis and treatment.

#### 8.9.1 Palliative care interventions

Patients should have access to appropriate interventions to maintain good quality of life, relieve symptoms and prevent or reduce the speed of deterioration even when the disease is considered incurable. The benefit of invasive interventions must be weighed against the burden to the patient. The NCAG report highlighted the need for clinicians to make clear to patients the benefits, and also the risks, of chemotherapy in the late stages of the disease.<sup>107</sup>

Palliative treatments such as stenting lung and gastrointestinal tumours and palliative surgery like GI bypass surgery should be carried out in elective surgery

<a href="http://www.cancer.nhs.uk/rehabilitation/index.htm">http://www.cancer.nhs.uk/rehabilitation/index.htm</a> [accessed February 2010]

National Chemotherapy Advisory Group, Chemotherapy Services in England: Ensuring quality and safety, 2009

<sup>&</sup>lt;sup>106</sup> Draft versions of these pathways are currently available from the NCAT along with guidelines for Supporting and improving commissioning of cancer rehabilitation services.

settings as far as possible. Patients requiring these interventions will often present as emergencies and will therefore not be suitable for the elective setting. Some palliative treatments, such as vascular stenting for superior vena cava obstruction, are complex and need to be performed at a specialist centre. Access to lymphoedema services is not currently available to all patients and should be made available at specialist centres.

Provider networks should implement any recommendations that emerge from the ongoing pan-London lymphoedema review that are relevant to cancer services. Locally developed clinical pathways should specify which interventions should occur in which setting. Provider networks should determine pathways and protocols to allow multidisciplinary teams to make the appropriate and early referral of patients to the correct setting. To make best use of expertise and equipment, palliative surgery should be consolidated in specialist centres as appropriate.

## **Key recommendations:**

The NICE guidance on supportive and palliative care should be implemented across London.

Holistic assessments should be embedded in the patient pathway. Holistic care of patients should contain assessments of the need for psychological support and the support requirements of carers.

Patients should be consulted on the development of a rehabilitation care plan prior to treatment as appropriate.

Palliative care and rehabilitation specialists should form part of all multidisciplinary teams. Provider networks should ensure that criteria for review of patients at multidisciplinary team meetings are developed and standardised across the network.

Complex palliative interventions should be performed at specialist centres. Locally developed clinical pathways should specify which interventions should occur in which setting.



# 9. Rarer cancers and specialist care

### 9.1 Introduction

This chapter covers the following rarer cancers and specialist procedures: Upper gastrointestinal; urological; head and neck; brain and central nervous system (CNS); gynaecological; sarcoma; haematopoietic progenitor cell transplantation (HPCT), molecular diagnostics, specialist imaging, and specialist radiotherapy.

The *case for change* for rarer cancers and specialist care sets out the following key themes:

- Certain rarer and specialist procedures have become concentrated in a core team of surgeons while other procedures continue to challenge the NICE compliant models of care.
- Ongoing drivers to improve quality of care are dictating a further consolidation of services, surpassing the simplistic argument of volume advantages towards maintaining a clinical environment that provides a platform for the delivery of best practice developments.
- Specialist multidisciplinary teams are not organised or resourced in a way that
  maximises the number of patients being seen. Managing the delivery of care
  plans of patients is constrained by organisational boundaries in London.
- Planning for the delivery of specialist and rarer cancer services on new sites should consider the improvements in cancer care that result from clinical trials and high quality translational research.

The proposed model of care addresses these issues by applying the principles set out in the common cancers surgery section of this document, where clinically appropriate, for each rarer cancer and specialist treatment discussed:

- 1. It is the ambition of London's NHS to provide consistent world-class services.
- 2. The integration of research with clinical care is essential for the continuous improvement in the provision of high quality services. Consolidation of services would improve the research environment. Specialist and rarer cancer services should be linked to high quality cancer research institutions that can demonstrate and improve uptake to clinical trials and promote translational research in the cancer field including, where appropriate, Academic Health Science Centres (AHSCs) and specialist cancer organisations.
- Consolidating services reduces duplication of effort and equipment and dilution of expertise.
- 4. NICE Improving Outcomes Guidance (IOGs) recommends minimum volumes for a variety of services. Where services have been rationalised, London should aim to go beyond the minimum volumes laid out in NICE IOGs.



- 5. London has a younger population than the national average and should therefore aspire to exceed recommended national minimum volumes.
- The population served by London's NHS is swelled beyond the eight million people resident within the metropolitan area by inflows of patients from outside the capital.

A principal theme of the *case for change* is that the future improvement in the treatment of cancer patients would be best supported by specialist cancer services being provided by fewer teams with a higher concentration of expertise and the associated larger workloads. The additional capacity required may involve the provision of some protected surgical beds for cancer patients in order to prevent emergency work compromising the ability of the provider to deliver timely cancer care.

NICE IOG minimum volumes for rarer cancers are set out in figure 11 below. The recommendation to further consolidate services is based on the relationship between volumes and outcomes and on the wider ambition to provide high quality services to all Londoners.

Figure 11: NICE IOG minimum volumes for rarer cancers

	Upper GI	Rarer	Head and neck	Gynaecology	Brain and CNS	Sarcoma
		urological				
Multidisciplinary	1-2m OG	>4m penile	>1m UAT	>1m	N/a	7m bone
team catchment						
area	2-4m pancreatic	2-4m testicular	>1m thyroid			2-3m soft tissue
Multidisciplinary	100 per 1m pop.	25 penile	100 UAT	N/A	100	50 bone
team new cases	OG					
per year	150 per 1m pop.	50-100 testicular				100 soft tissue
	gastric					
	200 per 2m pop.					
	pancreatic					
Multidisciplinary	100 per 1m pop.					
team operations	OG					
per year	30 per 2m pop.					
-	pancreatic					

### 9.2 Non-surgical oncology for rarer cancers

Chapter 8 of outlines the proposed model of care for non-surgical treatments and general care for all cancers, including rarer cancers. The are key messages of the 8 that relevant to the treatment of rarer cancers, but there are other specific requirements for the non-surgical treatment of rarer cancers.

Given the rarity of these cancers, a minimum caseload for specialist non-surgical oncologists treating each rare tumour type should be defined to maintain specialist expertise. Sufficient volumes are required to ensure critical mass while non-surgical service provision needs to be sufficiently localised to ensure accessibility. This also applies to the provision of follow-up and survivorship services for rarer cancers which should be balanced so that both sufficient patient volumes for clinical expertise and local access for patient experience are provided. The

specialist oncologists should be members of relevant specialist multidisciplinary teams.

For all rarer cancers, centralised assessment and decision making for every aspect of the patient's care plan is fundamental, and should be undertaken by the specialist multidisciplinary team. The specialist team should recommend appropriate sites for delivery of subsequent care.

For the provision of systemic anti-cancer therapy (SACT), chapter 8 sets out that inpatient delivery should be minimised and that services should be provided closer to patients' homes where clinically appropriate. The SACT section also describes occasions where a simple regimen may sometimes need to be administered at a specialist centre if the patient requires other medical support or complex supportive care needs. This may also apply if the patient is participating in a clinical trial.

To enable provision of high quality care close to home, satellite services should be set up and linked to a central unit in the provider network. Specialist multidisciplinary teams should work across provider networks to enable treatment, follow-up, and rehabilitation to be delivered close to the patient's home except in exceptional clinical circumstances. The governance of quality, safety and shared care arrangements would be ensured by the provider network.

Chapter 8 recommends that centralised commissioning of radiotherapy should be considered to ensure that patient flows are managed more efficiently across London and that high safety and quality standards are maintained. Specialist radiotherapy treatments are detailed in section 9.10 below.

Where applicable, further recommendations for non-surgical oncology for specific tumours are set out below.

#### **Key recommendations:**

Provider networks should set minimum caseloads for specialist oncologists for each rarer tumour type to maintain specialist expertise.

Specialist oncologists should be members of relevant specialist multidisciplinary teams.

Assessment and decision making for every aspect of the patient's care plan should be undertaken by the specialist multidisciplinary team which should recommend appropriate sites for delivery of care.

Shared care arrangements should be developed across each provider network to ensure that treatment plans determined by the central specialist multidisciplinary team can be delivered as close to the patient's home as possible.

### 9.3 Upper gastrointestinal cancers

The case for change sets out drivers for further consolidation of specialist services



for upper gastrointestinal cancers.

Post-operative morbidity is high for these cancers so the support service requirements are complex. The majority of pancreatic cancers are inoperable so the number of new cases each year does not equate to the number of procedures undertaken. Improved imaging has led to a reduced number of resections as it more frequently identifies inoperable cancers. Instead, improvements in available chemotherapy treatment will lead to the more common primary treatment option being a mix of chemotherapy and radiotherapy.

There is duplication of services and minimum requirements set out in the upper gastrointestinal cancers IOG<sup>108</sup> are not currently being met by some providers. These providers are not serving minimum recommended catchment populations. In addition, the upper gastrointestinal IOG states that:

"All hospitals which intend to provide services for patients with upper gastrointestinal cancer should be fully involved in appropriate Cancer Networks which include inter-linked Cancer Centres and Cancer Units."

The IOG states that particularly high input is required from consultant surgeons. Life threatening complications are common after surgery so adequate intensive care, high-dependency facilities and specialist post-operative care (including out of hours consultant cover) must be provided to minimise mortality.

The Association of Upper Gastrointestinal Surgeons (AUGIS) was asked by the Department of Health in England for a recommendation on minimum surgeon volumes for major oesophago-gastric and hepato-pancreato-biliary (HPB) resections. <sup>109</sup> The world literature was reviewed in detail and the AUGIS working party was very grateful to the Clinical Effectiveness Unit at the Royal College of Surgeons of England for their assistance. <sup>110</sup>

AUGIS considered that the European and North American literature overwhelmingly supports the view that there is a strong relationship between increasing hospital (institutional) volume and reduced operative mortality in major oesophago-gastric and hepato-pancreato-biliary resections. There is also evidence that some long term outcomes are improved. Recent data now demonstrate that, not only are outcomes also improved by increasing individual surgeon volumes, but that specialisation of the surgeon and the unit also has an important role to play.

AUGIS recommended that an ideal oesophago-gastric unit would therefore consist of four to six surgeons, each carrying out a minimum of 15-20 resections per year, serving a population of 1.5 to 2 million.

Pancreatic cancer has a surgical resection rate of 15-20%. Primary liver cancer is rare and most liver resections occur due to metastases. The indication for liver

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<sup>&</sup>lt;sup>108</sup> NHS Executive, *Improving Outcomes Guidance in Upper Gastrointestinal Cancers – The Manual*, 2001

Association of Upper Gastrointestinal Surgeons, *Guidance on Minimum Volumes*, 2010 Professor John Birkmeyer of the University of Michigan, a national leader in surgical outcomes research, quality, and health policy, was also consulted. The initiative received strong support from Sir Bruce Keogh, NHS Medical Director.

resection is colorectal metastases in 60-70% of patients and with the increases in resection rates due to more effective chemotherapy agents it is expected that 7-8% of colorectal cancer patients would undergo liver resection. The majority of hepatopancreato-biliary (HPB) units provide a pancreatic and liver resection service with a single surgical team. AUGIS recommend that ideally a team of six surgeons would serve a population of 2.5 to 3 million. All surgeons should have full participation as a core member of the relevant MDTs.

It was, however, also recognised by AUGIS that presently units that serve a smaller catchment population may carry out large numbers of resections due to referral patterns which cross boundaries. These referral patterns often exist for historical reasons and surgical excellence. This should be considered by commissioners if they choose to implement the proposals of this model of care.

It is important that London's cancer services look beyond the measure of minimum surgical volumes and addresses all aspects of the quality of care that they provide. Given the great need to improve outcomes for patients with upper gastrointestinal cancer, it is essential that they are cared for by highly sophisticated clinical teams beyond surgery alone, who work in excellent facilities, possess multi-modality cancer expertise, make a strong contribution to national and international research, and offer access to clinical trials for patients.

Oesophago-gastric provider volume and pancreatic specialist multidisciplinary team volume should be at least 100 new cases a year, serving catchment populations of at least 2 million and 3 million respectively. For pancreatic services, a similar infrastructure needs to be in place for benign disease and malignant tumours and it may be helpful to have an integrated service as diagnosis may be made during surgery.

Given the numbers of new cases a year in London, three pancreatic surgical providers and four oesophago-gastric surgical providers pan-London would meet these requirements.

There are currently five providers of liver cancer services in London. *The National Liver Plan* recommends that patients with hepatocellular carcinoma (HCC) and cholangiocarcinoma are managed in centres that offer the services of resection, liver transplantation, loco-regional therapies and novel drugs, or have the necessary relationships to ensure efficient local provision. With regard to cholangiocarcinoma, however and in particular, it was expressed that the current data do not show the necessity for it to be operated upon within a liver transplant centre. The plan also stipulates that hepatologists are central to the multidisciplinary team. While transplantation is only an option in a small minority of liver cancer patients early referral for potential transplant patients should be made to a liver transplant unit, where the specialist multidisciplinary teams should determine their suitability for transplant.

<sup>&</sup>lt;sup>111</sup> British Association for the Study of the Liver, British Society of Gastroenterology, *The National Plan for Liver Services – A time to act: Improving liver health and outcomes in liver disease*, 2009

Three integrated hepato-pancreato-biliary (HPB) services would ensure that the codependencies between liver cancer and pancreatic cancer services are met. These centres would either host or have strong links with a liver transplant unit, be collocated with specialist surgery (such as pelvic surgery, sarcoma and reconstruction), and at least one centre should have access to intra-operative radiotherapy.

HCC surgery in cirrhotic patients should only be undertaken in a liver transplant centre because there are small surgical volumes, extended resections and the requirement for extended multidisciplinary teams with access to liver transplantation.

AUGIS considers that changes in healthcare commissioning, surgical manpower and advances in treatment are likely to influence their recommendations on minimum surgical volumes, which should therefore be reviewed on a regular basis.<sup>112</sup>

Surveillance (a screening modality) for HCC in at-risk groups has been recommended in best practice guidelines but the UK does not have a robust surveillance programme. The aim should be to ensure appropriate surveillance of all patients with established cirrhosis to identify HCC at an early stage and to allow for effective therapy.

The collocation of some specialist radiotherapy treatment with specialist surgery would have the advantage of enabling increased specialisation. In a large centre, it would be possible for interventional radiologists to specialise in upper gastrointestinal cancers. Oncology centres should be linked to the surgical centre in research programmes. Appropriate levels of nutrition and dietetic support are also required.

# Evidence of outcomes: reducing mortality through centralisation of major surgery<sup>113</sup>

An example of the combined benefits of centralisation is in Ontario, where Cancer Care Ontario undertook a regionalisation programme for major pancreatic cancer surgery. Changes included surgeon training, hospital resources, and public reporting of mortality data. The provincial mortality rate from major pancreatic cancer surgery has decreased by more than 50% since the introduction of the programme.

#### **Key recommendations:**

Four oesophago-gastric surgery providers should be commissioned in London, serving catchment populations of at least 2 million.

Three integrated hepato-pancreato-biliary (HPB) providers should be commissioned in London, serving catchment populations of at least 3 million.

There should be early referral of potential transplant patients to a liver transplant unit,

Langer B, 'Role of volume outcome data in assuring quality in HPB surgery', *HPB*, 2007

Association of Upper Gastrointestinal Surgeons, *Guidance on Minimum Volumes*, 2010

where the specialist multidisciplinary team should determine their suitability for a transplant.

# 9.4 Rarer urological cancers

There are three testicular cancer services in London, and two providers for penile cancer services. The *case for change* shows that the configuration for rarer urological cancer services (testicular, penile, and renal cancers) currently exceeds the IOG requirement. Clinical consensus is that there is an appropriate number of providers, and therefore no change to the number of providers is necessary.

The *case for change* identifies the need to address the low consultant numbers for testicular and penile malignancies, dependencies on single surgeons for service delivery of some procedures, and the challenge of providing adequate 24-hour cover throughout the year.

Improved communication between general and specialist urology multidisciplinary teams is required to ensure that complex cases are referred on to specialist centres for treatment, reducing treatment delays. Quality accounts should include metrics to measure appropriate referrals by tumour type, as well as targets for referral and repatriation times between local and specialist multidisciplinary teams to ensure efficient transfers.

Access to psychosexual support is not currently available to all testicular and penile cancer patients and should be available at the supra-network centres.

Clinical management of renal malignancies has changed in recent years, with the increased use of laparoscopic techniques for renal surgery. As such, management of renal malignancies should be confined to specialist urology multidisciplinary teams. There is renal representation on local multidisciplinary teams but consolidation of expertise is required. In the last few years there have been major developments in the systemic treatment options for patients with advanced renal cancer. Patients requiring these targeted therapies should be managed by an experienced medical oncologist with access to relevant clinical trials.

# **Key recommendations:**

Providers should establish protocols to ensure 24-hour cover for interventional radiology, an on call rota for consultant cover, and resident surgical juniors at all surgical sites.

Providers should establish protocols to ensure appropriate referrals between urology multidisciplinary teams and specialist urology multidisciplinary teams to ensure that complex cases are referred to specialist centres and are treated at these sites.

The management of renal malignancies should be confined to specialist urology multidisciplinary teams.



#### 9.5 Head and neck cancers

The case for change outlines the drivers to further consolidate specialist services for upper aero-digestive tract (UAT) and thyroid cancers. An increasing number of head and neck cancers are treated with a chemotherapy and radiotherapy regimen as a primary or adjuvant treatment. There are benefits of providing a reasonably centralised service due to the number of specialties involved (maxillofacial; ear, nose and throat (ENT); plastic surgeons; clinical oncologists; speech and language therapists; dieticians; restorative dentists; and clinical psychologists).

In 2007/08 there were 26 providers of UAT surgical cancer services in London. This has since been reduced to seven providers. For malignant thyroid surgery there were 23 providers in 2007/08 which has now been consolidated into twelve. There were only 241 thyroidectomies performed in London for cancer in 2007/08. Further consolidation is recommended for UAT and thyroid cancers. Five providers should be commissioned to deal with both UAT cancers and thyroid cancers. An integrated pathway in each provider network would ease access to pathology, radiology, radiotherapy, and chemotherapy; and facilitate transfer of data and permit follow-up locally with access to relevant information.

There should be rapid access diagnostic one-stop clinics for patients with neck lumps and these should be integrated with equivalent services for haematological cancers. Clinics should operate in the local setting to enable ease of patient access. They would require a range of diagnostic tests to be available which should include cytologist supported fine-needle aspiration and access to diagnostic ultrasound. Their location and number would need to be determined by caseload and utilisation of equipment and workforce.

There is a need for joint consultant appointments in ENT and maxillofacial surgery between peripheral units and the centre to ensure that screening appointments, initial investigations, and rehabilitation can be delivered locally.

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 in centres with specialist head and neck services and neurosurgery given the high level of overlap between them. Two of the five specialist head and neck services should be collocated with neurosurgery, which would also provide economies of scale benefits and reduce duplication. Links are required between specialist neurosurgeons and all specialist head and neck multidisciplinary teams.

The head and neck cancers IOG allows thyroid cancers to be managed either together with the UAT cancers or in a separate multidisciplinary team. However, since thyroid cancer is a relatively rare condition with an incidence rate of roughly two patients per 100,000 population per year, it is recommended that malignant thyroid tumours should be managed by specialist head and neck multidisciplinary teams. The number of thyroid cancers operated on each year is small and the majority of these cases are undertaken by ENT surgeons (rather than general surgeons or endocrine surgeons who manage benign thyroid cases). Thyroid

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<sup>&</sup>lt;sup>114</sup> NICE, Improving Outcomes in Head and Neck Cancers – The Manual, 2004

multidisciplinary teams who manage benign thyroid cases should have strong links to the specialist head and neck multidisciplinary team.

