London
Strategic Clinical Networks

LONDON CHILDREN AND YOUNG PEOPLE
STRATEGIC CLINICAL NETWORK

FEBRUARY 2015

London paediatric oncology review

Report of the Independent Expert Panel
Chaired by Professor Mike Stevens

Minor editorial amendments – November 2015

CONTENTS

1 LIST OF ACRONYMS

AYPH	Association for Young People's Health
BMT	Bone Marrow Transplant
CAMHS	Child and Adolescent Mental Health Services
CCG	Clinical Commissioning Group
CCLG	Children's Cancer and Leukaemia Group
CCN	Children's Cancer Network
CCNCG	Children's Cancer Network Co-ordinating Group
CCPG	Childhood Cancer Parents Alliance
CRG	Clinical Reference Group
CYP	Children and Young People
DH	Department of Health
ENT	Ear, Nose and Throat
GA	General Anaesthetic
GOSH	Great Ormond Street Hospital for Children NHS Foundation Trust
HOSC	Health and Overview Scrutiny Committee
IOG	Improving Outcomes Guidance
ITU	Intensive Therapy Unit
LC	London Cancer (North and East)
LCA	London Cancer Alliance (West and South)
MDT	Multi-Disciplinary Team
MSN	Managed Service Network
NCAT	National Clinical Advisory Team
NHS	National Health Service
NICE	National Institute for Health and Care Excellence
NRCT	National Registry of Childhood Tumours
NSF	National Service Framework for Children, Young People with Cancer
PBT	Proton Beam Therapy
PCC	Paediatric Critical Care
PICU	Paediatric Intensive Care Unit
PTC	Principal Treatment Centre
POSCU	Paediatric Oncology Shared Care Unit
RCPCH	Royal College of Paediatrics and Child Health
RMH	The Royal Marsden NHS Foundation Trust
SCN	Strategic Clinical Network
SCT	Stem Cell Transplantation
SGH	St George's University Hospitals NHS Foundation Trust
SUI	Serious Untoward Incident
TYA	Teenage and Young Adult
UCLH	University College London Hospitals NHS Foundation Trust

2 FOREWORD

Cancer in children is rare but will nevertheless affect approximately 1:500 children in Great Britain before their 15th birthday[1]. Despite impressive improvement in survival rates over the past 40 years, cancer remains the most important health related cause of death in children aged over 1 year of age. Treatment is complex and arduous, and the impact of the diagnosis of cancer in a child is long lasting, felt throughout the family and extends into the child's wider community. Many of those who are cured face life long disadvantage from damage to their physical health, educational progress and psychological wellbeing. There is an imperative to ensure that the care they receive is both effective and safe; that predictable treatment toxicity is optimally managed; and that unexpected complications are identified promptly and responded to by skilled clinical teams.

The organisation of cancer care for children in the United Kingdom, as in all comparable countries, has evolved around the development of centres with specialist expertise (Principal Treatment Centres - PTCs). The further devolution of aspects of a child's care and subsequent follow up to hospital and community services closer to home is now well established but varies in its complexity and implementation across the country. This model, delivered through a network of Paediatric Oncology Shared Care Units (POSCUs), is established in London but operates at a lower level of clinical complexity than in some other parts of the country.

Whilst specialist care delivered across a network of providers to a common set of standards is a model entirely consistent with current policy within NHS England, it creates organisational complexity for good governance and requires excellent communication, experienced clinical teams at all sites, and a commitment to work to agreed policies and procedures. Serious clinical events have occurred in London which relate to failures in these areas and have highlighted the need for this review.

The Review Panel has reached its conclusions by considering the history of children's cancer services in London; reviewing the delivery of existing services; considering feedback from parents, children and young people and from professionals working within the service; and by re-visiting the policies which address the needs and standards of children's services in general and paediatric oncology services in particular. It has taken advice where necessary and sought additional evidence where available. Ultimately, the Review Panel has used its collective experience and judgement to propose significant changes to the organisation of children's cancer services for London. Its aim is to offer recommendations which will ensure the safety and sustainability of those services for the future.

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[1] Cancer Research UK. (2015) *Childhood Cancer – Cancer Statistics.*

To paraphrase a section from the Letter to the Mayor of London, written by Lord Darzi as the introduction to the report from the London Health Commission[2], *"the ideas and proposals in this report have been developed for London. Yet they could just as easily apply to other regions in the UK – but London should be the leader, not an exception".*

It is the Review Panel's belief that its recommendations will, once implemented, deliver a world class service for children with cancer in London and opportunities for national and international leadership in children's cancer care.

Professor Mike Stevens

Chair, London Paediatric Oncology Expert Review Panel

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[2] London Health Commission. (2014) *Better Health for London*.

3 SUMMARY OF RECOMMENDATIONS

The Terms of Reference under which the Review Panel has undertaken its work require recommendations in three key areas – the optimal number of Principal Treatment Centres (PTC); the critical interdependencies (clinical service co-locations) within which PTCs must operate; and the model of shared care with, and within which, the PTC should operate. The Review Panel has addressed these points and, in order to offer a comprehensive view for the future delivery of care for children with cancer in London, also provides recommendations about other elements of the service, specifically: age boundaries and the interface with services for teenagers and young adults with cancer; the delivery of radiotherapy; governance and network structures; and the implications and opportunities that arise for research and training. The Review Panel also offers suggestions for 'next steps' in the implementation of its recommendations. It is clear in its view that the status quo is not acceptable and that significant change is required.

It is important to emphasise that this review relates only to cancer services for children resident in London. Services are also provided by hospitals in London for children with cancer from elsewhere in South East England, including parts of East of England, Kent, Surrey and Sussex. The implications of the recommendations in this report, and their implementation, will need to be considered separately by commissioners responsible for those populations.

3.1 Context

3.1.1 The key driver for this Review derived from concerns about the quality and, in some cases, safety of patient care in existing services in London. Previous reviews have recommended changes, the most important of which have not been implemented, and there is evidence of continuing concern amongst families of children using current services about fragmentation of service delivery, poor communication and lack of access to skilled and knowledgeable staff at all points in their child's treatment pathway. Professionals working within the large shared care network assess that communication is not as good as it might be, that governance arrangements should be improved and that there are too many POSCUs delivering low complexity care.

Whilst none of this negates the positive experiences of many families or the excellent care received by many children, it is against the experience of those for whom the quality of care has been shown to be inadequate that the Review Panel has assessed the current service and proposed it's vision for the future.

3.1.2 The development and reconfiguration of a clinical service should be directed not only to respond to the challenges identified within it but also to the landscape amongst which it sits.

Health care needs to change. The Five Year Forward View[3] published by NHS England has set out reasons why this is so and what response is required. The recent report by the

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[3] NHS England. (2014) *Five Year Forward View*.

London Health Commission[4] has raised the entire profile of health and healthcare in London. It provides a strong focus on the care of children, highlighting the multiplicity of providers of paediatric specialist services and the heterogeneity of the care offered across the population. Using methodology to identify groups with similar health care needs, the Commission has identified children and young people with *'one or more long-term conditions or cancer'* as a specific group within its proposed model for assessing need and setting budgets for care.

3.1.3 The Five Year Forward View explicitly addresses the challenges of specialised care. Whilst it may be difficult to demonstrate a clear relationship between patient volume and quality of care in paediatric sub-speciality practice (further discussed in sections 6.1.3 and 6.3.6), lessons from other specialities (in London and elsewhere) promote the case for a greater concentration of expertise and resource. The Forward View specifically promotes the need for specialised providers to develop networks of services, and the shared care approach in cancer which *"would enable patients to have chemotherapy, support and follow up care in their local community hospital or primary care facility, whilst having access to world-leading facilities for their surgery or radiotherapy"*[5] is explicitly used as an exemplar.