Adjuvant treatment may be either radiotherapy or chemo-irradiation and services should ideally be collocated. However, this is not essential provided there is easy access to both services throughout the provider network. An endocrine physician and clinical oncologist expert in delivering radio-iodine therapy should be core members of the specialist multidisciplinary team. The facility to administer radio-iodine should ideally be collocated with the surgical centre but again, this is not essential provided this is readily accessible in the provider network.

The head and neck IOG requires that a wide range of support services should be provided and each provider should develop these services to be available from diagnosis until completion of rehabilitation. The IOG stipulates that coordinated local support teams should be established to provide long-term support and rehabilitation for patients in the community. These teams should be fully integrated with the expertise of the specialist centre by inreach and outreach arrangements and should also have close links with local palliative care provision.

# **Key recommendations:**

Five surgery providers should be commissioned to deal with both UAT cancers and thyroid cancers. Thyroid cancers should be managed as part of the specialist head and neck multidisciplinary team.

Rapid access diagnostic one-stop clinics should be established locally for patients with neck lumps and these should be integrated with equivalent services for haematological cancers.

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.

#### 9.6 Brain and CNS cancers

The case for change outlines the drivers to further consolidate specialist services for brain and central nervous system (CNS) cancers. Nationally, there is a need to increase the proportion of patients operated on by a brain and CNS surgeon with a specialist interest in these tumours. This would require a reorganisation of surgical teams which is likely to be challenging for services managing smaller populations.

London cancer networks have identified gaps in core and extended specialist multidisciplinary membership and in the resources for assessment, support, and rehabilitation services for brain and CNS services. Multi-professional assessment is required given the complex needs of brain patients likely to require a full team of medical, nursing, rehabilitation, and psychology experts. This does not inevitably require collocation as staff could see patients at

different times, but from a patient point of view the provision of a one-stop centre would be beneficial.

Nationally, brain and CNS services support populations significantly larger than those served by some of the London neuroscience units. Greater concentration of London's brain and CNS cancer related work would deliver more sustainable and cost effective teams.

The National Clinical Advisory Group is considering whether to recommend a minimum number of patients for each sub-specialist multidisciplinary team for the very rare tumours (base of skull, pituitary, and spinal cord tumours). The metastatic spinal cord compression (MSCC) IOG<sup>115</sup> recommends definitive treatment, if appropriate, before any further neurological deterioration, ideally within 24 hours of the confirmed diagnosis of MSCC. This would require ensuring that there is an adequate spinal surgical on-call rota for MSCC.

The head and neck cancers section of this model of care recommends the commissioning of two centres in London for base of skull and pituitary tumours, collocated in centres with neurosurgery and two of the five specialist head and neck services. There should also be two spinal cord specialist multidisciplinary teams collocated with these services.

The case for change notes that there were eight providers of significant volumes of brain and CNS cancer surgery in 2007/08. Currently there are seven providers of adult brain and CNS cancer surgical services in London. It is recommended that commissioners reduce this to four providers serving catchment populations of at least 2 million, with neuro-oncology services located on these sites and strong links with local acute hospitals for referral.

Neurologists should be more engaged with managing patients, both pre- and postoperatively. There should be rapid access diagnostic one-stop clinics with access to magnetic resonance imaging (MRI) for patients with suspected brain tumours. Such clinics could be run under the care of neurologists.

Currently, patients may have to be referred from the neurosurgery centre to an oncology centre for treatment. Collocation of neuro-oncology services at four centres would allow development of highly specialist molecular and genetic neuropathology laboratories and expertise.

There is an evolving need for molecular genetics in cancer care, and it is of particular importance in managing CNS malignancies. Individual centres, as a baseline, must have the ability for MGMT marker and 1p 19q analysis. Newer markers are now available (such as EGFR receptor markers) and others are rapidly becoming of clinical value.

Centres should have all the appropriate radiological investigations available at the relevant stages of the pathway. It is evident that this is particularly important in treating metastatic disease. All four centres should have access to stereotactic

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<sup>&</sup>lt;sup>115</sup> NICE, Improving Outcomes in Metastatic spinal cord compression, 2008

radiotherapy facilities consisting of either linac-based stereotactic, gammaknife, or cyberknife facilities.

There is a shortage of neuro-psychologists nationally: this expertise should be present at neuroscience centres.

There is also a national shortage of rehabilitation facilities, particularly for those patients with spinal cord tumours such as ependymomas and other tumours with a longer term prognosis. Supportive care and rehabilitation is of key importance and requires development and consolidation with commissioned rehabilitation facilities to each of the four neurosciences centres. Significant disability can result from brain and CNS tumours and bulky rehabilitation equipment, a gym, and a high staffing ratio per patient are required. Due to the specialised and extensive rehabilitation requirements, collocating facilities and beds with major neuroscience centres would ensure that these patients are not competing with much larger groups of patients, limiting access to generic rehabilitation services. Highly specialised dedicated rehabilitation facilities would ensure immediate and effective access.

Equally, rapid access to appropriate levels of neuro-rehabilitation is required for those patients with palliative care needs and those with shorter prognosis CNS tumours. For these patients rehabilitation can be complicated by a prolonged period of physical and cognitive disability with a profile of distressing symptoms that are hard for patients and families to endure. These groups of patients often require a different rehabilitation approach and those with a shorter prognosis would require care closer to home. Collaboration between health and social care is required to develop appropriate placements for those people who need ongoing institutional care and may have challenging symptoms.

#### **Key recommendations:**

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.

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.

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

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 neurorehabilitation closer to home.

# 9.7 Gynaecological cancers



The case for change sets out that the range in populations served by gynaecological cancer centres suggests that fewer services could manage increased volumes per multidisciplinary team with more effective use of specialist resources. The case for change also points to the variation across London in lengths of stay following gynaecological procedures and the provision of support services.

The case for change shows that there are 24 providers of gynaecological cancer services in London and six centres for specialist surgery. In line with the gynaecological cancers IOG116, it is recommended that specialist cancer treatment (all gynaecological surgery except for cervical cancers and early endometrial procedures) is commissioned from five specialist centres. These centres should serve populations of approximately two million, with around 200 new referrals a year. 117 In addition, the commissioning of five specialist gynaecological cancer centres would enable the clinical co-dependency and optimal collocation with specialist urology<sup>118</sup> to be fully met, as this model of care proposes that specialist urological cancer is consolidated to five centres.

There is evidence to show improved outcomes using the minimally invasive approach to surgery, and this should be offered where appropriate.

Where duplication exists, services and expertise should be rationalised in specialist multidisciplinary teams. Individual surgeon caseload could increase for specialist procedures and brachytherapy departments could be shared between centres. For example, laparoscopic hysterectomy for the morbidly obese is highly specialised and requires experienced anaesthetists, surgeons and theatre team as well as high dependency unit (HDU) facilities and should only be undertaken in specialist centres. If the expertise to provide the minimally invasive approach is not available at a centre, the patient should be offered referral to a specialist centre where appropriate expertise exists.

This model of care does not propose an optimum number of providers for low complexity gynaecology procedures. Instead, providers should become subject to an accreditation scheme (see section 10.5). The need to gain accreditation would encourage low volume providers to exit the market and in this way the optimal level of providers would be achieved.

The number of people suitable for cervical surgery is falling both because cervical screening is effective, but also because a large number of patients present at a stage where they are inoperable. Non-surgical treatment is becoming more specialised, with MRI planning for radiotherapy and targeted radiotherapy. Laparoscopic para-aortic lymph node dissection for surgical staging should be available, alongside facilities to administer extended field radiotherapy.

Enhanced recovery after surgery programmes should also be adopted by all surgical and anaesthetic teams treating patients with gynaecological cancer to improve care and reduce hospital length of stay (see section 8.7). The patient's personal circumstances must be taken into account when planning earlier discharge and it



<sup>&</sup>lt;sup>116</sup> NICE, Improving Outcomes in Gynaecological Cancers: The manual, 1999

NICE, Improving Outcomes in Gynaecological Cancers: The manual, 1999

As shown in the supporting document – the cancer co-dependencies framework

must be ensured that appropriate support arrangements are fully in place prior to their departure from hospital.

As with other tumours, ovarian cancer patients should always be considered for clinical trials. Tissue should be made available for translational research. The number of endometrial cancers continues to rise in line with increasing prevalence of obesity. Treatment of this disease is becoming more complex and these women should also be considered for clinical trials.

All patients should have access to supportive care. Examples include:

- Reproductive medicine such as in vitro fertilisation (IVF) and embryo cryopreservation where appropriate before curative but fertility destroying treatment
- Laparoscopic ovarian transposition to maintain ovarian function in women having pelvic radiotherapy
- Management of treatment-induced menopause
- Screening for psychological distress prior to, during or after treatment
- The management of radiotherapy-related bowel toxicity.

As more women are likely to survive gynaecological cancer, attention should be focused on quality of life issues, such as preserving ovarian function or fertility where appropriate, and on research to minimise treatment related physical and psychological morbidity.

Adopting a minimally invasive approach and enhanced recovery programmes, ensuring access to clinical trials and supportive care, and addressing quality of life issues, would be more manageable if the treatment plan is determined by one of the five specialist multidisciplinary teams. This would also contribute to reducing the variation in length of stay across London for gynaecological surgical operations.

# **Key recommendations:**

Specialist gynaecological surgical treatment (all surgery except for cervical and early endometrial procedures) should be commissioned from five specialist providers.

Providers should establish protocols to ensure that the following are addressed: a minimally invasive approach and enhanced recovery is offered where appropriate; all ovarian and endometrial cancer patients are considered for clinical trials; access to supportive care services, and quality of life issues, including preservation of fertility is offered.

Treatment plans should be determined by a specialist multidisciplinary team and these aspects of care could be delivered locally, where appropriate.



#### 9.8 Sarcoma

There are two soft tissue sarcoma centres in London. One of them is a combined bone and soft tissue sarcoma centre split across two sites; it is one of the five national supra-regional bone tumour treatment centres. The *case for change* sets out that the configuration of sarcoma services exceeds the sarcoma IOG<sup>119</sup> requirement and that the clinical consensus is that there is an appropriate number of providers. No change to the number of providers is therefore necessary.

The creations of linkages between sarcoma multidisciplinary teams and multidisciplinary teams in upper gastrointestinal, gynaecological, and head and neck, is required so that sarcomas occurring in these anatomical sites have input from a sarcoma multidisciplinary team. These linkages should be seen primarily to be from multidisciplinary teams towards the sarcoma multidisciplinary team, rather than in the reverse direction. Quality accounts should include metrics to measure appropriate referrals by tumour type, as well as targets for referral and repatriation times between local and specialist multidisciplinary teams to drive efficient transfers.

# **Key recommendation:**

Providers should establish protocols to ensure linkages between sarcoma multidisciplinary teams and teams in upper gastrointestinal, gynaecological, and head and neck so that sarcomas occurring in these anatomical sites can have input from a sarcoma multidisciplinary team.

# 9.9 Haematopoietic progenitor cell transplantation (HPCT)

The case for change sets out the economies of scale benefits associated with greater centralisation. HPCT is a high risk and complex service requiring substantial and costly infrastructure. In addition, investment in specialist facilities and specialist staffing is required to create a sustainable and cost effective model. High volume is also required for experimental research activity for cord blood transplants.

In 2007/08 there were eight providers of adult HPCT services in London. Commissioners should further consolidate HPCT services to five providers undertaking a minimum of 100 new cases each year. All providers should be accredited by the Joint Accreditation Committee of International Society for Cellular Therapy and European Group (JACIE).

Most HPCT is for malignant disease but there is a significant minority of HPCT for non-malignant conditions (aplastic anaemia and haemoglobinopathies) and provision must be made for these within any service reconfiguration.

Interdependencies with molecular diagnostics and radiotherapy exist. Collocation with paediatric transplantation would provide economies of scale given that this treatment spans the whole age range.

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<sup>&</sup>lt;sup>119</sup> NICE, Improving Outcomes for People with Sarcoma, 2006

#### **Key recommendation:**

Commissioners should further consolidate HPCT services to five providers each undertaking a minimum of 100 new cases a year.

### 9.10 Specialist care

# 9.10.1 Specialist radiotherapy

There should be one centralised commissioning and planning structure for specialist radiotherapy (stereotactic, cyberknife, and proton beam therapy (PBT)) in London. Where appropriate, its provision should be concentrated in specialist centres so that sufficient cases are seen to justify the technology cost and sufficient trained staff to use it.

Individual institutions are currently submitting proton beam facility bids in response to the Department of Health's call for submissions. A cooperative approach between individual institutions would ensure equal access for patients. Drivers for the provision of PBT include:

- Less morbidity and collateral damage to critical structures, increased quality of life, and reduced side effects
- Approximately 200-300 primary brain patients, 150 sarcoma cases, and 150 head and neck cases in London can be treated more effectively with PBT each year
- The increasing incidence of hepatitis C has led to many more cases of HCC for which PBT is proving to be the preferred treatment modality.

For intensity-modulated radiation therapy (IMRT), the National Radiotherapy Advisory Group (NRAG) recommends that all replacement and newly installed machines are capable of delivering IMRT. The NRAG has held a tendering process and is now implementing a nationwide multidisciplinary training programme to ensure the delivery of IMRT in at least one centre in each network nationally by 2012.

### 9.10.2 Specialist imaging

For rarer cancers, commissioning of specialised imaging centres should be considered. Simple imaging can be performed locally but should be performed to a common standard to avoid repeat investigations when the patient is referred to a specialist centre. Fast transfer of images to the centre, and not just a report, is also required to avoid repeats and consequent delays. Positron emission tomography (PET) scanning and other more complex imaging should be performed in the specialist centre.

Integrating imaging technologies such as positron emission tomography – computerised tomography (PET-CT) scanning, ultrasound, and MRI, is an important element in diagnosis, staging and response assessment because frequently a



combination of these modalities is required to define abnormalities.

# 9.10.3 Molecular diagnostics

Molecular diagnostic facilities should be developed for each tumour type and expertise rationalised and shared between specialist centres.

Integrating molecular diagnostics with sophisticated imaging enables patients' treatment to be individualised from the time of first diagnosis.

# **Key recommendations:**

A centralised commissioning and planning structure should be established in London for specialist radiotherapy (stereotactic, cyberknife, and proton beam therapy), with technologies concentrated in specialist centres where appropriate.

For rare cancers, commissioning of specialised imaging centres should be considered. Molecular diagnostic facilities should be developed for each tumour type and expertise rationalised and shared between specialist centres. Integrating molecular diagnostics with sophisticated imaging would enable patients' treatment to be individualised from the time of first diagnosis.



#### 10. Enablers

If it were adopted by commissioners, the implementation of this model of care would require significant changes in the way that cancer services in London are commissioned and delivered. Implementing the model of care will require the harnessing of a number of enablers for change.

# 10.1 Commissioning

"In future, performance will be driven by patient choice and commissioning; as a result, there will be no excuse or hiding place for deteriorating standards."

### **Equity and excellence: liberating the NHS**

Strong commissioning should be at the core of cancer services in London. Commissioners should commission on the basis of high-quality patient pathways. Services should be commissioned from provider networks rather than organisations, although lead contracts may still be held by individual organisations.

During 2009/10 the NCAT commissioned 21 commissioning exemplars across 16 cancer networks. These are intended to demonstrate the kind of improvements in quality and productivity that can be delivered through effective commissioning. A particular focus is on engaging with service users; managing knowledge and asset needs; stimulating the market; promoting improvement and innovation; and securing procurement skills. The pilots are due to report by mid-2010. Every project will be evaluated and recommendations will be rolled-out across all cancer networks.

Some of the NCAT pilots are exploring the principle of commissioning by pathways and their results will provide insights to allow the principle to be implemented successfully.

Commissioning a comprehensive service means moving away from silos of care to service integration between cancer professionals and with other professions. This is particularly important for patients with physical and psychological co-morbidities and co-morbidities with other disease. Commissioners should consider the level of service integration when commissioning care pathways. This should not be taken to imply that non-cancer conditions requiring specialist care in primary or secondary settings are inappropriately referred to the oncology team (for example, diabetes patients). Instead, primary care physicians should take a coordinating role in patients health and healthcare needs and ensure the most appropriate care for, and where possible, co-management of patients with co-morbidities.

Expert commissioning advice should be provided by cancer commissioning networks made up of the management teams of the current cancer networks. This would ensure that this valuable source of expertise is not lost to the London cancer

<sup>&</sup>lt;sup>120</sup> Department of Health, Cancer Reform Strategy, achieving local implementation – second annual report, 2009

community. Initially, these teams would take on the role of change managers, making change happen.

Where appropriate, consideration should be given to further centralising commissioning to a single commissioning structure at a pan-London level for the provision of some rarer services and specialist treatments, for example radiotherapy.

Representatives of the cancer commissioning networks would sit on the boards of provider networks, providing a feedback loop from providers into the commissioning process. The teams would continue the work of the current cancer networks in gaining an insight into patient experience by engaging meaningfully with patients and carers.

Cancer commissioning should be informed by both clinical, patient and carer engagement. Patient and public involvement is fundamental to commissioning cancer services that meet local need. The NCAT has published guidelines on involving service users in commissioning. Key recommendations include providing a designated lead to support continuing patient involvement in commissioning services and direct participation of service users in decision making.

Strong commissioning would shift the balance of power away from providers towards commissioners and thereby drive up standards. *Liberating the NHS* has pledged that information on commissioner performance will be published, as well as that on provider performance, to allow them to be held to account for their use of public money.<sup>121</sup>

The Cancer Commissioning Guidance has been developed to support commissioning of cancer services. 122 It outlines key issues and questions that commissioners and cancer network teams should take into consideration when assessing health needs, reviewing services, developing their contract service specifications and monitoring performance.

#### 10.2 Contracting

The proposed model of care states that cancer services in London should be commissioned on the basis of patient pathways rather than organisational structures. This model would require significant change in commissioning structures and organisational cultures. New contractual arrangements would need to be made to reflect these changes. While the new provider networks would have management boards, they would not be legal entities. This presents commissioners and provider networks with a contracting challenge.

One solution would be to designate a 'lead contractor' in provider networks for each pathway. Commissioners would create a quality specification that the provider network must meet in order to be fully reimbursed. Rather than contracting with each individual provider in the pathway, the commissioner would have an agreement with

Department of Health and National Cancer Action Team, Cancer Commissioning Guidance, 2008

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<sup>121</sup> Department of Health, Equity and excellence: Liberating the NHS, 2010

the lead contractor. This lead contractor would then subcontract the various parts of the pathway to other members of the provider network.

In this way, the responsibility to ensure that all parts of the pathway are in place and that patients experience a seamless transfer between settings would lie with a single member of the provider network. Performance against the commissioned specification would be monitored by the cancer commissioning teams. Commissioners would have a single point of contact when discussing or revising the services provided. This lead contractor model would be particularly appropriate where patient pathways are clear and well-defined.

Commissioning

Commissioner

Contracts for parts of pathway

Commissioning through a lead contractor

Contract for whole pathway

Lead contractor

Subcontracts

Figure 12: The lead contractor model

# 10.2.1 Provider Performance Analytics

The Commissioning Support for London Provider Performance Analytics (PPA) portal is a secure, online resource which enables NHS commissioners across London to see how their providers are performing. It helps inform commissioning decisions through key performance indicators and allowing effective contract monitoring.

Contract monitoring is facilitated through an online solution for commissioners to monitor and manage their acute contracts. This online analytical tool allows commissioners to investigate provider over-performance quickly and simply. The tool will also enable commissioners to identify where activity is continuing at momcommissioned sites. Commissioners can then seek redress through a process of claims management.