3.1.4 At its first meeting, the Review Panel was briefed by Dr Andy Mitchell, Medical Director for NHS England (London Region), by Mr Will Huxter, the Regional Director of Specialised Commissioning (London Region). Their charge to the Review Panel was to provide visionary, future proof and, if necessary, radical recommendations that will offer world class services to the children of London with cancer. This is reflected in one of the London Health Commission's ten aspirations for London, to *"Create the best health and care services of any world city, throughout London and on every day."*[6]

The Panel were also briefed by Professor Russell Viner, the Clinical Director of the London Children and Young People Strategic Clinical Network, in relation to the current provision of health services for children in London.

3.2 Key Recommendations

These are the Review Panel's principal recommendations: further details are given in the relevant sections of each chapter.

The Review Panel wishes to commend the recent publication of standards for all Trusts delivering acute care for children in London[7] and expects that these will apply to all those delivering any part of children's cancer care.

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[4] London Health Commission. (2014) *Better Health for London*.

[5] NHS England. (2014) *Five Year Forward View*.

[6] London Health Commission. (2014) *Better Health for London*.

[7] NHS England London Children and Young People Strategic Clinical Network. (2014) *Draft London acute standards for children and young people*.

Principal Treatment Centres (PTC):

- The optimal model for the future delivery of care for children with cancer in London is the creation of a single children's PTC, located on a single site with the co-location of all necessary services as defined in this report.
- Allogeneic stem cell transplantation for children with malignant disease in London should be only undertaken on one site - at the children's PTC.
- Paediatric neurosurgery for children with brain tumours in London should only be undertaken by the neurosurgical service co-located with the children's PTC as part of an integrated London paediatric neuro oncology service.

Clinical Speciality Co-location at the Principal Treatment Centre:

- The Review Panel has constructed a framework which defines the requirements for service co-location at the children's PTC.
- Unless radiotherapy services can also be provided at the PTC, on site co-location of the children's PTC with other paediatric speciality services should be prioritised over on site co-location with radiotherapy facilities and other cancer services.

Radiotherapy:

- The Review Panel recommends that all forms of radiotherapy for children should be delivered on one site in London and, given the previously agreed development of Proton Beam Therapy at University College Hospital, believes that this is the only site at which paediatric radiotherapy should be undertaken in London in the future.
- The paediatric radiotherapy service must be supported with resources that provide Level 3 POSCU in patient care in addition to those (play specialist, nursing and paediatric anaesthesia) required to deliver safe radiotherapy to children.
- Centralising paediatric radiotherapy on one site must be supported by the further development of accommodation and other facilities for children and their families and include adequate provision for day care and outpatient review.
- The Review Panel recommends that a major research programme is established in London linked to paediatric radiation therapy.

Paediatric Oncology Shared Care Units (POSCU):

- No more than nine POSCUs of approximately equal size would be sufficient to meet the needs of the service. All of these units should deliver care at Level 3.
- The Review Panel does not see a useful role for the continuing presence of a Level 1 POSCU and believes that, although the necessary development will need to be managed incrementally, there is also little advantage in POSCUs delivering Level 2 care except as an interim step towards achieving Level 3 status.
- The Review Panel does not feel it appropriate to set a minimum size for an individual POSCU (a metric generally defined as the number of new patients seen each year) as it recognises many other factors will need to be taken into consideration in designating

sites for POSCU care in London.

- Patients who live in immediate proximity to the PTC should be able to receive all their care at the PTC and should not be referred to a more distant POSCU.
- The Review Panel recommends that the full reconfiguration of all POSCU services in London should be completed (i.e. with the delivery of Level 3 care) within 3 years from a formal decision to provide such care at the agreed sites.
- Funding to each POSCU should be incremented from the time of its designation, and thereafter should follow the activity seen, at an appropriate tariff in order to adequately support the Trusts offering POSCU care.
- Each patient must have a named consultant responsible for oversight of his / her care throughout each stage of care. Designated PTC consultants must be linked to individual POSCUs for appropriate groups of patients and should undertake clinics jointly with POSCU staff (at the POSCU) at intervals of no less than once in every 4 months.