Claims management is the process by which commissioners validate activity from a provider of health services (whether acute, community or mental health) and challenges them as appropriate. The PPA claims management tool enables commissioners to obtain the information they need to raise challenges on the data submitted by providers.

The claims management tool will help commissioners identify activity which does not conform to their acute contracts. This may represent either poor data quality or issues of clinical inefficiency. Further development of the claims management tool is planned and this has the potential to provide a mechanism through which commissioners can hold provider networks to account for failing to meet the quality of service commissioned for.

# 10.3 Funding arrangements

"The Department will accelerate the development of pathway tariffs for use by commissioners."

# Equity and excellence: liberating the NHS

For the proposed model of care to work, incentives need to be in place to foster appropriate collaborative behaviours and shared working. Work must be undertaken to ensure formalisation of financial flows around provider networks with mechanisms for sharing any surpluses created between network members.

#### 10.3.1 Rewarding quality

The Revision to the Operating Framework for the NHS in England 2010/11 outlines the intention to make payment systems reward excellent performance and be tough on poor quality. This concept is underlined in *Liberating the NHS*, which states that commissioners will be given the power to impose contractual penalties on providers delivering poor quality care. This would bind together quality and financial aims for providers. Full tariffs should be tied to evidence of active submission to national audits and the delivery of agreed trajectories for the spread of quality innovation and modelled to support service improvement.

Liberating the NHS includes a commitment to extend the scope and value of providers' income that is conditional on quality and innovation through the Commissioning for Quality and Innovation (CQUIN) payment framework. The key aim of the CQUIN framework is to support a shift towards the vision of an NHS where quality is the organising principle. This approach makes quality improvement and innovation integral to what commissioners pay for rather than assuming that more money is always needed to drive them.

Department of Health, Equity and excellence: Liberating the NHS, 2010

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<sup>&</sup>lt;sup>123</sup> Department of Health, *Revision to the Operating Framework for the NHS in England 2010/11*, 2010

<sup>&</sup>lt;sup>24</sup> Department of Health, *Equity and excellence: Liberating the NHS*, 2010

It is expected that every organisation will move to using the framework to reflect specific quality goals which represent measurable improvements on previous quality performance and innovation aimed at better outcomes.

The 2010/11 regional CQUIN schemes for acute providers and the associated framework have now been agreed for London under the following three themes:

- Delivery of London's clinical strategy
- Patient safety
- Quality of transfer of care, the timeliness of hospital discharges and communication with primary care.

Each theme includes a number of specific indicators. Two of the three themes, patient safety and quality of transfer of care, include indicators that are emphasised in the model of care. These indicators are:

- Implementation of enhanced recovery after surgery programmes
- Supporting effective discharges in a hospital setting
- Increased effectiveness of inpatient discharge information
- Increased effectiveness of outpatient care planning.

It has been suggested that, over time, up to 10% of trusts' income could be dependent on patient experience and satisfaction measures. <sup>126</sup> If adopted, this vision would represent a clear shift from a commoditised, production-line NHS to one that is people-centred; where staff are at all times encouraged to see care through the eyes of their patients and their carers. The participation in the National Cancer Patients' Experience Survey Programme would prove a valuable resource in this respect. All providers of adult acute cancer services in London should participate fully in the national survey programme.

## 10.3.2 Tariffs

There are technical challenges in accurately costing and developing tariffs for some complex areas of cancer service, including radiotherapy, chemotherapy and multidisciplinary teams. Work is underway to develop solutions to these challenges.

The NCAT has been working in partnership with the Department of Health's Payment by Results team to develop a costing framework to support the implementation of external beam radiotherapy. 127 It is anticipated that this work will lead to greater consistency in applying costs, as well as a better understanding of how variations in the capital costs of radiotherapy bunkers might affect tariffs.

Department of Health, Cancer Reform Strategy, achieving local implementation – second annual report, 2009

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<sup>126</sup> Department of Health, The NHS 2010-2015: from good to great, 2009

A project has also been launched to develop an improved understanding in the variations in the cost base for chemotherapy, with the intention of improving reference cost guidance and validating HRG4 as the basis of a national chemotherapy tariff. This project is drawing on the data generated from the new C-PORT financial module.

Multidisciplinary teams play a vital role in delivering high quality cancer care and it is important that they are properly resourced and fairly reimbursed. It is important that host organisations report costs as part of their reference costs returns. Although quality and uptake have improved over the last few years, the numbers of reference cost returns in this area are still low.

Work is also underway to ensure that the tariff provides fair payment for highly complex cancer procedures. As an example, the NHS Information Centre is working to develop a new HRG for head and neck reconstructive surgery based on case-mix data.

# 10.4 Transparency and high quality information

"We are committed to publishing detailed data about the performance of healthcare services."

# Revision to the Operating Framework for the NHS in England 2010/11

At the heart of the model of care is the collection and publication of high quality performance information. *Liberating the NHS* promises an 'information revolution' in the NHS to drive commissioning and patient choice. Providers will be under clear contractual obligations, with sanctions, in relation to accuracy and timeliness of data for use by commissioners and the public. It is vital that commissioners and cancer commissioning networks have access to high quality, contextualised data in order to make effective commissioning decisions. As more sophisticated measures are developed, quality metrics should be based on outcomes rather than on measures focused on improving health outcomes through improving processes of care that are considered to be linked to health outcomes.

Currently the Cancer Commissioning Toolkit is an invaluable source of information for cancer commissioners. It is aimed at supporting commissioning of cancer services across the NHS by making information on cancer care freely available. It includes a range of high-level indicators as well as a number of links to more detailed information right across the patient journey. All NHS organisations involved in commissioning cancer services are encouraged to use this information to benchmark the services they commission against the very best, setting the highest standards of care and improving outcomes for patients.

High quality information is also a driver of performance among clinical teams and helps to ensure that the right services and best possible care are provided to patients. A clinical dashboard is a series of visual displays developed to provide clinicians with the relevant and timely information that they need to inform their daily



decisions. Dashboards are currently being piloted in different services across the country and, if the results are positive, should be rolled out across London's provider networks.

Giving patients and the public a clear understanding of the quality of experience offered by their local providers is crucial to improving quality and informing choice. Ensuring patient choice is fundamental to the ambition to drive up the quality of cancer services. The high quality information necessary for the commissioning and managing services and provider networks would be made available to the public to inform this choice.

London's Quality Observatory (LQO) is a new web-based information portal supporting the NHS quality agenda for London. It will serve commissioners, clinicians and provider organisations, offering one-stop access to robust, high quality data and information. The Quality Observatory provides a vehicle to increase participation in the quality metrics that emerge from the model of care and its role should effectively be the coordinating, enforcing, and consolidating of data submissions.

#### 10.4.1 National audits

Providers should fully partake in all national cancer audits that pertain to their services, for example the national bowel cancer audit programme (NBOCAP) and the lung cancer data audit (LUCADA). This would allow national comparisons of performance to be considered, allowing services in London's provider networks to benchmark themselves against each other and other national cancer centres. Participation in national audits should be taken into account in any accreditation process to ensure ongoing compliance.

# 10.5 Accreditation and quality accounts

Liberating the NHS sets out plans to extend existing plans to compel providers working for or on behalf of the NHS to publish quality accounts. These will be reports to the public on the quality of services they provide – looking at safety, experience and outcomes. Easy-to-understand, comparative information will be available on the NHS Choices website at the same time. To ensure the availability of transparent high quality performance information, London's provider networks should publish consolidated cancer quality accounts. The content of these accounts will be developed in partnership with commissioners and, where appropriate, standardised across the capital through the pan-London governance board. Reporting on performance should be by provider network and by institution. The consolidated cancer quality account would profile both provider network quality and the performance of individual providers in each network.

London's NHS should use an accreditation process and publication of cancer quality accounts to help implement the recommendations in this proposed model of care, drive up quality, and inform commissioners, patients and the public. Accreditation

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<sup>&</sup>lt;sup>128</sup> Department of Health, Equity and excellence: Liberating the NHS, 2010

and cancer quality accounts could be developed through building on the National Cancer Peer Review (NCPR) programme, subject to agreement with regional and national directors. By building on the NCPR team's workforce, processes and experience instead of setting up separate structures, the additional administrative and financial burden on providers is minimised. The development of this concept would require further consideration in partnership with the NCPR team.

Providers of cancer care must be able to demonstrate that their service is comprehensive, safe, effective and research active. They must achieve these objectives within the context of a caring environment and provide the patient and family with a positive experience. Providers must have systems in place to measure and monitor their outcomes in these areas.

Examples of the metrics that can be used to ensure compliance with these clinical goals are:

- Safe care reduction in health care associated infections, full compliance with NPSA guidance, use of the WHO Surgical Safety Checklist
- Effective care clinical outcomes such as survival, electronic recording of clinical minimum data sets (for example, cancer staging information), engagement in relevant national audits, initiatives to reduce the length of inpatient stay (enhanced recovery)
- Patient experience real time monitoring of patient and family satisfaction surveys, systematic review of complaints, patient and family engagement in design of care
- Research active accrual into clinical trials, systematic collection of tissue for research, demonstrable links to high quality translational research institutions.

Indicators should also be developed that encourage collaborative working, such as targets for referral and repatriation times between local and specialist multidisciplinary teams to ensure efficient transfers.

Liberating the NHS sets out plans for patients to be enabled to rate services and clinical departments according to the quality of the care they receive. 129
Commissioners and provider networks should engage service users in the development of patient satisfaction measures for cancer quality accounts. This should include the outcomes of the National Cancer Patients' Experience Survey Programme. Providers of adult acute cancer services in London should participate fully in this programme. The latest survey programme will run in 2010 and results will be published in November 2010. These results will allow assessment of whether there has been further improvement since the last survey in 2004 and where efforts over the coming years should be focused.

*Liberating the NHS* also restates the importance of patient generated information in realising its vision of an information revolution. <sup>130</sup> Patient reported outcome measures

Department of Health, Equity and excellence: Liberating the NHS, 2010



<sup>129</sup> Department of Health, Equity and excellence: Liberating the NHS, 2010

(PROMs) should be included as they are developed for cancer services. Initially there might be limited health outcome measures that can be used as quality measures; the focus of the quality measures should therefore be on improving health outcomes through improving processes of care that are considered to be linked to health outcomes. Ever more sophisticated quality measures should be used as they are developed through patient and public involvement.

Cancer quality accounts would be assured so that patients and the public can rely on them as a fair and accurate assessment. They would be published widely to allow patients and the public to make comparisons between services. Service user involvement has shown that, while best use of modern technology should be made, reliance on it can serve to exacerbate inequalities. Consideration should therefore be given to access to cancer quality accounts, for example through Local Involvement Networks (LINks), Citizens Advice Bureaux, libraries, commissioner newsletters, and community groups.

To ensure all cancer services are accredited, the requirement to have accreditation should be included in commissioning intentions. If a service does not have accreditation due to the review visit not having yet taken place it should have plans in place to obtain accreditation, and in the interim, would need to meet a specific set of quality measures. In addition a service would not get the value of their contract fully reimbursed unless and until it obtains accreditation. If a service fails to obtain accreditation or to make progress towards accreditation, it would not be commissioned in the next commissioning round. Commissioning intentions should also include the requirement for non-accredited providers to make a special case for payment for occasional performance.

### 10.6 Clinical leadership

The proposals contained in this document are rooted in the ambition to provide world-class cancer care across London, improving both outcome and experience for patients. The development of the proposals has been clinically led with wide clinical engagement. Implementing the proposed model of care will require significant cultural change. If it were adopted by London's cancer commissioners, the implementation of the model of care must have the same level of clinical leadership to ensure the ongoing engagement of the clinical community, and the London population, with the proposed changes.

# 10.7 Partnership models and collaborative working

Funding flows and incentives must be in place to ensure that organisations in provider networks work collaboratively where necessary. This collaboration will enable the standardised services and shared learning essential to improve cancer services for all Londoners.

Provider networks should consider using formal partnership models to facilitate this shared learning and standardisation. One possibility would be for foundation trusts based in one area to provide both acute and

community services in other areas, if the relevant commissioners want to commission from them.

Full vertical integration has its disadvantages, however, and models such as shared ownership, franchising or 'virtual integration' may be preferred to support the provision of high-quality services throughout the provider network.

# Case study: day chemotherapy services at Kingston Hospital

Day chemotherapy services at Kingston Hospital are directly managed, staffed and supported by the Royal Marsden NHS Foundation Trust with agreed governance arrangements. Patients requiring inpatient chemotherapy or inpatient admission for side effects are transferred to the Royal Marsden.

The lead nurse for chemotherapy is a Royal Marsden appointment and nurses supporting the unit at Kingston rotate through the Royal Marsden. Royal Marsden oncologists provide oncological support and opinion at joint clinics and multidisciplinary meetings.

# 10.7.1 Independent and third sector partnerships

The use of independent sector capacity for NHS patients is appropriate for consideration by commissioners. Where private sector providers are involved in the patient pathway on a short-term basis, contracts must be in place to ensure that services are specified to the same standard. Where the use of private sector providers is ongoing, these providers should be represented and held to account by the provider network governance board.

Partnerships with independent and third sector organisations should also be considered where innovative models of care are proposed. This consideration should take into account best practice and the trialling of models elsewhere in the country.

#### Case study: chemotherapy at home

A pilot is being carried out in Bristol to find out whether patients want the option of nurses administering chemotherapy where they live rather than having to travel to hospital for treatment.

Under the scheme, which is being carried out in partnership between Bristol Haematology and Oncology Centre and NHS Bristol, patients are visited by nurses from the private firm, Healthcare at Home.

The pilot began in November 2009 and findings are expected in 2010.



### 10.8 Patient choice and contestability

"Competition and choice are key mechanisms to create a patient-centred and quality-focussed NHS."

## Revision to the Operating Framework for the NHS in England 2010/11

Although some aspects of the model are based largely on collaboration, there is the deliberate inclusion of scope in the model of care for the maintenance of patient choice and contestability to drive up quality.

The new service delivery models proposed would have implications for the competitive landscape. Retaining competition when, for example, reducing numbers of providers would require robust performance monitoring mechanisms and contractual agreements for providers of relevant services. Systematic review of quality and productivity would be fundamental. Length of contracts should be defined and centres invited for competitive tender if providers are underperforming to ensure competition for accreditation and the driving up of quality. Organisational barriers should not act as a hindrance to competitive contracting arrangements.

Liberating the NHS states that Monitor (the regulator of foundation trusts) will be developed into an economic regulator from April 2012, with responsibility for all providers of NHS care from 2013/14. Part of Monitor's role will be the promotion of competition and prevention of anti-competitive behaviour.

#### 10.9 Focus on patient and carer experience

"Patient experience is only as good as the weakest point in the patient pathway."

#### **Cancer Patient Panel**

Improving outcomes and experience for patients is the aim of the proposed model of care. *Liberating the NHS* lays out the ambition to achieve healthcare outcomes that are among the best in the world. This can only be realised by involving patients fully in their own care, with decisions made in partnership with clinicians, rather than by clinicians alone. Patients will only experience high quality care if all parts of the pathway are in place and care is coordinated across it. Information must be readily available about what their choices are and what they can expect from their care. Patient and carer involvement through the cancer patient panel and stakeholder events has shown that there are a number of contributory factors to patient experience in addition to the quality of care.

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<sup>&</sup>lt;sup>131</sup> Department of Health, *Equity and excellence: Liberating the NHS*, 2010

### 10.9.1 Communication and patient information

"Patients will be at the heart of everything we do. So they will have more choice and control, helped by easy access to the information they need."

# **Equity and excellence: liberating the NHS**

One of the four key winning principles identified by the NHS Improvement programme to transform cancer inpatient care is that patients and carers need to know about their condition and symptoms to encourage self-management and know who to contact when necessary. 132

Service user involvement has confirmed the importance of good quality patient information, which is fundamental both to inform patient choice and improve patient experience. It is important to ensure that patient information is tailored to suit the needs of different groups in local communities, for example in the appropriate language and in different formats.

# Case study: cancer translation project for London and Hertfordshire – Macmillan Cancer Support

The project was established to produce leaflets and a combined audio version which aimed to meet the needs of people affected by lung cancer. The project recruited representatives from target communities and established focus groups for each local community. The focus groups produced health advice and advocacy booklets designed for that community, with suitable content and in the appropriate language.

Community engagement was vital for the project as cultural issues, the authenticity of the languages and content of the booklets had to be taken into consideration. It also provided the opportunity to promote mainstream cancer organisations and their services, which most of the targeted communities were unaware of.

The Cancer Reform Strategy states that tumour specific national information pathways should be adopted and implemented. This would make nationally agreed information available to frontline cancer health professionals to offer to patients at key points in their cancer journey. The National Cancer Action Team has been working with information providers to develop these and the pathways are being rolled out in 2010. The pathways should also form the basis of information prescriptions.

<sup>&</sup>lt;sup>132</sup> NHS Improvement, *Transforming care for cancer inpatients: spreading the winning principles and good practice*, 2009

### **Case study: information prescriptions**

The concept of information prescriptions was announced in *Our Health, Our Care, Our Say* as a way of directing people to all the latest information and advice on their condition. <sup>133</sup> IPs have been piloted in twenty sites across England, including the Royal Marsden Hospital.

Information prescriptions should be offered to everyone with a long-term condition in consultation with a health care professional. Information prescriptions guide people to relevant and reliable sources of information to allow them to feel more in control and better able to manage their condition and maintain their independence.

Information prescriptions are nationally recognised as a source of key information on services and care that is seamlessly and formally integrated into the care process.

Patient and carer feedback has shown that the standard of patient information currently available across London varies. Provider networks must control the quality of patient information material from all sources in the network. This can be achieved through the Information Standard accreditation scheme, which guarantees the quality of information for patients.

Information materials should be standardised where possible throughout the provider network but sufficient flexibility should remain to ensure that local needs and demands are met.

Patient information areas should be developed at all sites providing cancer services to allow patients to search for, and digest, information at their own pace. Consideration should be given to working in partnership with the third sector in developing these information areas.

#### 10.9.2 Financial help

A patient's information requirements should be considered in the round. The *Cancer Reform Strategy* states that, as part of integrated services, commissioners should ensure that all people affected by cancer are given information about financial help, including welfare benefits. Information should cover how to access help and an individual's rights under the Disability Discrimination Act. The provision of information prescriptions would be an appropriate way of meeting patient information needs.

# 10.9.3 Transport

"Transport can be a barrier to accessing care. The Social Exclusion Unit estimates that 1.4 million people miss, turn down or simply choose not to seek health care because of transport problems."

Our Health, Our Care, Our Say

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<sup>&</sup>lt;sup>133</sup> Department of Health, *Our Health, Our Care, Our Say: a new direction for community services*, 2006

For some patients, travelling to receive healthcare can present difficulties. The journey may be lengthy, complex, or costly, or there may be poor access to public transport. In particular, patients receiving benefits or low incomes can find it difficult to meet the cost of travelling to hospital or other healthcare premises for treatments or diagnostic tests. This can widen health inequalities by disproportionately affecting vulnerable groups. In addition, it may potentially have serious consequences for the health of the patient as patients may avoid treatment. These difficulties can be particularly acute for cancer patients due to the need to travel regularly to receive treatments such as chemotherapy and radiotherapy.

Service user involvement has confirmed that the practical arrangements for patients travelling to and from hospital or other care settings are a vital factor in their overall experience of services. Commissioners should commission pathways that take this fact into account and provide patient transport solutions, where appropriate. These solutions may range from in-house or outsourced patient transport providers to partnership working with the voluntary sector. Consideration should also be given to the development of systems to provide free car parking for patients and carers who must regularly attend healthcare settings.

Providers should also make full use of existing support services such as the Healthcare Travel Costs Scheme. Provider networks should ensure that all cancer patients are aware of the support that is available to them, including support from outside of the NHS such as the London Taxicard Scheme.