Age interfaces and links to Teenage and Young Adult (TYA) Cancer Services:

- All newly diagnosed children aged 0 – 15 years (i.e. to the 16th birthday) should be referred to, and treated under the direction of, the children’s PTC. Older teenagers (from 16 years to 19th birthday) may be treated by the children’s PTC, if agreed by both the children’s and TYA PTCs.
- All newly diagnosed children aged 0 – 15 years must be discussed at a paediatric oncology MDT.
- All children aged 0 – 15 years requiring support from other specialised clinical services, including critical care, should receive this from children’s services co-located with the children’s PTC as described in this report.
- The age structure for children and young people receiving shared care should reproduce that applying to PTCs. All children aged 0 - 15 years should be treated within a POSCU. Young people from 16 years to 19th birthday may be treated either within a POSCU or within a designated TYA service under the direction of the TYA PTC.
- Where young people from 16 years to 19th birthday elect to be treated by the children’s PTC, or at a POSCU, this requires the provision of TYA appropriate accommodation.
- There should be greater cohesion in the future design of shared care networks between the children’s and TYA PTCs so that POSCUs are co-located with a TYA designated service in the same hospital.

Governance and Network Structure:

- A single network is required for all children’s and young people’s cancer services in London. The London CYP Cancer Network would operate across all Children’s and TYA PTCs, POSCUs and TYA Designated Hospitals.

- A transitional clinical director should be appointed to provide clinical leadership to the reconfiguration process.
- Formal documented and agreed communication pathways and governance structures between the PTC and the POSCUs should be initiated as soon as possible. This should not wait for the service reconfiguration recommended in this report.

Research and Training:

- The proposed London CYP Cancer Network should appoint both an Associate Director for Research and an Associate Director for Education to work with the transitional clinical director to drive, direct and enhance opportunities for research and training across the network of care.
- Plans for the commissioning of a single PTC for London must protect, and further develop, existing high quality research. This must be approached from a multiprofessional perspective.
- Plans for the commissioning of a single PTC for London within a network of Level 3 POSCUs must be supported by a strategy to educate and train staff across the network to ensure the delivery of high quality care.
- Early implementation of a plan to recruit and train staff to Level 3 POSCU standard will be required in order to achieve the target for designated POSCUs functioning at Level 3 within 3 years. A parallel programme must be offered to London children's community nurses to support children with cancer in the community.

4 BACKGROUND TO THE INITIATION OF THE EXTERNAL REVIEW

4.1 Previous Work

4.1.1 In 2006, the London Specialised Commissioning Group designated two Principal Treatment Centres (PTCs) for children's cancer services in London, one linked to London Cancer North and East, and one to London Cancer Alliance South and West – the two integrated cancer systems operating in London. Both operate on two sites and between two Trusts; one in North Thames comprising Great Ormond Street Hospital for Children NHS Foundation Trust (GOSH) and University College London Hospitals NHS Foundation Trust (UCLH) and one in South Thames comprising The Royal Marsden NHS Foundation Trust (RMH) and St George's University Hospitals NHS Foundation Trust (SGH). Both PTCs operate with a network of 17 Paediatric Oncology Shared Care Units (POSCUs) in London – 11 linked to GOSH/UCLH and 6 to RMH/SGH. Both are also responsible for the delivery of PTC care to children with cancer living in parts of the East of England, Kent, Surrey and Sussex.