# Case study: Healthcare Travel Costs Scheme 134

The Healthcare Travel Costs Scheme was set up in 1988, as part of the NHS Low Income Scheme, to provide financial assistance to those patients who do not have a medical need for ambulance transport, but who require assistance with their travel costs.

Under the scheme, patients on low incomes or receiving specific qualifying benefits or allowances are reimbursed in part or in full for (public transport or petrol) costs incurred in travelling to receive certain NHS services, where their journey meets certain criteria.

#### **Case study: the London Taxicard Scheme**

The London Taxicard Scheme is funded by the participating London boroughs and the mayor of London. London Councils Transport and Environment Committee (TEC) manages the London Taxicard Scheme on their behalf.

Taxicard is a method of providing subsidised door-to-door transport for people who have serious mobility impairment and difficulty in using public transport. Taxicard holders make journeys in licensed London taxis and the subsidy applies directly to each trip.

<sup>&</sup>lt;sup>134</sup> Department of Health, *Healthcare Travel Costs Scheme: instructions and guidance for the NHS*, 2008

Patient and carer engagement has revealed that the Taxicard Scheme was developed for individuals with chronic conditions and is therefore not always considered applicable for cancer patients. Provider networks should work with local authorities to extend the scheme so that it is available on a shorter-term basis to cover cancer patients receiving regular treatment.

#### 10.9.4 Support on discharge

The new model of care will see reduced length of stay through increased rates of day case surgery and laparoscopic techniques for common cancers, and enhanced recovery programmes across all cancer types. These techniques would only be used if it is clinically appropriate to do so. For some patients they would only be appropriate if sufficient support is available, both for them and for their family or carers, to allow earlier discharge. The keyworker should liaise with both local NHS and social services to plan for discharge to ensure that the appropriate arrangements are in place.

For 2011/12 the Government is planning changes to tariff structures to cover reablement and post-discharge support. 135 Alongside this, the Government has also announced the intention to ensure that hospital providers are responsible for patients for the 30 days after discharge, with further payment withheld if the patient is readmitted during this period.

#### 10.9.5 Keyworker and clinical nurse specialists

The Manual of Cancer Services recommends that multidisciplinary team operational policies should include identification, and recording in case notes, of a single named keyworker for each patient's care. 136 Service user involvement has confirmed that patients view the keyworker as central to their experience of the care that they receive.

The Cancer Reform Strategy identified the vital role that clinical nurse specialists can play in improving the experience of people living with and surviving cancer. Nurse specialists play a hugely valuable role across many different elements of cancer patient management and support, carrying out a range of technical, informational, emotional and coordination functions, including:

- Familial risk assessment
- Communication and information
- Delivering treatment (such as chemotherapy)
- Psychological and emotional support for patients and families
- Providing continuity of care

<sup>&</sup>lt;sup>135</sup> Department of Health, Revision to the Operating Framework for the NHS in England 2010/11, 2010 .

136 Department of Health, *Manual for Cancer Services*, 2004

- Supporting and advising patients' families and carers
- Developing a post-treatment plan to ensure that care issues are addressed rapidly.

# 10.9.6 Carer support

The national carer strategy, *Carers at the heart of 21*<sup>st</sup> century families and communities, states that demographic changes mean that the needs of carers must be elevated to the centre of family policy and receive the recognition and status they deserve.<sup>137</sup>

The Cancer Reform Strategy states that families and carers need access to information and support throughout the care pathway. Feedback from service user engagement through the Cancer Patient Panel indicates that the support needs of family and carers can be neglected. Providing and coordinating support for carers is an important role of the keyworker and must form part of the patient's holistic assessment.

Commissioners need to ensure that adequate provision is available so that all patients, families and carers can access the appropriate support. This would include establishing service level agreements where appropriate with local mental health services for more advanced support.

#### 10.10 Research

"Research is vital in providing the new knowledge needed to improve health outcomes and reduce inequalities. Research is even more important when resources are under pressure. It is essential if we are to increase the quality and productivity of the NHS."

#### Equity and excellence: liberating the NHS

One of the major strengths of London is its high level of basic biomedical research expertise leading to opportunities in translational research. The patient numbers are sufficient to speed implementation of new developments into clinical practice, although such expertise is not currently fully utilised for patient benefit. There is a need to commission, and set targets for, this element to be incorporated into future models of care to ensure that London fully exploits its scientific strengths.

The case for change shows that cancer patients who participate in clinical trials can have better outcomes and that generally all patients treated in an environment that undertakes clinical research do better whether or not they are part of a clinical trial. London's NHS should ensure that patients are afforded every opportunity to enrol in national trials.

Research should be fully integrated with clinical care to provide the highest quality cancer care possible for Londoners. Provider networks should form strong links with

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<sup>&</sup>lt;sup>137</sup> HM Government, Carers at the heart of 21<sup>st</sup> century families and communities, 2008

high quality cancer research institutions including, where appropriate, Academic Health Science Centres (AHSCs) to ensure that research findings are translated into improved care across the whole network. London has internationally renowned cancer research centres within its boundaries, as well three of the country's five AHSCs.

The systematic collection of all data, both bioinformatic and clinical outcome data, is vital not only to assessing effectiveness of clinical intervention but also in allowing academic outputs. Investment in information collection for commissioning purposes provides a good opportunity to form links with academic database collection, including links with bio-banks.

#### 10.10.1 Bench to bedside research

London has a large population but, as described in the *case for change*, there is no pan-London strategic approach to the development of new treatments in collaboration with the pharmaceutical industry or universities. Developments of pan-London tissue banks would allow pooling of precious resources and enhance access for development of new targets and biomarkers of disease. The development cycle of new agents could be shortened by pooling resource to ultimately benefit patients.

Commercial trial activity could be enhanced with London becoming the preferred provider for commercial trials of new drugs. This would have advantages for patients as well as commissioners; patients would gain access to drugs not otherwise available, commissioners would not have to pay for these treatments and providers would be able to generate income as well as academic output. This would also draw in patients from around the periphery of London and further afield.

Investment and prioritisation in predictive and prognostic biomarkers research should lead to enhanced outcomes, provide substantial savings to London's NHS, and provide the tools to evaluate and introduce new treatments into clinical practice.

There is also a need to marry together the more basic elements of cancer research with the translational and clinical aspects. The experience in London and at some centres internationally is that this can considerably increase the rapidity of transfer of basic discoveries into new therapeutic strategies. Moreover, the availability of clinical material from trials can facilitate and expand the scope of more fundamental approaches.

#### **Case study: British Columbia Cancer Center**

The British Columbia Cancer Center seeks to enhance cancer control with focus on a translational research organisational model, linking the pathway from discovery research to improved health outcomes, and vice-versa, by establishing a collective interdisciplinary resource across the domains of discovery research (basic), clinical research and population application.

To bring added focus to the translational research agenda, the organisation's direction and resources are in three broad areas – the discovery agenda of Predictive and Personalised Cancer Medicine; the clinical or validation agenda of

Interventional Cancer Management, and the population application agenda directed to Population Health and Cancer.

#### 10.10.2 Qualitative research

Qualitative research is often used to measure patients' experiences and 'softer' areas of service provision. London has leading cancer nursing research departments that undertake such research. Qualitative research is an important component of the cancer research portfolio and should be encouraged and fostered across provider networks.

#### 10.11 Innovation

One of the key roles of provider networks would be to disseminate best practice where there is innovation in service provision. Examples of innovations currently partially disseminated are laparoscopic colorectal surgery, day case breast surgery, and enhanced post surgical recovery.

Cancer commissioners and provider networks should agree challenging year-onyear rates for diffusion of innovation. The rate should balance pace to bring the benefits of innovation to a much wider population as soon as possible, with sufficient time to ensure that the professional training and cultural change required to deliver diffusion is robust. Agreed rates of diffusion should be tied to differential tariff rates. Where provider networks fall off the agreed pace of diffusion they would be required, at their expense, to invite a top decile performer to review their adoption of innovation plan and make recommendations.

The NHS Improvement programme to transform cancer inpatient care has highlighted that some of these innovative delivery models are now being adopted. Pilot sites have noted that successful spread automatically follows across tumour sites if the baseline evidence and measure of benefits from testing was robust.

# 10.12 Estates and facilities

The specialist nature of buildings housing radiotherapy facilities is a particular driver for the physical capacity planning of specialist cancer services in London. The London Cancer Network Board's comprehensive assessment of the implications of the NRAG report for London made it clear that London has enough radiotherapy capacity built, even given the increases it needs to plan for, if it is used efficiently. There are some areas however where the travel time requirement cannot be met

<sup>138</sup> NHS Improvement, *Transforming care for cancer inpatients: spreading the winning principles and good practice*, 2009

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Recommendations: A review of the implications for London, A baseline assessment of London Radiotherapy Services, 2009

without the construction of satellite linear accelerator bunkers. No additional capacity should therefore be commissioned without full business case assessment by the London Specialised Commissioning Group.

The wider physical capacity and facilities that are currently collocated with radiotherapy bunkers, including inpatient beds, should be included within London commissioning strategy plans to optimise both quality and productivity through implementation of the specialist care elements of this model of care. It is likely that current providers would need to work together, and across commissioning boundaries, to achieve this optimal and affordable use of sites.

# 10.13 Information technology

A sound IT infrastructure underpins many of the proposed service configuration changes in the model of care. Improved information technology will be crucial in ensuring that the patient experiences seamless services, whilst being seen in the most appropriate settings within the provider network.

# 10.13.1 Call and recall services (screening)

A key recommendation from the London Specialised Commissioning Group's review of NHS screening programmes was the reconfiguration of the call and recall services for the breast and cervical screening programmes. Once implemented, this reconfiguration will enable greater flexibility of appointments for women and increase access. Additionally, this will combat the problems of GP catchment areas which result in patients being missed or called to screening services in the wrong borough.

#### 10.13.2 Electronic referrals

Systems for making electronic referrals, either between primary and secondary care or secondary to tertiary, can have a major impact in reducing the amount of missing information and ensuring that delays are reduced. The cost of these systems is now negligible as they are run on existing web-based systems, such as NHSNet. Such systems should be implemented where they are not currently used.

#### 10.13.3 Diagnostics and image sharing

A secure and stable mechanism is required for safe sharing and transfer of images across provider networks. This would help to provide a timely diagnosis and may reduce the duplication of tests. Two systems, PACS Exchange and Image Exchange Portal, are currently being rolled-out across London providers to ensure that PACS systems can share images, both within and outside of London.

Compatible IT systems along the pathway, within and across provider networks are needed to enable the onward referral of patients with positive test results to multidisciplinary teams.

#### 10.13.4 Avoiding admissions

One of NHS Improvement's winning principles for transforming inpatient care is that emergency patients should be assessed prior to

the decision to admit. Information technology can be used to ensure that cancer patients presenting as an emergency are assessed by the correct team. The example of recurring admission patient alert (RAPA) systems, which work with patient administration systems to alert clinical teams to the presence of previously-diagnosed patients, is outlined in section 8.7.

# 10.13.5 Multidisciplinary meetings

Effective video-conferencing and other technologies for successful team working should be explored. The use of electronic systems, such as Infoflex and eMDT, to record recommendations in real time would also assist multidisciplinary teams in coordinating meetings and improving the availability of information about the patient. The recording of team decisions in real time would ensure that minimum datasets are captured. This would drive therapeutic decisions as well as audit and research.

# 10.13.6 Follow-up

New models of bespoke follow-up are contingent on the ability of cancer patients to report readily and easily on their condition through a self-assessment programme. Information technology has the potential to make these new models viable by allowing online self-reporting by patients through sites such as HealthSpace.

### Case study: HealthSpace

HealthSpace is a free, secure online personal health organiser. It can help people to manage their health, store important health information securely, or find out about NHS services in their area.

Anyone living in England aged 16 or over, with a valid email address can register for a HealthSpace account.

Although access to and literacy in computing and the internet is growing, commissioners should ensure that alternative forms of self-reporting are available to patients.

10.13.7 Systems to enable patient information sharing and e-prescribing across the provider network

Transparent performance information forms the foundation of the new model of care. Data collection and information exchange systems must be in place to enable measurement of patient experience and outcomes. This would have a cost implication but it is the responsibility of London's NHS to provide integrated IT solutions fit for the 21<sup>st</sup> century.



# Case study: EMIS Web

EMIS Web<sup>140</sup> is a system that links patient data and information from community and acute providers. The system is currently being used in Tower Hamlets PCT.

The system delivers two key benefits to general practices: access to shared patient records between GPs and community or secondary care, and advanced functionality for everyone in the practice.

Patient data is also accessible from non-EMIS systems using what is known as an interoperability portal. A secure, shared record that GPs, health visitors and other community staff can access means there is less chance of a problem or important information getting missed.

The use of electronic prescribing through an agreed national data set would allow data collection along the patient pathway, facilitate audit and support Payment by Results. Most importantly it minimises clinical risk by negating the need for chemotherapy facilities to use paper-based prescriptions. Systems to deliver e-prescribing are currently being implemented across London. Provider networks should ensure that e-prescribing is fully implemented to help deliver safe and effective systemic therapy services.

#### 10.14 Workforce

Currently the vast majority of cancer diagnosis and treatment in London is provided in secondary and tertiary care. Delivering care in the future in the most appropriate settings as described in the *Cancer Reform Strategy* may require a programme of disinvestment in current models of care and reinvestment in new ones together with major changes in workforce.

The cancer workforce has expanded considerably since 2000 and looks set to continue to do so in coming years. Overall, it is projected that there will be a 23% increase in consultants in specialties with a major role in cancer care between 2008 and 2012. The second annual review of the *Cancer Reform Strategy* explains that despite these increases there are still workforce pressures, because expansion has not kept pace with increases in activity in some areas.<sup>141</sup> It will also be important to consider how other disciplines can be given appropriate training

#### 10.14.1 Joint posts and regional contracts

Flexible working arrangements where clinicians and medical staff work across the pathway would encourage collaborative working and allegiance to the provider network, rather than exclusively to individual institutions. New staff could hold joint contracts across two or more organisations in the provider network. There is also the

Department of Health, Cancer Reform Strategy, achieving local implementation – second annual report, 2009

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<sup>&</sup>lt;sup>140</sup> Produced by Egton Medical Information Systems Ltd (EMIS)

possibility of a system of central contracts, where individuals work for the provider network, although such a model may be some years off.

# 10.14.2 Implications of provision of local services

The case for change highlights that there are too many small and unsustainable multidisciplinary teams for cancer services in London. Fewer, larger multidisciplinary teams that are properly supported and contain all of the necessary specialist skills are required to achieve critical mass. Providing some cancer services on an outreach basis from fewer, fully comprehensive multidisciplinary teams addresses the problems that would result from reducing the number of multidisciplinary teams in London. This would have several workforce implications however.

Strong links have been made with the Chief Nursing Officer's Modernising Nursing Careers initiative, and cancer is one of the pilots for mapping the new Nursing Career Framework. One of the aims of the initiative is to assess the contribution made by nurses across the care pathway and consider if and how the role of the clinical nurse specialist needs to evolve and change to reflect the shift of care away from secondary care.<sup>142</sup>

# 10.14.3 Multidisciplinary meetings

The Cancer Reform Strategy made clear that multidisciplinary team working would remain the core model for cancer service delivery in the future. The focus to date has been on getting the multidisciplinary teams in place. The focus now needs to be on how these multidisciplinary teams are working. Key messages from a 2009 survey of successful multidisciplinary teamworking included:

- Team members need protected time for preparation, travel, and attendance at meetings
- Dedicated team meeting rooms should be the gold standard, with robust and reliable technology
- Tools to support the assessment of team effectiveness are needed.

The next steps identified in the report were to:

- Develop a toolkit based on the characteristics, which include examples of local practice and national products such as checklists, proforma, specifications and templates for local adaptation
- Pilot approaches to self-assessment, feedback and support with a small number of teams to inform any future national programme.<sup>143</sup>

<sup>143</sup> NHS National Cancer Action Team, *Multidisciplinary team members views about MDT working:* Results from a survey commissioned from the National Cancer Action Team, 2009

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<sup>&</sup>lt;sup>142</sup> Department of Health, Cancer Reform Strategy, achieving local implementation – second annual report, 2009

#### 10.14.4 Provider networks

As an essential first step in establishing provider networks, all clinical multidisciplinary team posts, whether new or replacement, should be considered by the appropriate NSSG prior to any recruitment process. The aim of this is to identify opportunities to create more integrated care pathways. A condition of being part of a provider network would be that individual providers will not process unilaterally with any such appointments. It is also proposed that the staffing levels relative to workload of all existing multidisciplinary teams should be identified so that the NSSG is able to promote increased consistency of care being provided across a provider network.

# 10.14.5 Management of change

If these proposed changes were to be adopted, particularly those involving the creation of fewer multidisciplinary teams, it is proposed that provider networks should develop plans to ensure that the existing pool of expertise is well utilised. Existing high quality clinicians that have an established sub-specialised involvement in a particular service should be given first consideration for being a member of any merged teams. It would be expected that such staff would have a number of sessions at the host provider of the merged team and carry out a substantial proportion of the workload of the team. It would not be expected that the transitional pattern that has existed of in-reach surgeons doing a small number of operations a year would be considered as an option for delivering such specialised services in the future. As this proposal involves the minimum workload per surgeon being set at a higher level than those quoted in various IOGs, fewer surgeons may be involved in carrying such specialist procedures in the future.

The host provider of a specialist team has the clinical governance responsibility for the quality of services it provides and so has to be prepared to offer new team members substantive contracts. On behalf of the provider network the relevant NSSG should ensure the membership of such enlarged teams is achieved through an open and transparent process. There are examples of such changes being effectively introduced whereby clinicians have been able to remain involved in a specialised area of work by substantially changing their sessional commitment between the local and the specialised centre. Such joint contracts can be an excellent way of providing increased continuity of care for patients.

# 10.14.6 Teaching and training

Training has historically been reactive and slow to keep pace with the pace of change in service delivery. It has also traditionally been conducted in silos along professional lines. The future workforce must be equipped with the skills required to deliver care in the future clinical arena. Training must be tailored to need and be multi-professional where appropriate and highly specialised when necessary. Unless these factors are taken into account then improvements in services issuing from the proposed model of care would not be maintained.

Organisational boundaries in London hamper the delivery of teaching and training. To break down these organisational boundaries, London should take advantage of the new proposed Health Innovation and Education Clusters (HIECs) model. HIECs will bring together organisations across boundaries

to ensure the workforce has the breadth and depth of skills and experience to deliver high quality care regardless of setting.

Staff rotation around the provider network would strongly encourage the dual achievements of collaborative working and faster uptake of innovation and new techniques.

As proposed in the Cancer Reform Strategy, findings from the national audit in primary care should be used to make decisions about how best to provide more support to primary care professionals to ensure early diagnosis of cancer. The Department of Health and the Royal College of General Practitioners will examine how lessons learned from the audit could inform the education and training of GPs, including continuous professional development and appraisal. The audit could also assist in developing decision aids to support healthcare professionals in assessing symptoms and making decisions about further investigation or referral.

# 10.15 International best practice: cancer care in the USA

Pre-arranged, semi-structured teleconference interviews were held with a senior representative of four leading American, and arguably leading international, cancer centres. They were the Memorial Sloan Kettering Cancer Center, New York; the Dana-Farber Cancer Institute, Boston; the Sidney Kimmel Comprehensive Cancer Centre at Johns Hopkins, Baltimore; and the Stanford Cancer Center, California.

Three questions were posed:

- How consistent is the approach to configuring cancer services proposed by the CSL review with the service model in your institution? What are the similarities? What are the differences?
- With regard to the collocation of services have any clearly demonstrable benefits of service collocation been identified? If so, what are they?
- Research on international cancer centres undertaken as part of this review has highlighted the importance of collocating research with clinical services. Does the collocation of research improve your clinical environment? If so, how and by how much?

All four centres described very similar philosophies, attitudinal approaches and ways of providing cancer care. Furthermore, they were very much in broad agreement with the proposals made in this proposed model of care.

All centres place great emphasis on the search for excellence in clinical care and in cancer research. It is through their individual reputations that they compete with surrounding high quality hospitals to attract patients. Each centre has high subspecialisation of its clinical teams, most often with an individual team looking after patients with only one type of cancer. In addition, each centre has its own non-oncology clinical experts on the same hospital site or else for some few specialties in an adjacent hospital, perhaps connected by a bridge walkway.



Patient volumes are deliberately kept high within specialties with the purpose of maintaining high levels of expertise in the clinical teams. One centre performs 1600 prostatectomies a year. Clinical performance metrics are monitored closely internally. One centre has introduced a robust electronic health record system, which is used as an intervention tool to improve quality. The inappropriate overuse of treatment is beginning to be examined, for example is the time between last therapy and death clinically acceptable. Publically available performance data are limited in America but where they are available they are used by centres to benchmark themselves against other hospitals. One centre believes that these data will soon have to be made available to the public through government legislation. All centres frequently advise changes to the treatment care plans brought by patients referred from elsewhere.

Much emphasis and value is placed on active research programmes. One centre is currently engaged in approximately 500 clinical trials. Senior staff divide their time between clinical and research activities and are expected to bring revenue into their centre. Some staff members are provided with around 40% of protected time for research activities. Clinical trials of new anti-cancer treatments act to draw previously treated patients with recurrent disease to the centres, but not newly diagnosed patients who simply want immediate proven curative treatment.

Centres have variable numbers of ambulatory care facilities at other locations, run and staffed by the centres, which hold the responsibility for patient care. They are placed within or next to community hospitals. Because of the higher costs of providing care in academic centres private insurers are increasingly beginning to enquire about the added benefits of patients being treated in them. As a response to this considered threat, one centre has begun to develop the idea of diagnostic and treatment planning centres to reduce costs. Such planning centres make a definitive diagnosis, discuss care in a multidisciplinary meeting and provide advice on best treatment. The treatment can often then be implemented at a local hospital as far as it is skilfully possible to do, although this usually excludes some types of surgery.

National Cancer Institute designated cancer centres are mandated to have cancer prevention and control programmes, such as smoking and obesity prevention, reaching into their local communities.



# 11. Conclusion

This proposed model of care is presented to commissioners by London's cancer community. This model of care proposes robust, clinically-led solutions to the issues highlighted in the *case for change*. If it were adopted, this proposed model of care would ensure the future provision of world-class cancer services for all Londoners.

The collection and publication of high quality performance information is at the heart of the model of care. It is vital that commissioners have access to high quality, contextualised data in order to make effective commissioning decisions. This information should also be made available to the public, to enable them to make informed choices, and to providers, to allow them to benchmark themselves against others.

Achieving the recommendations for earlier diagnosis has the greatest potential for improving outcomes and survival for cancer patients in London. Raising survival rates in England to match the best in Europe could save approximately 1,000 lives per year in London.

The model of care proposes the provision of care outside of hospital settings where possible, but recognises the case to provide complex investigations and treatments in only a few centralised settings. This would ensure that services are high quality and as safe as possible.

Commissioning for cancer should be on the basis of care pathways. High quality care should be delivered by networks of providers to allow the sharing of best practice and drive improvements in cancer services. Commissioners should commission services from provider networks rather than organisations and ensure that pathways and clinical practice are standardised. The implementation of these changes would challenge many aspects of the way the NHS has worked in recent years.

The key challenges during transition would be achieving and maintaining the engagement of all parties and ensuring strong clinical leadership. There would be a development process to work through for both commissioners and providers. For providers, this new way of delivering clinical services could prove to be challenging unless they find ways of making these networks function effectively across organisational boundaries. Success would largely depend on the willingness of the organisations in London to make these arrangements work.

The configuration of provider networks should be determined as the recommendations of the model of care are implemented, particularly those regarding the further consolidation of specialist surgical services. It is fully expected that this would result in fewer than the present five cancer networks. In the interim, if commissioners adopt the recommendations, implementation planning should identify which of them can be implemented immediately and progressed while provider networks are emerging.



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# **Glossary**

**Abdominoperineal excision (APE):** an operation for rectal cancer.

**Academic Health Science Centre (AHSC):** a partnership between one or more universities and healthcare providers focusing on research, clinical services, education and training.

**Adjuvant:** treatment that is given in addition to the primary therapy.

**Aplastic anaemia:** a condition where bone marrow does not produce sufficient new cells to replenish blood cells.

**Barrett's oesophagus:** a disorder in which the lining of the oesophagus (the tube that carries food from the throat to the stomach) is altered, usually related to reflux of stomach acid.

Basal cell carcinoma: a type of non-melanoma skin cancer.

**Bio-bank:** a place that collects, stores, processes and distributes biological materials and the data associated with those materials.

**Bio-informatics:** the application of information technology to the field of molecular biology.

**Biomarker:** a substance used as an indicator of a biological state and is a characteristic used in many scientific fields as an indicator of normal biological responses to a therapeutic intervention.

**BME:** Black and minority ethnic.

**Brachytherapy:** form of radiotherapy where a radioactive source is placed inside or next to the area requiring treatment.

Cancer Awareness Measure (CAM): a tool that has been designed to measure symptom awareness of cancer amongst the general public.

**Cancer Commissioning Toolkit (CCT):** an online library of key cancer information and data developed to support commissioners to develop their strategies for implementing the *Cancer Reform Strategy*.

**Cancer Reform Strategy (CRS):** a strategy published in 2007 building on progress made since the publication of the NHS Cancer plan in 2000 setting out a programme of action across 10 areas to be achieved by 2012.

**Central Nervous System (CNS):** a part of the nervous system that functions to coordinate the activity of all parts of the body.

**Chemo-irradiation:** a treatment that combines chemotherapy with radiation therapy

**Cholangiocarcinoma:** a cancer of the bile ducts which drain bile from the liver into the small intestine.

Colorectal: pertaining to the colon and rectum.

**C-PORT (Chemotherapy Planning Online Resource Tool):** a web application which gives cancer professionals and healthcare managers the ability to model chemotherapy service delivery in a cost-free, risk-free online environment.

**Cryopreservation:** a process where cells or whole tissues are preserved by cooling to low sub-zero temperatures.

**Cyberknife radiotherapy:** a method of delivering radiotherapy, with the intention of targeting treatment more accurately than standard radiotherapy.

**Distal mesorectum:** the membrane that forms the lining of the abdominal cavity that is attached to the rectum from its most distant point of attachment.

**Egton Medical Information Systems Ltd (EMIS):** a primary care software provider that produced EMIS Web, a system currently in use in Tower Hamlets.

**Endocrine:** relating to glands that involve the release of hormones.

**Enhanced Recovery after Surgery (ERAS):** a method of patient management (pre/intra/ post operative) to aid the speed of recovery and reduce length of stay.

**Fine-needle aspiration:** a diagnostic procedure sometimes used to investigate superficial (just under the skin) lumps or masses.

**Fractionation:** administering of radiotherapy in divided doses at regular intervals over a period of time.

**Gleason:** a grading system for prostate carcinoma.

**Gynaecological:** pertaining to the study of the female reproductive system.

**Haematological:** pertaining to the study of blood, blood-forming organs, and blood diseases.

Haematopoietic progenitor cell transplantation (HPCT): the transplantation of blood stem cells derived from the bone marrow or blood.

**Haemoglobinopathies:** inherited single-gene disorders.

**Health Innovation and Education Clusters (HIECs):** 17 new government funded networks aimed at delivering high quality patient care through better trained clinicians and faster translation and adoption of research and innovation

**Hepatocellular carcinoma (HCC):** a primary malignancy of the liver.

**Hepato-pancreato-biliary (HPB):** a medical term used in conjunction with conditions and procedures related to the liver, pancreas and biliary tract.

**HRG4:** Healthcare Resource Groups (HRGs) are standard groupings of clinically



similar treatments which use comparable levels of healthcare resource and HRG4 is the newly revised and updated version of this.

**Improving Outcomes Guidance (IOG):** service guidance produced by the National Institute for Health and Clinical Excellence on improving outcomes for patients.

**Intensity-modulated radiation therapy (IMRT):** a sophisticated use of ionising radiation as part of cancer treatment to control malignant cells.

**International Society for Cellular Therapy (ISCT):** the global forum and resource for developing and supporting innovative cellular therapies.

**Joint Accreditation Committee of ISCT & EBMT (JACIE):** a non-profit body established in 1998 for the purposes of assessment and accreditation in the field of bone marrow transplantation.

**Keyworker:** A person who, with the patient's consent and agreement, takes a key role in co-ordinating and promoting continuity of the patient's care, ensuring the patient knows who to access for information and advice.

**Laparoscopic surgery:** a modern surgical technique in which operations in the abdomen are performed through small incisions, also called minimally invasive surgery (MIS), bandaid surgery, and keyhole surgery.

**Levator muscles:** any of the muscles that raise a body part.

**Linear accelerator (Linac):** used to deliver a uniform dose of high-energy x-ray treatment to the patient's tumour.

**London Cancer Network Board (LCNB):** a pan-London board comprising of representatives from the five London cancer networks.

**London Cancer New Drugs Group (LCNDG):** a sub-committee of the London Cancer Networks Steering Group which has delegated responsibility to develop recommendations for the managed entry of new chemotherapy treatments in cancer across London.

**London Commissioning Group:** the committee at which pan-London commissioning decisions are taken.

**London Specialised Commissioning Group (LSCG):** a joint committee of London PCTs working in partnership with neighbouring specialised commissioning groups, NHS London, patient and public engagement groups and NHS Trusts which commissions specialised services collaboratively using a variety of contracting and financial risk-sharing arrangements, run by consortia.

**Lymphoedema:** a side effect that can begin during or after cancer treatment or recurrence involving swelling of the soft tissues of the arm, hand or leg.

**Lynch syndrome:** an inherited genetic mutation associated with an increased risk of cancer of the colon.



**Magnetic resonance imaging (MRI):** a medical imaging technique most commonly used in radiology to visualise the internal structure and function of the body.

**Metastasis:** the spreading of cancer from one organ or part to another non-adjacent organ or part.

**Monitor:** the independent regulator of foundation trusts, whose role will be developed into an economic regulator from April 2012.

**Multidisciplinary team (MDT):** comprises a group of expert doctors, nurses and other health care professionals with a special interest in the diagnosis, treatment and management of people with cancer.

**National Awareness and Early Detection Initiative (NAEDI):** initiative with the role of co-ordinating and supporting activities that promote the early diagnosis and treatment of cancer.

**National Cancer Action Team (NCAT):** a team that reports to the National Cancer Director. Its role is to support the NHS and facilitate the implementation of the Cancer Reform Strategy and works along side the Cancer Policy Team in the Department of Health and with NHS Cancer Networks.

**National Cancer Equality Initiative (NCEI):** a group of key stakeholders who advise the National Cancer Director and ministers on the delivery of the actions to reduce inequalities set out in the Cancer Reform Strategy.

**National Cancer Peer Review (NCPR):** a national quality assurance programme for NHS cancer services.

**National Chemotherapy Advisory Group (NCAG):** a group commissioned by the Department of Health to recommend how chemotherapy services should be developed.

National Collaborating Centre for Primary Care (NCCPC): a partnership of primary care professional associations formed as a collaborating centre to develop guidelines under contract to the National Institute for Clinical Excellence (NICE).

National Institute for Health and Clinical Excellence (NICE): an independent organisation responsible for providing national guidance on promoting good health and preventing and treating ill health.

**National Patient Safety Agency (NPSA):** An arm's length body of the Department of Health responsible for leading and contributing to improved, safe patient care by informing, supporting and influencing organisations and people working in the health sector.

**National Radiotherapy Advisory Group (NRAG):** a group set up in 2004 to advise Ministers on how to improve radiotherapy services in England.

**Network Site Specific Groups (NSSGs):** Cancer network groups whose role is to agree evidence-based, clinically effective care pathways that build on best practice



in service and workforce redesign, together with clinical guidelines.

National Training Programme for Laparoscopic Colorectal Surgery (LAPCO): a programme developed by the Department of Health to train NHS consultant colorectal surgeons in England.

**Neutropenia:** a condition in which the number of neutrophils (a type of white blood cell) in the bloodstream is decreased.

Non-obstetric ultrasound: is used for diagnosis of conditions outside of pregnancy.

**Oesophago-gastric:** pertaining to the oesophagus and stomach.

**Oncology centre:** a centre offering a range of services for the treatment of cancer.

**Oncoplastic surgery:** the combination of the best and latest techniques in plastic surgery with surgery for breast cancer.

**Palliative:** any form of medical care or treatment that concentrates on reducing the severity of disease symptoms.

**Para-aortic lymph node:** a group of lymph nodes that lie in front of the lumbar vertebral bodies near the aorta.

**Payment by results (PbR):** a financial system which provides a transparent, rules based system for paying trusts which rewards efficiency, supports patient choice and diversity and encourages activity for sustainable waiting time reductions.

**Perineal:** pertaining to the diamond-shaped region of the body between the pubic arch and the anus.

**Picture archiving and communications system (PACS):** an electronic system enabling images such as x-rays and scans to be stored and viewed on screens, creating a near filmless process and improved diagnosis methods.

Positron emission tomography - computerised tomography (PET-CT) scanning: a nuclear medicine imaging technique that produces a three-dimensional image or picture of functional processes in the body.

**Professional executive committee (PEC):** a group of nurses, GPs and other health and social care professionals identifying health and social care priorities within the local community and driving forward action plans to respond to these priorities

**Proton beam therapy (PBT):** a type of particle therapy which uses a beam of protons to irradiate diseased tissue, most often in the treatment of cancer.

**Radiotherapy:** the medical use of ionizing radiation as part of cancer treatment to control malignant cells.

**Receptor marker:** a protein molecule, embedded in either the plasma membrane or the cytoplasm of a cell, to which one or more specific kinds of signalling molecules may attach.

**Royal College of General Practitioners (RCGP):** a professional membership body for family doctors in the UK and abroad committed to improving patient care, clinical standards and GP training.

**Sarcoma:** a malignant tumour arising in tissue of mesodermal origin (as connective tissue, bone, cartilage, or striated muscle) that spreads by extension into neighbouring tissue or by way of the bloodstream.

**Sentinel lymph node:** the first lymph node to receive lymphatic drainage from a tumour.

**Sentinel node biopsy:** using a radioactive isotope and/or a blue dye to find the first lymph node (the 'sentinel' node) that the cancer drains into.

**Sigmoidoscopy:** the minimally invasive medical examination of the large intestine through the rectum into the last part of the colon.

**Significant event audit (SEA):** the audit and shared learning of a significant positive or negative patient outcome.

**Stenting:** the insertion of a man-made 'tube' into a natural passage/conduit in the body to prevent, or counteract, a disease-induced, localized flow constriction.

**Superior vena cava obstruction:** the result of the direct obstruction of the superior vena cava by malignancies such as compression of the vessel wall.

**Supra-network:** extending across the boundaries of more than one cancer network.

**Systemic anti-cancer therapy (SACT):** used to kill or slow the growth of cancer cells or, post-surgery, for cancer cells still remaining. SACT comprises chemotherapy, endocrine therapy, and hormonal therapy.

**Thoracic:** pertaining to the region of the body formed by the sternum, the thoracic vertebrae and the ribs extending from the neck to the diaphragm not including the upper limbs.

**Trans-anal endoscopic microsurgery (TEMS):** a specially designed technique which allows surgery to be performed within the rectum using a special instrument called an endoscope.

**Trans-urethral resection (TUR):** a surgical procedure that is used both to diagnose bladder cancer and to remove cancerous tissue.

**Upper aerodigestive tract (UAT):** referring to areas of the head and neck including lip, mouth, oral cavity, salivary glands, sinuses, pharynx and larynx.

Upper gastrointestinal (UGI): refers to oesophagus, stomach and duodenum.

**Urological:** referring to the urinary tracts of males and females and the reproductive system of males.



# Document 5: Integrated cancer systems in London – Final integrated cancer system specification

London Health Programmes, NHS London. May 2011.





# **Integrated cancer systems in London**

Final integrated cancer system specification

May 2011

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# **Summary and milestones**

This specification sets out the characteristics of integrated cancer systems. Integrated cancer systems will drive delivery of the agreed cancer model of care<sup>1</sup> and related service co-dependencies framework<sup>2</sup>, including the proposals for the further consolidation of rare and specialist cancer services.

The following documents have been issued alongside this specification:

- Covering letter from Rachel Tyndall (London cancer senior responsible officer) and Chris Harrison (London cancer clinical director).
- Integrated cancer system submission guidance.
- Integrated cancer system assurance criteria.
- A guide to the submission and assurance process.

Proposed integrated cancer systems are expected to respond with how they intend to meet this specification and the recommendations in the model of care and codependencies framework by the **30**<sup>th</sup> **June 2011**.

Submissions will be subject to formal assurance from 1<sup>st</sup> July 2011. The evaluation panel will be made up of London's cancer clinical director and other clinical and commissioning experts. The panel will conduct a series of meetings and visits in July and August 2011.

Implementing the model of care will result in cancer service changes in London. We will continue to engage stakeholders and the public as proposals are developed. Should service changes be deemed significant then formal consultation will be required in the autumn.

Integrated cancer systems will be commissioned from April 2012.

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<sup>&</sup>lt;sup>1</sup> Commissioning Support for London, *A model of care for cancer services – Clinical Paper*, 2010

<sup>&</sup>lt;sup>2</sup> Commissioning Support for London, *A model of care for cancer services – Co-dependencies framework*, 2010

# Introduction

- The cancer case for change was published in December 2009. It provided a
  compelling set of arguments for the need to improve cancer services in London. It
  showed that that the lack of progress in implementing consistent, high quality
  coordinated cancer services in the capital means that services may be excellent in
  some instances but this is variable.
- 2. Over forty London cancer clinicians were selected to lead the development of London's proposed cancer model of care. The proposed model of care was published in August 2010.<sup>3</sup> It made robust, clinically-led recommendations to drive cancer service improvements in the capital.
- 3. The proposed model of care was the subject of a three-month engagement period from August to November 2010. The proposals were discussed with GPs, the public and local authorities. This period of engagement revealed widespread agreement with the proposals, with over 85% of respondents to an online survey showing support. A report on the engagement process was published in January 2011.<sup>4</sup>
- 4. The model of care makes it clear that cancer commissioners in London should commission provider networks. During the process of engagement this has sometimes been confused and interpreted to mean the existing cancer networks. These are very different things. To avoid confusion we will now use the term integrated cancer systems instead. This integrated cancer system specification sets out the minimum expectations of how these systems will work.
- 5. Provider chief executives, medical directors, directors of finance, cancer managers and information managers attended a number of workshops in March 2011 to develop the proposals. In addition, the relevant literature has been reviewed to identify what factors enable integrated systems and networks to work effectively. This specification is the result of this work.
- 6. We now call for NHS providers in London to respond to this specification. Providers should work together to decide how they will form integrated cancer systems and how these systems will respond to the requirements set out in this specification. This specification outlines both the vision for integrated cancer systems and what submissions will be required by 30<sup>th</sup> June 2011.
- 7. **Proposed integrated systems (not individual providers)** should respond in full to the requirements in this specification by 30<sup>th</sup> June 2011. Proposed systems will submit three documents:
  - A memorandum of agreement from all participating organisations.
  - An integrated cancer system plan outlining how the proposed system will work.