4.1.2 In 2010, the Medical Director of NHS London, Dr Andy Mitchell, requested the National Clinical Advisory Team (NCAT) to review the RMH/SGH joint PTC. The request for the NCAT review was triggered following a declared Serious Untoward Incident (SUI) in late 2009 when a child with leukaemia died following admission for febrile neutropenia at the SGH site. The investigation summary included the statement *"The SUI raises serious clinical governance concerns about the medical and nursing paediatric training and provision for children admitted to SGH with cancer as part of the joint development of SGH with RMH as a tertiary children's cancer centre".* The NCAT review panel was also given information about a similar incident at SGH in 2010 where there appeared to be a failure to identify a child with febrile neutropenia and act appropriately in a timely fashion.

The NCAT review was asked to consider the strengths and weaknesses of the existing model, and whether any changes in clinical or governance arrangements should be made in the short term. In addition, it was asked to consider national guidance and recommendations arising from the London Review of Tertiary Paediatrics[8] in determining whether the joint PTC model in South Thames would deliver a safe and sustainable long term model of service provision.

4.1.3 The final NCAT report[9] was published in May 2011. This made both short term and longer term recommendations. Many of the shorter term recommendations related to the need to strengthen governance arrangements between the two partner Trusts in the PTC. The longer term recommendations set out an aim to deliver PTC services from a single site, co-located with other paediatric services.

4.1.4 Some of the short term recommendations were implemented. However, no progress has been made in delivering the longer term aim of re-location of the PTC on one site.

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[8] NHS Commissioning Support for London. (2011) *Children's and young people's project - London specialised children's services: Guide for commissioners.*

[9] National Clinical Advisory Team. (2011) *South London Paediatric Oncology – NCAT Review Report.*

4.1.5 In March 2011, the London Review of Tertiary Paediatrics published a guide for commissioners. The review recommended greater consistency with national policy on specialised children's services specifically to address the co-location requirements for children's cancer services.

4.1.6 Under the chairmanship of Professor Sir Alan Craft, work was initiated to generate new models of care for children's cancer services. This concluded that, in addition to considering the service model for the PTCs, the role and number of POSCU sites needed to be reviewed.

4.2 Work undertaken by the London Strategic Clinical Networks

4.2.1 In April 2013, as part of structural changes brought about by the Health and Social Care Act 2012, NHS London and the London Specialised Commissioning Group were disbanded. The work undertaken under the auspices of the tertiary paediatric review lost momentum. A new organisation, NHS England, was formed which incorporated specialised commissioning as well as medical directorate functions; London was designated one of four regions within NHS England.

4.2.2 A new element of the reorganisation was the formation of Strategic Clinical Networks (SCN)[10] to work in areas of healthcare where a whole system, integrated approach is needed to achieve change in quality and outcomes of care. SCNs are intended to help commissioners bring about sustainable improvements in services. Clinical Reference Groups[11] were established at the same time, intended to provide the primary source of clinical advice on the development and assurance of specialised services specifications and commissioning policies.

4.2.3 Once established, in late 2013, the London SCN undertook to support ongoing work in developing the model of care for CYP cancer services in London. This was driven by a further critical incident resulting in a Coroner's Regulation 28 report, sent to Dr Mitchell, which highlighted issues of quality and safety around the CYP cancer shared care model.

4.2.4 In December 2013, the SCN commenced work on establishing a clinical group to support the development of a model for CYP cancer care in London. The leads for CYP cancer in both the integrated cancer systems (London Cancer and London Cancer Alliance) were invited to co-chair the SCN group: Dr Darren Hargrave, co-chair of the London Cancer North Thames Children's Cancer Network Coordinating Group, and Dr Julia Chisholm, co-chair of the London Cancer Alliance Children, Teenagers and Young Adults Pathway Group, respectively).