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<sup>&</sup>lt;sup>3</sup> Commissioning Support for London, *A model of care for cancer services – Clinical Paper*, 2010

<sup>&</sup>lt;sup>4</sup> Available at www.lhp.nhs.uk/publications/cancer

# A service plan outlining:

- Six priority pathways or areas for implementing integrated cancer care (three common and three rarer and specialist cancer types). Alternatively, one of these can be a system-wide improvement priority. Integrated cancer systems should use these priority areas to demonstrate adoption of new ways of working across constituent parts of the system.
- How the proposed system will implement the model of care recommendations and clinical co-dependencies. This includes how the proposed system will influence the quality of care and outcomes of the whole pathway and, in particular, how it will influence the earlier diagnosis of cancer.
- 8. Proposed integrated cancer systems should develop three-year plans. Systems will be the significant providers of cancer care in the future; they are expected to improve outcomes and consistency of service quality across the capital. There is no intention to formally re-commission cancer services or put them out to tender. Plans should therefore be updated annually.
- 9. The first few years of integrated cancer systems will see significant development of both the systems and how they are commissioned. Assessment of the functioning and continued commissioning of integrated cancer systems will take place periodically. It is proposed that this will initially take place in 2015/16. Systems will be expected to continually meet the requirements in the model of care and any subsequent national and local commissioning guidance.

#### **Definition**

- 10. An integrated cancer system is defined as a group of providers that come together in a formal, governed way to provide comprehensive, seamless cancer patient pathways. Integrated cancer systems will be commissioned to provide cancer care based on defined care pathways to meet patients' needs.
- 11. The model of care sets out that integrated systems should:
  - Be clinically led.
  - Have responsibility for delivering the specified care pathways for different tumour sites.
  - Have responsibility for governing and delivering services across the system.
- 12. Integrated cancer systems are a new way of delivering services. They will be significantly different from the existing cancer networks in that they will have stronger governance and accountability frameworks and their funding flows will be tied to their delivery of specifications.

# **Commissioning arrangements**

13. This section sets out the initial thinking on the proposed commissioning arrangements for cancer services across London. The commissioning arrangements will be developed alongside the integrated cancer systems so that they are aligned as far as possible. As commissioning arrangements are in flux, the arrangements reflect both the transition and the future state.

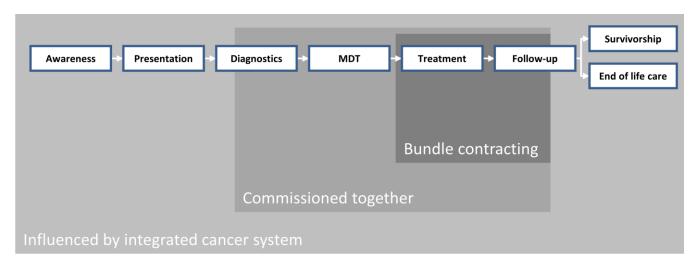
# Strategic priorities

- 14. The model of care recommends a London-wide governance board for cancer services. The pan-London board will have a formal role in providing leadership for cancer service development for Londoners. The pan-London board will set standards and monitor performance. This will include identifying issues of concern regarding investment decisions, quality, performance and outcomes.
- 15. It is proposed that the pan-London board is established in 2011. In the first instance, membership will include representatives from NHS London, the clusters, current network teams, emergent GP consortia and the London Specialised Commissioning Group as well as provider organisations and clinicians. It is proposed that a strategic plan and a London-wide scorecard are developed for 2012/13.
- 16. In the longer term individual GP consortia may not commission for populations large enough for effective cancer care planning. Therefore, GP Consortia and the National Commissioning Board (which will have taken on responsibility for rare and specialised cancers) may wish to work together to determine the needs, strategy and priorities for cancer care across London.

# **Commissioning specification**

- 17. The model of care makes clear that commissioning for cancer will be based on pathways, reflecting national expectations (a generic cancer care pathway is illustrated in appendix 1). There will be a closer alignment between pathway descriptions, quality standards, outcome measures and the way that services are paid for and monitored. This should strengthen commissioning arrangements.
- 18. Commissioning specifications for pathways (descriptions and key measures or outputs), based on the model of care, will be developed over the next few months. These will be based on existing work completed by cancer networks, the London Specialised Commissioning Group and the project team. Clinicians and patient groups will continue to be involved in their development. In the first instance, the specifications will span the parts of the pathway in the commissioned together section of figure 1.
- 19. Commissioners intend to commission integrated cancer systems rather than individual organisations to deliver these cancer pathways. At all stages the contracting arrangements for universal services, for example GP and generic end of life care services, may remain separate to the integrated system.

Figure 1: The scope of integrated cancer systems



# **Contracting arrangements**

- 20. The term *bundle contracting* refers to those elements of a care pathway that will be brought together in a contract between a commissioner and provider(s). While there are many examples of defined care pathways in the NHS, there are fewer instances of those pathways being translated into a specific contract between commissioners and providers.
- 21. Proposals will be developed to pay for some activity along the pathway differently (bundle contracting in figure 1). In general, the proposal is to bundle related activities and establish a single price (for example, for a course of chemotherapy or radiotherapy). This should reduce the transactional costs associated with separate billing and checking. There will be a stronger focus on the quality and outcome of treatment. Where possible different behaviours will be incentivised through setting prices or best practice tariffs. Initially, these arrangements will be predominantly hospital based care, following diagnosis.
- 22. Commissioners will work to align different payment arrangements and tariffs with the six priority pathways identified by proposed integrated systems (see paragraphs 56-59).
- 23. Decisions need to be made about:
  - The level of differentiation within tumour type.
  - Whether and how activities along the pathway may be bundled into one tariff.
  - How the tariff price is set.
  - How risks will be managed.
- 24. There also needs to be further discussion about how activity not covered by bundle contracting will be contracted for.

# **Performance requirements**

- 25. Based on the specifications, commissioners will set performance requirements for integrated cancer systems as a whole. These will primarily be monitored by tumour type and not by organisation. A summary of suggested metrics and indicators is outlined in the illustrative breast cancer pathway in appendix 2.
- 26. A London cancer scorecard will be produced for 2012/13 to benchmark and monitor performance.

# **Integrated system management**

- 27. Integrated cancer systems will oversee the delivery of cancer care to the pathway specifications and be held to account for this. Integrated cancer systems will also be expected to performance manage constituent parts of systems.
- 28. Ultimately, if part of the integrated cancer system fails to provide services based on the specification and the integrated cancer system is unable to improve performance, then commissioners will decommission all or that part of the pathway.

#### **Commissioner incentives**

- 29. Contract currencies to support the contracted pathway are a significant lever for change. These incentives will be used to drive the behaviours and outcomes expected of an integrated cancer system. These, along with other levers, will be developed over the coming months. Options include:
  - Best practice type tariff arrangements for bundled activity along the care pathway.
  - CQUIN type payments across an integrated cancer system.
  - Penalties for over-centralisation of services (especially for common cancers).

# Scope

- 30. Integrated cancer systems should take ownership of and influence the whole of the cancer care pathway (as illustrated in figure 1). The performance of integrated cancer systems will be assessed using outcome measures that span the whole pathway, for example one and five year survival rates (a summary of suggested metrics and indicators is outlined in the illustrative breast cancer pathway in appendix 2).
- 31. As a minimum in the short term (by April 2012), integrated cancer systems should include all London-based secondary and tertiary care providers in the system area. Only providers that are part of an integrated cancer system will be commissioned to provide these elements of the pathway.
- 32. When responding to this specification at the end June 2011, proposed integrated cancer systems should outline:
  - Which providers will be part of the system.
  - How the integrated cancer system will develop relationships with providers across the whole care pathway including primary, community, independent and third sector providers.
  - How the system will exert influence over the quality of care and outcomes of the whole pathway.
  - The components of the cancer pathway for which the integrated system will be accountable. Commissioners will hold the integrated cancer system to account for these defined parts of the pathway rather than commissioners holding the individual organisations to account.
  - How the integrated system will ensure that patients are provided with informed choice throughout the pathway. The system should demonstrate that it is not being anti-competitive. It is expected that integrated cancer systems will be mindful of what NHS providers and other willing and qualified providers can contribute. The proposed system should outline what links the system has or intends to have with out of London, and third sector and other voluntary providers.

# Governance

### **Governance system**

- 33. An integrated cancer system will function as an integrated, actively managed, single entity, taking responsibility for governance of all cancer patients in the cancer system.
- 34. Patients with cancer should not notice their transition between organisations that are part of the integrated cancer system. They should know that one entity has the accountability and responsibility for their care and experience across the entirety of the pathway.
- 35. Each system will need to design and demonstrate a governance system most appropriate to delivering integration locally. The model of care recommends collaborative and not hierarchical arrangements. However there should be clear organisational and integrated governance (including clinical governance) systems and structures with clear lines of accountability and responsibilities for all functions.
- 36. Integrated cancer systems should note that:
  - There should be an overarching governance board (as part of a lead organisation, or a holding company or joint venture) to lead and manage the integrated system as a single entity.
  - Commissioners will need to contract with a legal entity that can enter into an NHS contract.
  - A lead contracting body should be identified to hold this NHS contract (this
    does not have to be the lead organisation itself).
- 37. Effective multidisciplinary team working across the integrated cancer system will be at the heart of delivering collaborative care to patients along care pathways (see paragraph 59).

# Overall governance and accountability

- 38. When responding to this specification, proposed integrated cancer systems will be expected to be clear about:
  - Terms of reference for the governance board.
  - Membership of the governance board. Integrated cancer systems should decide their governance board membership arrangements themselves, however, the board will require a chair, clinical lead and research advisor.
  - Patient and public involvement. Patients should be at the centre of decision making regarding cancer services.
  - How commissioners will be engaged in active governance (required to prevent anti-competitive processes).
  - How the governance board will hold constituent members of the integrated cancer system to account for delivery through assurance systems and

performance management. This includes what intervention the governance board would take if parts of the system are not providing an adequate service and fail to improve.

- Who will be responsible for the development, management and ultimate clinical accountability of services for each tumour type.
- The overall clinical lead.
- The management of a single risk register. Systems should outline how this links to each organisation's board assurance framework.
- Board-level support, direction and leadership from each provider organisation.
- Management of peer review across the integrated cancer system.

# Financial flows and strategy

39. Integrated cancer systems will be expected to outline:

# Financial governance

- Heads of terms for financial flows and governance with board support from all providers within the proposed integrated cancer system.
- Approaches to the sharing financial risks and benefits. This includes developing a risk-based approach to financial planning and budgeting in line with analysis of financial and activity flows.
- Process for resolving financial disputes.

#### Service distribution

- The current estimated expenditure on cancer care spilt by pathway, activity and trust.
- The location of cancer specific assets, for example, radiotherapy bunkers.

#### **Transactions**

The basis of inter-trust invoicing for services.

#### **Capital investment**

Their approach to capital investment planning.

# Information

# **Publishing information**

- 40. Integrated cancer systems will publish up-to-date, accessible information for patients and the public about services and service outcomes (for example, laparoscopic and open colorectal surgery, immediate and delayed breast reconstruction, compliance with waiting time standards and performance in the national cancer inpatient survey). This information should support patients to exercise informed choice and promote personalised care in terms of treatment options and how to access services. The information provided should always be at a level and in a format appropriate to patients' and carers' understanding.
- 41. Integrated cancer systems will also publish annual cancer quality accounts in line with the cancer model of care. These reports will inform the public about the quality of services provided, including patient safety, patient experience, effectiveness and outcomes.

# **Common patient information**

42. Patient information should be standardised across the system in line with best practice.

# **Sharing information**

43. Integrated cancer systems will be expected to outline:

- How it will share information between constituent organisations and clinicians in order to manage patients across care pathways.
- A data sharing protocol that all constituent parts of the integrated system are signed up to. This should include guidance on the safe transfer of information.
- Plans for common information and data standards and policy.
- How the system will review comparative outcome and performance data between providers.
- A current benchmark of staging data and a plan of how they will achieve complete recording.

#### Information for commissioners

44. Commissioners will set outcome standards that will be required to monitor the performance of the integrated cancer system (a list of suggested metrics and indicators is outlined in the illustrative breast cancer pathway in appendix 2). These standards will form the minimum data set. The indicators will be linked to the national strategy *Improving Outcomes: A Strategy for Cancer*<sup>5</sup> and other outcome standards such as those in primary care and the National Cancer Intelligence Network.

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<sup>&</sup>lt;sup>5</sup> Department of Health, *Improving Outcomes: A Strategy for Cancer*, 2011

45. It will be the governance board's responsibility to ensure that the integrated cancer system provides commissioners with the outcome data from the minimum data set. In addition, it will be the governance board's responsibility to provide other contextualised data to support commissioning decisions as requested.

# **Research and innovation**

- 46. Integrated cancer systems should drive continuous improvement and excellence through innovation, research, knowledge and best practice.
- 47. Proposed integrated cancer systems should demonstrate:
  - How translational and clinical research will be implemented for patient benefit, recognising that there will be complex relationships for basic research and early phase trials.
  - Leadership arrangements for clinical and translational research.
  - Arrangements for promoting access to high quality clinical trials across the whole network.

# Workforce and culture

- 48. Integrated cancer systems are an innovative way of delivering cancer services.

  Developing these systems will require cultural change in the way people work and how services are managed and delivered.
- 49. Proposed integrated cancer systems should outline their plans for workforce development, including:
  - How the system will maximise the opportunities for improving training and development programmes, such as those for junior doctors.
  - How clinical leadership will be developed and supported.
  - Proposals for supporting multidisciplinary teams and engaging with clinicians who will work as part of the integrated cancer system.
  - Plans to develop joint posts and new ways of working across the integrated cancer system.
  - How partners will work together to tackle common operational problems such as recruitment and retention of staff.
  - How the system will work with staff on any potential service moves necessary to implement the model of care.
  - How the system plans to develop a single identity.

# **Incentives**

# Internal incentives

- 50. Commissioners, through contracting and other arrangements, intend to incentivise integrated cancer systems to deliver this specification and the model of care (see commissioning arrangements section, paragraphs 13-29).
- 51. In addition, incentives should be deployed *within* integrated cancer systems. All incentives should be linked with providing comprehensive pathways, and achieving the best patient outcomes and experience.
- 52. Proposed integrated cancer systems should:
  - Describe how constituent parts of the system will be incentivised. Systems should outline at least two proposed internal incentives.

# **Services**

- 53. Services within an integrated cancer system are expected to operate as a genuinely integrated body, with clear standards of practice and system-wide clinical care, governance and information protocols as set out in this specification.
- 54. At the end of June 2011 proposed integrated cancer systems should provide submissions on how they intend to deliver the model of care by outlining their priority areas and plans for implementing the model of care recommendations.
- 55. Systems should aim to exceed national, regional and local care and quality standards such as NICE improving outcomes guidance. The systems should meet the needs of the populations they service, be innovative and underpin all activity with cancer research programmes.

# **Priority areas**

- 56. Each proposed integrated cancer system should decide on six priority pathways for delivering integrated cancer care within the system. Three should be common tumour type pathways and three should be rare and specialist tumour type pathways. Alternatively, one of these can be a system-wide improvement priority from the following list: early diagnosis, acute oncology services, radiotherapy, chemotherapy, or survivorship. Integrated cancer systems should use these priority areas to demonstrate the adoption of new ways of working across constituent parts of the system.
- 57. The six pathways or areas to be prioritised will be agreed during the formal assurance process that will follow the receipt of submissions by 30<sup>th</sup> June 2011.
- 58. Commissioners will aim to change the commissioning and bundle contracting (as shown in figure 1) based on the priority pathways proposed.
- 59. The integrated cancer system should work through how it will develop these six pathways or priority area to deliver improved quality and outcomes in line with the model of care. Multidisciplinary teams (MDTs) and tumour groups should be the organising principles. Specifically, proposed integrated cancer systems should outline:
  - How clinical accountability, management and leadership arrangements will operate within each prioritised pathway.
  - How the system will achieve a standardised approach to patient care across MDTs in prioritised pathways.
  - What will be done to encourage collaborative working across constituent organisations.
  - The system-wide training and development opportunities for clinical and nonclinical staff, for example joint post arrangements.
  - The priorities and approach to service improvement.
  - What plans exist to influence and link parts of the pathway not directly within the scope of the integrated cancer system.

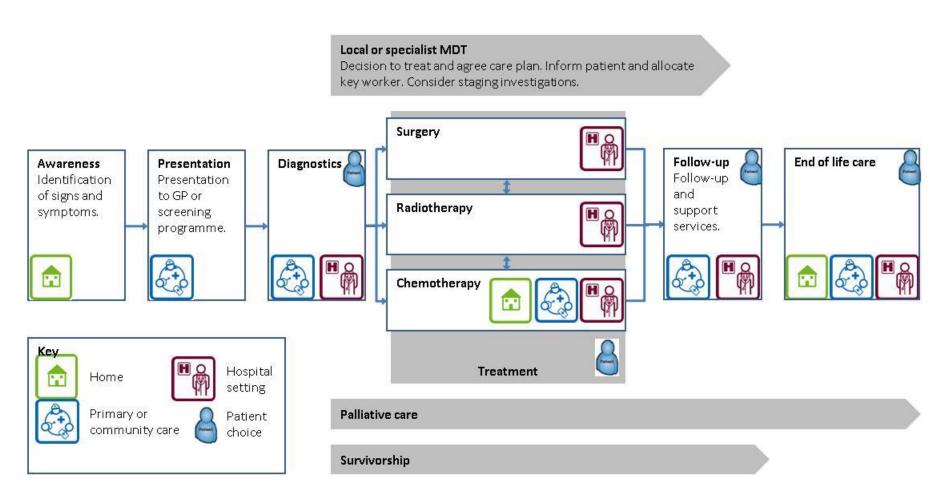
 The use of patient experience and other outcomes data to improve and develop MDT working and practices for the prioritised pathways.

# Implementing model of care recommendations

- 60. Each proposed integrated system should provide plans and timescales for implementing the key recommendations from the model of care, and specifically:
  - How it will lead improvements in early diagnosis and thereby increase one year survival, and ensure the quality and completeness of its data on stage at diagnosis.
  - How it will localise common cancer services, including the delivery of acute oncology services and chemotherapy locally and in appropriate settings.
  - How it will consolidate specialist surgery in line with the cancer codependencies framework.
- 61. If the proposed integrated cancer systems cannot achieve the recommendations and optimal co-dependencies for the delivery of specialist services then proposed systems will be expected to:
  - Identify service delivery and clinical outcome risks including how the system plans to mitigate these risks.

# **Appendices**

# **Appendix 1: Generic cancer care pathway**



# **Appendix 2: Indicative breast cancer pathway metrics**

Pathway stage	Example metrics (to be developed further)
Population awareness of symptom abnormality	Population awareness
Presentation to GP or screening	Screening uptake rates
	% screen detected
	% symptomatic diagnosis
	% diagnosed at stage 1 & 2
Diagnostic	Availability of rapid diagnosis clinics
Multidisciplinary team	Number of newly diagnosed cases by MDT
Surgery	Availability of 24 hour discharge
	% undergoing immediate reconstruction
Chemotherapy	% of new cancer recovery episodes chemotherapy
	% of chemotherapy episodes delivered at local hospitals
	% of chemotherapy episodes delivered within 30 mins of home
	30 day mortality after systemic therapy
	Death rate on adjuvant chemotherapy
Radiotherapy	% of new cancer rates receiving radical or adjuvant radiotherapy
	% of new cancer cases receiving palliative radiotherapy
	% Radiotherapy delivered within 30 mins of home
	Survival at 90 days following radical or adjuvant radiotherapy

Pathway stage	Example metrics (to be developed further)	
	Survival at 30 days following palliative radiotherapy	
Follow up care	% patients for which the full dataset is provided	
	1 year survival by stage	
	5 year survival by stage	
	<ul> <li>% relapse / disease progression over</li> <li>5 years</li> </ul>	
Palliative care	% of deaths when Liverpool pathway followed	
	% of deaths at home	
Research	% new patients entered into clinical trials	

Waiting time metrics will be applicable to all tumour pathways and throughout the pathway.