4.2.5 This new group was convened as the Children and Young People's SCN Oncology Pathway Group[12]. Interested clinicians and other partners were invited to become members through an expression of interest process. The pathway group undertook a number of

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[10] NHS Commissioning Board. (2012) *The Way Forward: Strategic Clinical Networks.*

[11] NHS Commissioning Board. (2013) *Clinical Reference Groups for Specialised Services: A Guide for Stakeholders.*

[12] NHS England London Children and Young People Strategic Clinical Network. (2013) *Terms of Reference for the London Children and Young People Oncology Pathway Group.*

pieces of work and developed documents including a case for change in paediatric oncology[13] and a model of care for POSCU services[14].

4.2.6 The group also summarised engagement activities which had taken place with children, young people and families[15], and with clinicians[16].

4.2.7 The Oncology Pathway Group had initiated work in trying to agree a new PTC model of care when it became clear that any recommendations made could have significant impact on services currently delivered by host organisations within which group members worked. This had the potential to generate conflicts of interest. For this reason, whilst acknowledging the work of the pathway group in setting direction and raising the case for change, Dr Mitchell felt that, in order to progress the work further, a panel of experts from outside London should be convened.

4.2.8 An expert external panel, accountable to NHS England (London), was jointly commissioned by Dr Mitchell and Mr Will Huxter, Regional Director of Specialised Commissioning (London Region) in August 2014 to determine the most appropriate model of care provision for paediatric oncology services in London.

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[13] NHS England London Children and Young People Strategic Clinical Network. (2014) *London Paediatric Cancer Service Model – Case for Change.*

[14] NHS England London Children and Young People Strategic Clinical Network. (2014) *Paediatric Oncology Pathway Group – proposed POSCU Model of Care.*

[15] NHS England London Children and Young People Strategic Clinical Network. (2014) *Patient and parent engagement summary.*

[16] NHS England London Children and Young People Strategic Clinical Network. (2014) *POSCU Leads meetings summary.*

5 THE PROCESS OF THE REVIEW PANEL'S WORK

5.1 Terms of Reference

5.1.1 In commissioning the externally-led review to determine the most appropriate model of care provision for services delivered to children with cancer in London, NHS England set a scope which included the model of care for both Principal Treatment Centres (PTCs) and Paediatric Oncology Shared Care Units (POSCUs).

The Independent Expert Review Panel was asked to make recommendations on the following:

- the critical interdependencies which should be delivered to achieve best value care pathways and best outcomes for children;
- the model of shared care and optimal number of PTCs that would best serve the population of children both within and outside London;
- the number of POSCUs and their level based on the model agreed for PTCs (taking into account activity that could be delivered close to home in a POSCU).

The review was asked to describe the above elements but was not asked to recommend sites to deliver the services. The Review Panel was advised that their recommendations and the model described would be used by NHS England commissioners to identify and commission providers able to fulfil the criteria defined for the model.

5.1.2 The Review Panel was accountable to NHS England (London region).

5.1.3 The London Children and Young People Strategic Clinical Network (SCN) acted as secretariat to the review.

5.1.4 It was agreed that the London Clinical Senate would critically examine the Review Panel's recommendations and give independent advice on:

- whether it feels the process through which the model of care had been developed was robust;
- whether it agrees with the recommendations from the Review Panel;
- any issues where the review has been unable to reach a recommendation;
- any issues where the Senate's recommendation differs from those of the Review Panel.

5.1.5 The full Terms of Reference are given in Appendix 1.

5.2 Establishing the Review Panel

5.2.1 In August 2014, Professor Mike Stevens, Emeritus Professor of Paediatric Oncology at the University of Bristol, accepted an invitation from Dr Andy Mitchell, Medical Director NHS England (London region) to set up and chair the Review Panel. Professor Stevens is former Chair of the Children's Cancer and Leukaemia Group (CCLG) and President of the International Society of Paediatric Oncology in Europe.

5.2.2 Members were identified and invited by the chair to represent clinical, patient advocacy and NHS commissioning constituencies with relevant expertise of paediatric oncology on the Review Panel. Review Panel members were:

- Dr Nigel Coad, Consultant Paediatrician and Level 3 POSCU Lead, University Hospitals Coventry and Warwickshire NHS Trust; Former Clinical Director of Paediatrics University Hospitals Coventry and Warwickshire NHS Trust.
- Chris Gibbs, Chair, Childhood Cancer Parents Alliance (CCPA); lay member on the NICE Improving Outcomes Guidance (IOG) group and on the NICE Quality Standards Advisory Committee for the IOG.
- Professor Brenda Gibson, Consultant Paediatric Haematologist, Royal Hospital for Sick Children, Glasgow; National Clinical Director, Scottish Managed Service Network (MSN) for Children and Young People with Cancer.
- Jeanette Hawkins, Assistant Director and Nurse Lead, CLIC Sargent; Former Lead Cancer Nurse, Birmingham Children’s Hospital.
- Louise Hooker, Lead Nurse, Teenage and Young Adult Cancer Service, University Hospital Southampton NHS Foundation Trust; Former member of National Cancer Action Team with oversight responsibilities for the implementation of the NICE IOG for Children and Young People with Cancer; Member of NHS England TYA Cancer Clinical Reference Group.
- Dr Bruce Morland, Consultant Paediatric Oncologist and Director of Research and Development, Birmingham Children’s Hospital NHS Foundation Trust.
- Dr Simon Parke, Consultant Paediatrician and Level 3 POSCU Lead, Royal Devon and Exeter NHS Foundation Trust; Chair, CCLG Shared Care Discipline Group.
- Dr Kate Wheeler, Consultant Paediatric Oncologist, Oxford University Hospitals NHS Trust; Member of NHS England Paediatric Oncology Clinical Reference Group (CRG).
- Dr Denise Williams, Consultant Paediatric Oncologist and Former Clinical Director of Paediatrics, Cambridge University Hospitals NHS Foundation Trust.

All clinical panel members work / have worked in UK Principal Treatment Centres at which higher level (level 2 and 3) shared care is part of the model of care.

5.2.3 As part of the review process Dr Nicky Thorp, Associate Medical Director and Clinical Oncologist at Clatterbridge Cancer Centre NHS Foundation Trust, and Dr Daniel Stark, Lead for the TYA Oncology Unit at Leeds Teaching Hospitals NHS Trust, were invited to provide advice on paediatric radiotherapy and teenage and young adult (TYA) services and their interface with paediatric services, respectively. Both attended one Review Panel meeting and also provided advice via email and via telephone.

5.2.4 Review Panel members and advisors completed conflict of interest documentation. Dr Kate Wheeler was the only Review Panel member to declare a potential conflict of interest with a connection to the work of the London Paediatric Oncology Review referencing her professional relationship with London PTC clinicians by referral for second opinion. All clinical panel members have professional relationships with clinicians working in London paediatric oncology services through their membership of the CCLG. None of these relationships were perceived to be a direct conflict of interest in the work of the Review Panel.

5.3 Review Panel meetings

5.3.1 Face to face Review Panel meetings took place in London on the following dates:

- 14 October 2014 (11:30-15:30)
- 13 November 2014 (14:00-17:00)
- 9 December 2014 (10:00-15:00)
- 8 January 2015 (10:00-15:00)
- 2 February 2015 (10:00-15:00)

5.3.2 In addition, a teleconference was held on 23 February 2015 (14:00-16:00) for Review Panel members to discuss and comment upon the draft panel report before it was finalised. Sections of the report were produced and revised during the Review Panel process.

5.3.3 Review Panel members who were unable to attend any meeting were provided with an overview of the meeting via subsequent teleconference with the chair, as well as having access to the minutes of each Review Panel meeting which were recorded by the secretariat.