Patient experience metrics will be applicable to all tumour pathways and throughout the pathway. The expert patient panel will be consulted regarding metric development.

# Document 6: Integrated cancer systems in London – Final evaluation panel assessment: London Cancer integrated cancer system

London Health Programmes, NHS London. September 2011.





# Integrated cancer systems in London

Final evaluation panel assessment: **London Cancer** integrated cancer system

September 2011

### Introduction

On 30<sup>th</sup> June 2011 the cancer implementation board received two collaborative submissions from London's cancer care providers to become integrated cancer systems. The implementation board formed an evaluation panel to assess these submissions and make a recommendation to London's commissioners on their respective strength. The evaluation panel met as a group on two occasions and in addition conducted an assessment day with delegations from each of the proposed systems. The membership of the panel is outlined in the appendix.

This document contains the final evaluation panel assessment of the integrated cancer system submission received from **London Cancer**.

Section 1 gives a broad overview of the evaluation panel's conclusions and recommendations to the cancer implementation board and London's commissioners.

In section 2 the assessment looks in detail at London Cancer's system proposals. It outlines the evaluation panel's view on extent to which the proposed system's memorandum of understanding meets the requirements set out in the submission guidance<sup>1</sup> and how its submission fares against the criteria in the final specification<sup>2</sup>.

Section 3 considers London Cancer's service proposals, while section 4 considers the next steps that the evaluation panel consider necessary in the development of the system.

<sup>&</sup>lt;sup>1</sup> London Health Programmes and NHS London, Integrated cancer systems in London: Submission Guidance, May 2011

<sup>&</sup>lt;sup>2</sup> London Health Programmes and NHS London, Integrated cancer systems in London: Final integrated cancer system specification, May 2011 Both available at http://www.londonhp.nhs.uk/publications/cancer/implementation/

### 1. Overview and recommendation

The provisional risk rating of London Cancer's system arrangements is **Amber**.

The panel recognised the enthusiasm for London Cancer's proposed integrated system and the hard work to date to develop the plans. It felt that the proposed members of London Cancer presented themselves as a united and cohesive whole and that the vision presented is ambitious, focussing rightly on populations rather than institutions. The panel felt that it was clear that the proposed system had a good history of collaborative working to build on and that this commitment and energy have the potential to deliver real change. The panel considered that there is a clear drive to make this system work and this has been reflected through the clinical discussions and evidence of strong clinical, patient and primary care engagement (although there remains work to be done on the latter). It welcomed the dispersed model of leadership in evidence, with a chief executive of a trust within the proposed system leading the work on the governance model. The panel also welcomed the presentation on research and innovation at the panel assessment day, which it felt brought London Cancer's proposals to life in a different and exciting way.

The panel felt that there will be some practical issues to work through in order for London Cancer to demonstrate that the system as a whole will work. At a high level these are the governance model and the role of clinical leaders, the system's culture and organisational development, how it will develop to work truly as a single system for north east and north central London, and how all of the evident energy within the proposed system can be harnessed to make a difference systematically and at scale. In particular the panel felt that the proposed system demonstrated an overreliance on clinical data for decision making and more work was needed on how research opportunities would be operationalised. In addition, the panel felt that the proposed system should not seek to minimise the potential opportunity that financial changes had to dive change and considered that more work was needed to involve primary care, patients and users in the proposed system. The panel would also encourage the proposed system to develop a clear understanding of the resource requirements to support this new way of working.

The panel acknowledged that London Cancer's overarching governance model would be clear by the end of October. The panel would encourage the proposed system to work up one or two pathways in a high level of detail to demonstrate how this and other aspects of the system will operate to support implementation across all pathways.

In relation to its service proposals the panel considered that London Cancer had made a good start in developing its proposals to implement the recommendations of the model of care and deliver the required consolidation of specialist services. The panel welcomed the commitment of the system to work to develop plans further during autumn 2011.

The evaluation panel therefore recommends to the cancer implementation board and London's commissioners that London Cancer be **provisionally authorised subject to an approved action plan**.

# 2. System proposals

### 2.1 Memorandum of agreement

Memorandum of agreement			
Requirement	Submission documents	Panel assessment	Rating
Name for the integrated cancer system.	•London Cancer	The panel noted the name of the proposed system but considered that it might need clarification	Amber
Lead or 'holding' organisation(s).	•UCLP (MoA p.3)	•The panel noted the role of UCLP	Green
Legal contracting entity.	•UCLP until at least March 2013 (MoA p.3)	•The panel noted the role of UCLP	Green
List of NHS providers in the system and confirmation of board-level support from each member.			
Statement of the vision and high-level objectives of the system.	<ul> <li>Drive superior outcomes and patient experience for our patients and local communities</li> <li>High level objectives: patient focus, optimising care along a co-ordinated pathway, embed research, increase value</li> </ul>	The panel welcomed the proposed system's strong patient-focused vision	Green
Diagram illustrating the system's accountability arrangements.	<ul> <li>Role of board, trusts and clinical pathway boards given</li> </ul>	The panel felt that a clear view of accountability arrangements was presented with plans to continue to develop the detailed arrangements	Amber

Terms of reference for the governance board.			
Process by which the governance board will hold constituent members of the system to account for delivery through assurance systems and performance management.			
Responsibilities for the development and management of services for each tumour type.	Role of clinical pathway groups clear	<ul> <li>The panel was pleased to see that the proposed system had begun thinking about clinical governance and accountability</li> </ul>	Amber
Governance and accountability arrangements for network site specific groups (tumour groups) and multidisciplinary teams within the system.	• Clinical pathway groups → clinical pathway board (rare/common) → London Cancer board (MoA p.1-2)	<ul> <li>The panel felt however that more work was required on the operationalising of proposals, how clinical leaders would get their authority, and how they would handle difficult issues</li> </ul>	Amber
Heads of terms for financial flows, governance and risk and benefit sharing arrangements.			
Process for handling financial and contractual disputes.			

Grey boxes indicate requirements covered elsewhere in preliminary assessment framework

# 2.2 Integrated cancer system specification

Scop	Scope				
	Specification criterion	Submission documents	Panel assessment	Rating	
Membership	Which providers will be part of the system.	•14 NHS Trusts plus Macmillan, UCL, Queen Mary University of London, City University, primary care and patient reps (System p.5)	<ul> <li>The panel considered that there was no clear strategy for inclusion and engagement with providers at the beginning and end of the pathway and therefore not covered formally by the integrated system</li> <li>However the panel noted that proposed system acknowledged the difference between engagement between centre and geographic periphery and true integration</li> </ul>	Green	
competition	How the integrated system will ensure that patients are provided with informed choice throughout the pathway.	Standards and protocols for delivery of pathway components that can be delivered on multiple sites (System p.8)	The panel noted the proposed system's vision for choice and competition	Green	
Choice and co	The system should demonstrate that it is not being anti-competitive.	•Involve commissioners in governance to ensure adherence to competition rules and contractual arrangements (System p.10)			

Pathway	How the integrated cancer system will develop relationships with providers across the whole care pathway.  How the system will exert influence over the quality of care and outcomes of the whole pathway.	<ul> <li>GPs on a sessional basis; work closely with Macmillan (System p.7)</li> <li>Examples: Whittington Health; Bart's and the London, Homerton, and Tower Hamlets PCT; Royal Free and Barnet PCT (System p.5)</li> </ul>	<ul> <li>The panel noted that there was no lack of will and welcomed the level of primary care and patient input to date</li> <li>The panel noted examples of good practice such as the patient perspective of pathway work and the patient navigator role</li> <li>The panel was unclear about how the system would scale up successes across a wide area (e.g. brain cancer learning on patient experience)</li> <li>The panel felt that more work needed to be done in understanding the range of work currently carried out in networks and developing a process for systematically embedding this work across the system</li> <li>The panel supported the proposal to use 1-year survival and patient experience as the proposed system's key measures</li> </ul>	Amber
Pat	The components of the cancer pathway for which the integrated system will be accountable.	• From diagnosis to end of acute treatment, immediate follow-up for surveillance and monitoring side effects. Build relationships "allowing London Cancer to influence the whole pathway of cancer care" (System p.5)		

Gove	Governance				
	Specification criterion	Submission documents	Panel assessment	Rating	
Governance board	Terms of reference for the governance board.	•Terms of reference (System p.13)	<ul> <li>The panel welcomed the chief executive-led process that was in place to develop a governance model by the end of October and that it would take into account FT guidance</li> <li>The panel noted the need for this work to be aligned with the ongoing establishment of the proposed academic health science system and for the timescales of both pieces of work to be aligned</li> <li>The panel acknowledged the proposed system's desire to discuss set-up costs and ongoing operating costs and expects this to be resolved by the end of September if not before</li> <li>Whilst it acknowledges that leadership may be dispersed across the system, the panel would encourage the proposed system to adopt a clear leadership model, so as to avoid an inefficient consensus development model</li> </ul>	Amber	
	Membership of the governance board.	Board membership multiprofessional; will 'migrate' to 10-12 members (System p.6)			
	The management of a single risk register.	Single risk register mentioned but not detailed (System p.13)			
	Patient and public involvement.	<ul> <li>Patient priorities identified: early diagnosis; CNS; info for active choices; written info; holistic, dignity and respect (System p.8)</li> <li>User scrutiny group (System p.10)</li> </ul>			
	Board-level support, direction and leadership from each provider organisation.	Outlined in MoA: some delegated responsibility and refer back 'tricky' decisions			

Accountability	How the governance board will hold constituent members of the integrated cancer system to account for delivery through assurance systems and performance management.  Who will be responsible for the development, management and ultimate clinical accountability of services for each tumour type.  The overall clinical lead and/or appointment process.	<ul> <li>Appointment of clinical pathway directors; open competition (System p.6)</li> <li>Remit of clinical pathway boards given (System p.15)</li> <li>Leadership qualities required: architect, operator, caretaker (System p.15)</li> <li>Appointment process outlined (System p.16)</li> </ul>	<ul> <li>The panel noted the clear process for choice of leaders</li> <li>The panel welcomed the fact that London Cancer acknowledge the need to link clinical leadership to the overall governance group</li> <li>The panel heard some of the system's delegation say that change would be easy as medical directors and CEOs would be signed-up to the ICS and doubted that this was the case</li> <li>The panel was positive about much of the proposal but was concerned that goodwill and good ideas alone would not suffice and that a governance model was needed to support the system's leaders to make difficult decisions</li> <li>The panel felt that the proposed system answered questions on difficult areas with a reliance on clinical database that did not yet exist</li> <li>The panel considered that the proposed system was yet to consider a lot of clinical governance issues</li> </ul>	Amber
	Management of peer review across the integrated cancer system.	Not detailed		

Commissioner engagement	How commissioners will be engaged in active governance.	Commissioners consulted by governance board on particular decisions relating to competition (System p.12)	The panel considered that the proposed system's submission did not acknowledge the role of commissioners and expected the relationship with commissioners to develop during the transition process  The panel was disappointed to see the proposels.	Amber
			<ul> <li>The panel was disappointed to see the proposals merely to consult commissioners on issues relating to competition rather than a vision of how providers and commissioners would work differently together in the future</li> </ul>	
governance	Heads of terms for financial flows and governance with board support from all providers within the proposed integrated cancer system.	No detail	<ul> <li>The panel noted that evidence from elsewhere suggests that proposed system expects 2012/13 financial flows to remain as they are now</li> <li>The panel encouraged the system to see incentives as an opportunity to use money as an enabler, not an opportunity to delay</li> <li>The panel would encourage the proposed system to think about harnessing the financial skills across the system to develop its financial governance proposals</li> </ul>	Red
	Approaches to the sharing financial risks and benefits.	No system-wide sharing		
Financial	Process for resolving financial disputes.	Not known		
i i i	The basis of inter-trust invoicing for services.	Not applicable		
	Their approach to capital investment planning.	No plans included in the proposals		

Inform	Information				
	Specification criterion	Submission documents	Panel assessment day	Rating	
Information sharing	How it will share information between constituent organisations and clinicians in order to manage patients across care pathways.	<ul> <li>To be developed by information working group (System p.18)</li> <li>Electronic MDT recording in real time by March 2011 (System p.19)</li> </ul>	<ul> <li>The panel agreed that delivering integrated information was a challenge and therefore welcomed the priority status given to information sharing in the proposals</li> <li>The panel agreed that any informatics platform needs to support research</li> </ul>	Amber	
	A data sharing protocol that all constituent parts of the integrated system are signed up to.	•Will agree (System p.18)	<ul> <li>The panel felt that further work was necessary to work up the costs of delivering integrated information across the system</li> <li>The panel felt that more work was needed on a clear articulation of the proposed system's information governance processes</li> </ul>		
	Plans for common information and data standards and policy.	•Will develop (System p.18)			
Clinical quality data	How the system will review comparative outcome and performance data between providers.	Not addressed directly	<ul> <li>The panel noted the proposed system's requirement of a large amount of clinical information to drive change but consider that its absence should not be a reason for delay</li> <li>Furthermore the panel were concerned that the proposed system was expecting the clinical data to make decisions for it rather than support the decisions that it had made</li> <li>The panel considered that proposed system should make full use of existing resources and felt that the lack of proposals to do so reflected the lack of interface with commissioners</li> </ul>	Amber	
	A current benchmark of staging data and a plan of how they will achieve complete recording.	Baseline of staging data quality in service plan appendices for individual pathways			

The panel also felt that full use should be made of all agencies agencies, including a link with the Thames Cancer Registry	
The panel considered that a clear plan for the investment required was necessary if a large amount of clinical information continued to be seen as an enabler	

Rese	Research and innovation				
	Specification criterion	Submission documents	Panel assessment	Rating	
innovation	How translational and clinical research will be implemented for patient benefit, recognising that there will be complex relationships for basic research and early phase trials.	Clear evidence of commitment to research and improvement of R&D (system p.22)	<ul> <li>The panel noted that R&amp;D was an integral part of overall vision and proposals as presented by the proposed system</li> <li>The panel noted the clear enthusiasm within the proposed system but felt that it needed to be specific on next steps</li> <li>The panel felt that further work was required to develop the detail of how research and innovation would be spread out across the whole system</li> </ul>	Amber	
Research and i	Leadership arrangements for clinical and translational research.	Permanent subgroup reporting to governance board (System p.14)			
Rese	Arrangements for promoting access to high quality clinical trials across the whole system.	Not very clear			

Workforce and culture				
	Specification criterion	Submission documents	Panel assessment	Rating
Training and development	How the system will maximise the opportunities for improving training and development programmes, such as those for junior doctors.	Well organised training and development strategy (System p.29)	The panel felt that further work was required to develop the actions and timescales for delivery	Amber
Leadership & engagement	How clinical leadership will be developed and supported.	Specific curriculum will be available (System p.30)	<ul> <li>The panel welcomed the clear proposals for the clinical leadership of working groups</li> <li>The panel would encourage the proposed system to ensure that, once the right individuals with the right</li> </ul>	Amber
	Proposals for supporting multidisciplinary teams and engaging with clinicians who will work as part of the integrated cancer system.	• At least four actions: admin support; management support; IT tools; training (System p.30)	skills are in place, its leaders are truly empowered to deliver change	
Joint working	Plans to develop joint posts and new ways of working across the integrated cancer system.	Single honorary contract and payroll recharge (System p.30)	<ul> <li>The panel would have been interested to see what practical measures had been done upfront to change culture and begin organisational development</li> <li>The panel noted that there was an operational tension</li> </ul>	Amber
	How partners will work together to tackle common operational problems such as recruitment and retention of staff.	Guidelines and expectations about recruitment (System p.28)	<ul> <li>in the submission between the proposed system and trusts' business as usual</li> <li>The panel considered that further work was necessary to strengthen the proposals for leadership</li> </ul>	

How the system will work with staff on any potential service moves necessary to implement the model of care.	Single change management framework (System p.30)	all the way through the system  The panel noted that the proposed system acknowledged that cultural change would be one of the hardest tasks but did not address this in its presentations on the assessment day	
How the system plans to develop a single identity.	<ul> <li>Vision, mission, behaviours; leaders; modular infrastructure for cultural change and organisational development (System p.27)</li> </ul>	The panel considered that more work need to be done on culture and organisational development, including the development of a resourced plan	

Incentives				
	Specification criterion	Submission documents	Panel assessment	Rating
Incentives	Describe how constituent parts of the system will be incentivised.	•Robust evolving incentive scheme: system-organisational-team-individual; undertake to understand existing incentives and disincentives (System p.32)	The panel felt that the proposed system had addressed the principle of internal incentives, but that further work was necessary to turn these ideas into reality	Red
		<ul> <li>Financial and non-financial (incl. awards) (System p.33)</li> </ul>		

Overall system proposals rating	Amber
	The panel felt that positive progress had been made, building on some of the existing close working relationships across the proposed system. It concluded that there were early signs of potential for a strong integrated cancer system. The panel encouraged the system to continue making good progress.
	The panel agreed that there remained work to be done, however. It felt that further development of a leadership model, governance structure and arrangements to support new ways of working would help make the vision sustainable and systematically implemented.

# 3. Service proposals

### 3.1 Priority pathways

Priority area	Submission documents	Panel assessment	Rating
Bladder and prostate	Priorities clear	<ul> <li>The panel considered that the proposed system's vision of delivery of whole pathways was positive</li> </ul>	None. See below.
Breast	Priorities clear	The panel noted a huge degree of enthusiasm and clinical buy-in	
Colorectal	Priorities clear	•The panel noted that the role of pathway director was clear	
Lung	Priorities clear	<ul> <li>The panel noted examples of areas where change had already occurred, such as upper GI and breast</li> </ul>	
Brain	Consolidation of surgery identified as a priority	<ul> <li>The panel considered that it was unclear whether support was system- wide and therefore whether potential difficulties had been fully acknowledged</li> </ul>	
Head and neck	Concentration into fewer centres identified as a priority as well as public	The panel considered that the proposed system's end point of whole pathway scorecards was clear but that further clarification was necessary on the method of developing these	
	awareness	•The panel considered that the proposed system undertake further	
Rare urological	Priorities clear	work on outlining the benefits of operating as a whole system rather than as two networks working together	
Early diagnosis	<ul> <li>Various approaches to influencing early diagnosis identified</li> </ul>		
Survivorship	Proposal to build on 'local expert initiatives'		

### Overall service proposals rating

The panel felt that ascribing a risk rating to the priority pathways of the proposed integrated cancer systems could be misinterpreted as a comment on the quality of the existing pathways. The panel therefore agreed not to do so.

The panel welcomed the ambition of London Cancer and the work it had carried out to date on its priority areas. The panel noted that the integrated cancer system specification asked for the identification of priority areas where the proposed system would work differently to drive up outcomes. It felt that the system may have prioritised too many areas to make progress quickly in this area.

The panel concluded that it would be of benefit if the proposed system chose a limited number of areas in which it would work up its plans in detail for how this new way of working would look and then spread these to all priority areas. In so doing the panel was clear that it did not want to imply that the good work going on in the other priority areas should cease.

### 3.2 Implementing the model of care and consolidating specialist services

The panel considered that London Cancer had made a good start in developing its proposals to implement the recommendations of the model of care and deliver the required consolidation of specialist services.

The panel was unclear on plans for the implementation of some elements of the model of care, such as bone marrow transplant. It welcomed the level of clinical engagement from across the system but acknowledged that in the short time available it has not been possible for the proposed system to develop a detailed service plan.

The panel would like to work with London Cancer to develop this plan in full and review the proposed system's progress in the autumn (as set out in section 3.3).

### 4. Next steps

### 4.1 Areas to address

### Leadership

A clearer leadership model should be developed that will provide support to clinical leaders in handling difficult decisions. The system should appoint to key leadership positions quickly. It should avoid an overreliance on consensus to drive action.

#### Governance

The system should flesh out its governance arrangements by the end of October. Two exemplar pathways should be chosen for which the governance arrangements should be worked up in detail and then tested. These exemplars will also allow the system to work through and respond to potential clinical governance issues.

### **Planning**

More detailed system planning is required to determine how the system will scale up its proposals and deliver them systematically. This should include more detail on information sharing and clinical data capture, research and innovation, training and development, and workforce and organisational development.

#### Measures and metrics

Progress is required in the development of the system's measures and metrics. These should include measures of the whole pathway and patient experience. This process should be used to drive the system's understanding of its current practice, the gaps that exist, and how improved services will be implemented. The system should, however, avoid an overreliance on detailed clinical data for decision-making.

### Ways of working

The system should use the development of the two exemplar pathways to demonstrate how the opportunity to work differently will be harnessed. It should use these exemplars to build a picture of how clinical groups will work in practice, how this will impact on the business as usual of its member organisations, and therefore the changes to existing arrangements that are required. These changes can then be introduced for all clinical working groups.

### Model of care

A full service plan outlining the system's response to the recommendations in the model of care is still required by the end October. This plan should reveal the order in which the system proposes to tackle these recommendations and this process should be undertaken with the input of the London clinical director.

### Commissioning for breast cancer and radiotherapy

The system has already made good progress. It will therefore be asked to work with the London implementation team to develop commissioning models for the whole breast cancer pathway and for radiotherapy delivery. This work will support the integrated cancer systems and the understanding of how money can be used as an enabler of change.

#### 4.2 Milestones

The recommendations of the evaluation panel will be presented to the cancer implementation board and London's commissioners in September. Subject to agreement the next phase will be the further development and co-production of integrated cancer system and service plans.

At the end of September proposed systems should have in place a plan for their development in the remainder of 2011/12 with agreed resources and programme governance arrangements. These plans will include clear milestones up to April 2012.

Depending on the strength and effectiveness of the programme governance arrangements put in place, the implementation board will take opportunity in November and December, and then again in February and March, to assess the extent to which these milestones have been met. This process will be used to provide commissioners with confidence that the development of integrated cancer systems in London is progressing as expected.

### **Appendix**

The evaluation panel was formed to review the integrated cancer system submissions, ensuring that they meet both the specification criteria and local priorities, whilst ensuring that they are strategically coherent with other plans. The membership of the evaluation panel included patient and GP representatives, out of London nursing and clinical experts, along with representation from commissioning clusters, the London Specialised Commissioning Group and Macmillan.

- Rachel Tyndall Senior Responsible Officer, Cancer Implementation
- Dr Chris Harrison Clinical Director, Cancer Implementation, and Medical Director, The Christie NHS Foundation Trust, Manchester
- Patient representative Natalie Teich, Co-chair, Cancer Implementation Patient Panel
- GP representative **Dr Clare Stephens**, General Practitioner, Barnet
- GP representative Dr Tony Brzezicki, General Practitioner, Croydon
- Non-London clinical expert Mr Martin Lee, Consultant Breast Surgeon, University Hospitals Coventry and Warwickshire NHS Trust;
   Medical Director, NHS Coventry and NHS Warwickshire.
- Non-London clinical expert Professor Mark Baker, Clinical Advisor, Centre for Clinical Practice, NICE
- Non-London nursing expert Helen Porter, Director of Nursing and Quality, Clatterbridge Centre for Oncology NHS Foundation Trust
- Macmillan representative Professor Jane Maher, Chief Medical Officer (deputised for by Lindsay Wilkinson, Head of Healthcare, on 9<sup>th</sup> and 10<sup>th</sup> August)
- Specialised commissioning representative Alex Berry, Divisional Director, London Specialised Commissioning Group (deputised for by Ursula Peaple, Rare Cancers Lead, on 24<sup>th</sup> August)
- Commissioning cluster representative (NE, NC) Will Huxter, Director of Procurement, Contracting and Performance, NHS East London
  and the City
- Commissioning cluster representative (NW, SW, SE) Kathie Binysh, NW London cancer network medical director
- NHS London representative Hannah Farrar, Director of Strategy and Commissioning (deputised for by Alastair Finney, Deputy Director of Strategy and Commissioning. On 24<sup>th</sup> August)

# Document 7: Integrated cancer systems in London – Guidance on delivering service change

Draft document. London Health Programmes, NHS London. December 2011.





# **London Cancer joint development group meeting**

# 12<sup>th</sup> December 2011

Title:	Integrated cancer systems in London: Guidance on delivering service change		
Agenda item:	5	Paper:	5
Action requested:	The group is asked t	to note this	document.
introduction:			I to support London's e further development of their
	wide-ranging. In all i will go through four of the stage and and in the stages will differ dep the change proposed the integrated cancer.	assess consult mplement should happ ending on the transfer systems a for each state	en in each of these four he nature and magnitude of er lays out the options facing it each stage. It then gives an ge in the differing contexts of
Summary of recommendations:	None.		
Reference to other docs:	Cancer model of car	е	
Date paper completed:	Draft completed 8 <sup>th</sup> December		
Other forums that have considered this paper:	None.		
Author name and title:	Thomas Pharaoh, C	ancer Imple	mentation Lead.





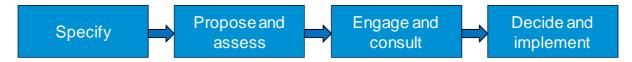
# Integrated cancer systems in London

Guidance on delivering service change

December 2011

### 1. Introduction

This guidance has been created to support London's integrated cancer systems in the further development of their service plans. Systems must continue to develop service plans that implement the recommendations of the agreed cancer model of care for London over the next three years. The service changes that integrated systems propose will be wide-ranging. Some changes will affect small numbers of patients and staff; some will affect large numbers. Some changes will be with the consent or at the insistence of the clinical body; others will be more contentious. In all instances the development of proposals will go through four distinct stages.



The details of what should happen in each of these four stages will differ depending on the nature and magnitude of the change proposed. This paper therefore lays out the options facing the integrated cancer systems at each stage. It then gives an idea if the timelines for each stage in the differing contexts of small, medium and large service changes.

### 2. Specify

The first step is for systems to identify the area in which change is necessary and specify the service that it aspires to provide. These service specifications may cover cancer pathways from diagnosis to end of life care. They will include details of the number of sites on which services will be delivered and the number of multi-disciplinary teams needed to deliver them. Service specifications should be clear about the co-dependencies between services and also be clear about what national guidance they meet or better, and what they do not.

There are a set of questions that integrated cancer systems should ask themselves before developing specifications.

### 2.1. Who specifies?

Clinicians, patients and managers must work together to create service specifications. There are a number of key issues that systems will need to address. Firstly, it is likely that the system will be able to draw on a wealth of national and international evidence of good practice. It should therefore make an early assessment of how much information for the specification is available elsewhere and to what degree there is clinical agreement on best practice.

Secondly, the system should decide who will be involved the development of specifications. Expert groups could, for example, be formed of individuals drawn entirely from within the integrated system. This option has the advantage of being cheap and easier to administer but could expose those on the expert groups to accusations of partiality. As such, this method might be better deployed when the outcome of the service change process is less likely to be contentious. Where a contentious outcome is likely, the system may wish to form a panel of outside

experts to take a disinterested view in the development of services. A third option would be to reduce the potential for bias through the creation of a fully representative expert panel from within the system, although such an option might result in an unwieldy and inefficient group.

Another key question will be whether the specification is developed in partnership with other stakeholders, such as commissioners and the existing cancer networks. The degree to which commissioners are involved in the creation of specifications will be reflected in the approval process so systems should consider carefully their engagement with commissioners.

### 2.2. What is the basis for the specification?

Service specifications should be developed in the light of a clear baseline of current services. Systems will have a wide range of data on factors such as activity, outcomes, research and workforce from which to chose. Systems will need to understand the nature and the magnitude of any changes proposed and be able communicate this to commissioners and other stakeholders. The detail at which systems choose to capture this baseline will clearly depend upon the magnitude of the change.

Integrated cancer systems will also need to judge the level of detail at which service specifications are set. This will depend in large part on the process that is envisaged for drawing up and assessing the proposals for service change.

Systems should guard against the perception that ever larger amounts of baseline data will make service change decisions ever easier. Contentious service change decisions will require strong clinical leadership. The clinical engagement that this strong leadership commands is likely to wane if decisions are delayed by the continual recourse to further data collection. Similarly, systems should resist the temptation to spend valuable time develop overly detailed service specifications in an attempt to avoid contention.

### 2.3. How will proposals be assessed?

Specifications should describe the criteria by which proposals will be assessed, including any weighting that will be applied to these criteria. Some of the criteria will be generic and can therefore be applied to the full range of service changes that the integrated system seeks to bring about. Changes to some services will require the specification to set out pathway or service specific assessment criteria.

Systems should choose criteria carefully as those chosen must give them the ability to distinguish clearly between the various change options. Integrated systems should consider two tiers of criteria, one that ensures that all proposals are of a sufficient standard ('hurdle' criteria) and a second that allows this discrimination between options. Again, the level of commissioner agreement necessary in the sign-off of assessment criteria is an important question for integrated systems to consider.

### 3. Propose and assess

Once specifications are set, integrated cancer systems can develop or invite proposals for service change and assess their relative merits. There are three main options for the delivery of this stage:

- 1. Agreement
- Option appraisal
- 3. Tender

### 3.1. Agreement

The evidence from the specification stage may produce a clear expectation in the integrated system that all relevant parties are agreed on the nature of the required change. If so, a preferred option can be developed through the agreement of all parties. This option is clearly the simplest and least costly. It might be the appropriate choice in the case of small changes or changes that have been worked towards for some time and for which this is the final stage of their delivery.

The implementation of the agreed cancer model of care is expected to achieve a step-change in cancer services in London. Service change by full agreement is unlikely to be able to deliver many of the change necessary. Where systems consider it to be appropriate, they should take care to be seen to formally assess all of the possible options. They should then confirm any agreement with all parties or face potential disruption later in the process.

### 3.2. Option appraisal

Where there is more than one option for service change, and there is no agreement on the path that should be followed, then the integrated system could carry out an option appraisal. The system's central team would collate the various options for delivering service change and make a comparative assessment of these alongside the option of making no change at all.

A disadvantage of this option is that it places a large workload on the system's central team. Considerable time and effort may be necessary to draw up all of the possible options, assess them, and arrive at a preferred option. This method also lays the system open to claims that the outcome was pre-determined. Systems could reduce the potential for accusations of partiality by forming an independent expert panel to assess the various options. The burden of the administration of the whole process will still lie with the central team and systems may need to build in an process to hear the appeals of any services that are not 'preferred'.

### 3.3. Tender

To avoid giving its central team the burden of both developing and assessing the options for change, the system could use a tendering process. The system would publish a service specification and invite organisations, or groups of organisations, to bid to provide the service for a set period.

This option introduces a competitive element to the change process. It has the advantage of incentivising bold, innovative and high quality bids. Encouraging

competition between bidders could however be detrimental if the specification outlines a service that is heavily reliant upon collaboration and partnership between different organisations. This competitive element could be reduced by emphasising that collective bids to meet the specification would be both accepted and favoured.

The tendering option has the advantage for the system that the onus for the delivery of proposals sits clearly with its member organisations. The system's central team will only be responsible for administering the assessment element. The assessment criteria that bids will be subject to will have been made clear during the specification stage and should be used to decide upon a preferred option.

A disadvantage is that systems may need to consult stakeholders on the specification itself before bids can be invited. Experience of past competitive processes shows that systems may to build in the opportunity for all bidders to confirm that they are content with all aspects of their tender and how it will be assessed before the window for bids closes.

### 3.4. Impact assessments

Systems should carry out preliminary impact assessments as part of developing their service specifications. Regardless of the process of proposal and assessment that systems choose, they should ensure that the appropriate assessments of the potential impact of the preferred option are made in full. As an example, for large change the following impact assessments should be mandatory. If the system chooses a tender process the responsibility for undertaking these assessments may fall to the bidder organisations or groups.

- Equalities the likely or actual effects on people in respect of disability, gender and racial equality
- Workforce analysis of the potential effects on the workforce
- Economic the effects on the economic contribution of individuals and the wider economy
- Other services analysis of the effect of proposed service changes on other related health care services

### 3.5. Gateway review

The Gateway review process is a series of short, focused, independent peer reviews at key stages of a project or programme. The reviews highlight risks and issues, which if not addressed would threaten successful delivery.

Gateway reviews are mandatory for all projects and programmes in the Department of Health, arms length bodies and NHS organisations which are assessed as high risk and should also be used for those assessed medium risk. A Gateway review is also required prior to public consultation when any service reconfiguration is proposed.

### 4. Engage and consult

Once a preferred option for service change has been identified, the integrated system should engage the views of its wider stakeholders. The degree of engagement necessary will again depend on the magnitude of the change proposed and the level of commissioner support that it has.

For proposals that will result in small changes to services and have the support of commissioners, engagement should take place as a minimum with those directly involved in the delivery of services and patient representation groups.

For medium to large service changes the net should be spread wider, especially if the change is not yet fully supported by commissioners. Systems should engage with clinical commissioning groups (CCGs) on all medium and large changes from an early stage. The system should also engage with representative bodies such as Local Involvement Networks (LINKs) and council Health Overview and Scrutiny Committees (OSCs) on the preferred option and the process that it went through to arrive at it.\*

Should the Health OSCs representing the population of the integrated system agree that the change proposed in the preferred option is 'significant' then public consultation will be necessary (under Section 244 of the National Health Service Act 2006). The need for public consultation in any one area will clearly add time and other costs to the integrated cancer system's programme and should therefore be avoided as far as possible.

The system should act to reduce the likelihood of Health OSCs deciding that changes require consultation by developing early relationships with committees. Systems should ensure that they understand both the ambition of the system and the evidence-base for proposed changes. Integrated systems should be clear with them on the likely nature of proposals from an early stage, set out the principles and benefits of service changes, and offer to provide regular updates. In dealing with Health OSCs, integrated cancer systems should work to emphasise the support for proposals from clinicians, patients and commissioners, and delegations to committees should reflect this broad support.

Systems will be helped in their engagement with Health OSCs by the work that London Health Programmes has already done in this area. The cancer project team engaged with committees on two occasions in recent times: in autumn 2010 on the model of care and in autumn 2011 on the implementation programme. The appendix shows the coverage of this engagement, which will have served to prepare Health OSCs for the changes ahead.

Should Health OSCs consider the service changes proposed to be significant enough to warrant full public consultation then integrated cancer systems must work together with commissioners to prepare for and deliver this process.

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In the future other bodies will undertake the roles currently held by these groups

### 5. Decide and implement

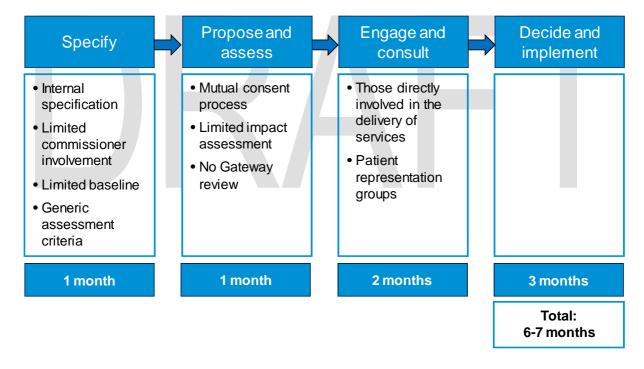
Integrated cancer systems should begin drawing up implementation plans for the delivery of the preferred option during the engagement and consultation phase. Systems should guard against accusations of pre-determined outcomes however and should therefore not begin the bulk of implementation planning before a formal decision has been made.

For medium and large changes, systems should maintain their relationships with Health OSCs and LINks and ensure that they are offered regular updates on implementation.

### 6. Indicative timescales

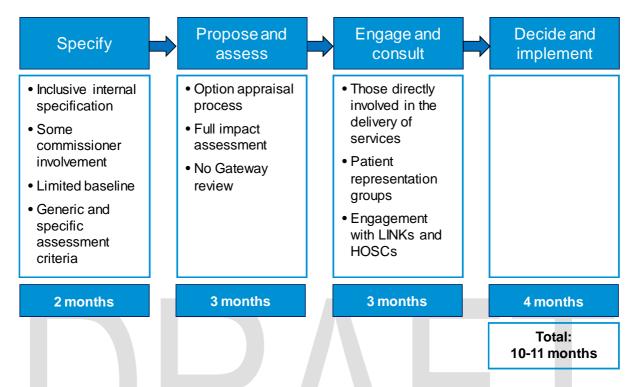
### 6.1. Small change

Such as hepato-pancreato-biliary and neuro-oncology changes in north central London and the localisation of chemotherapy.



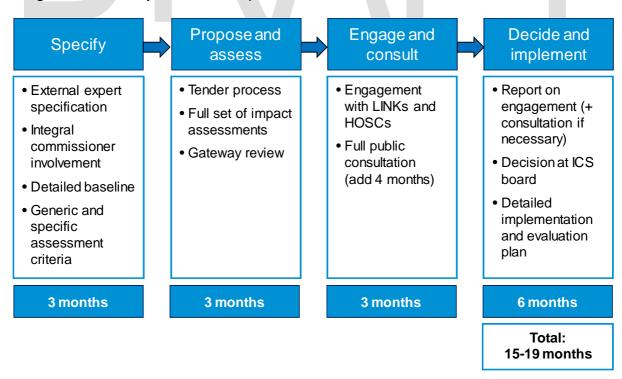
### 6.2. Medium change

Such as the consolidation of part of the pathway; as in common urology and head and neck in London Cancer.



### 6.3. Large change

Such as significant change to the profile of local services. This is unlikely to occur in integrated cancer system service plans.



### **Appendix**

### Autumn 2010

Below is the log of the local authorities where Health OSCs or other groups were visited as part of the engagement period on the model of care in autumn 2010.

Attended	Declined offer / unable to accommodate	No response	Team unable to attend
Barnet	Camden	Barking & Dagenham	Kingston
Bexley	City	Southwark	Newham
Brent	Enfield	Waltham Forest	
Bromley	Greenwich		
Croydon	Hackney		
Ealing	Lambeth		
Hammersmith & Fulham	Lewisham		
Haringey	Redbridge		
Havering	Richmond upon Thames		
Harrow	Tower Hamlets		
Hillingdon	Wandsworth		
Hounslow			
Islington			
Kensington & Chelsea			
Merton			
Sutton			
Westminster			

### Autumn 2011

Below is a list of the local authorities where Health OSCs or other groups were visited as part of engagement on the implementation programme in autumn 2011. In the four instances that the offer was declined, each Health OSC stated that it wished to wait until local implications were clear before receiving visits.

Attended	Declined offer / unable to accommodate	No response	Team unable to attend
Barking & Dagenham*	Harrow	Brent	
Barnet	Hounslow	Croydon	
Bexley	Lambeth	Ealing	
Bromley	Wandsworth	Greenwich	
Camden*		Kensington & Chelsea	
City*		Kingston	
Enfield*		Southwark	
Hackney		Westminster	
Hammersmith & Fulham			
Haringey*			
Havering*			
Hillingdon			
Islington*			
Lewisham			
Merton			
Newham*			
Redbridge*			
Richmond upon Thames			
Sutton			
Tower Hamlets*			
Waltham Forest*			

<sup>\*</sup>Engaged with as part of joint Health OSCs