5.3.4 Dr Andy Mitchell, Medical Director NHS England (London region) and Mr Will Huxter, Regional Director of Specialised Commissioning (London region) provided the Review Panel with a brief overview of the landscape of NHS services and paediatric oncology services at their first meeting. Will Huxter attended two further Review Panel meetings, and Alastair Whitington, Regional Programme of Care Lead for Women and Children's and Trauma and Orthopaedics Services, NHS England (London Region) attended a Review Panel meeting to provide specific NHS Commissioning advice to the panel process.

5.3.5 Dr Diana Hamilton-Fairley, Joint Director of Education and Quality, Health Education South London, and Consultant Obstetrician and Gynaecologist, Guys and St Thomas' NHS Foundation Trust attended each Review Panel meeting on behalf of the London Clinical Senate to observe the process in line with their assurance process (see section 5.1.4).

5.3.6 Professor Russell Viner, Clinical Director of the London Children and Young People (CYP) Strategic Clinical Network (SCN), attended four meetings of the Review Panel on behalf of the CYP SCN and provided an overview of children's NHS services in London at the first Review Panel meeting.

Tracy Parr, SCN Lead Maternity, Children and Young People, and Andy Martin, Senior Project Manager, CYP SCN, attended each meeting, in a secretariat capacity and provided an ongoing link to the SCN.

5.3.7 Professor Stevens met with Will Huxter and with Dr Mark Spencer, Deputy Medical Director NHS England (London Region) (on behalf of Dr Mitchell) on 8 January 2015 to review the progress made by the Review Panel.

5.4 Evidence gathered and considered

5.4.1 Prior to the first Review Panel meeting information was shared with the panel including:

- national guidance and standards (including European standards);
- relevant national data and associated reports;

- reports from previous reviews of paediatric cancer services in London;
- peer review reports;
- relevant documentation from NHS England (London region) including proposals from the London Children's SCN Paediatric Oncology Pathway Group;
- summaries of engagement activities with patients, parents and clinicians.

5.4.2 Other relevant documentation was proposed for consideration either by panel members or as a result of correspondence with the Chair. These were all shared with panel members.

5.4.3 A register of all documentation received and considered by the Review Panel is provided in Appendix 2.

5.5 Engagement with cancer commissioning systems clinical groups

5.5.1 Dr Darren Hargrave, and Dr Julia Chisholm, as CYP leads for their respective networks, were invited to submit the following information which was considered by the Review Panel at their second meeting:

- Annual Reports
- Evidence of shared policies and protocols within the network
- Governance arrangements
- Outcome data
- Action plans following peer review
- Patient experience analysis or any work undertaken with stakeholders

5.5.2 Dr Hargrave and Dr Chisholm were also invited to attend the second Review Panel meeting with representatives from each network to provide an overview of the process and engagement undertaken by the London Children's SCN Oncology Pathway Group, a group they co-chaired, as well as to present their joint vision for paediatric oncology services in London.

5.5.3 The following network representatives attended the Review Panel meeting with Dr Hargrave and Dr Chisholm:

- Julie Baylis, Nurse Consultant, Great Ormond Street Hospital for Children, NHS Foundation Trust
- Dr Vasanta Nanduri, Consultant Paediatrician, West Hertfordshire Hospitals NHS Trust
- Carly Snowball, Lead PTC Nurse, The Royal Marsden NHS Foundation Trust
- Dr Catherine Wynne, Consultant Paediatrician, Brighton and Sussex University Hospitals NHS Trust

5.5.4 A fourth representative was invited to attend the meeting from each network but this opportunity was not utilised by either.

5.5.5 A letter and information relating to TYA services in London were submitted to the Review Panel by Dr Rachel Hough and Dr Louise Soanes as the Co-Chairs of the North Thames TYA Cancer Network Coordinating Group and South Thames Children and TYA Cancer Network Clinical Co-ordinating Groups respectively. This was considered by the panel at its fourth meeting.

5.6 Engagement with provider Trusts

5.6.1 NHS Trusts in London involved in the delivery of paediatric oncology services were invited to submit a response to an online questionnaire. The invitation was sent to London acute NHS Trust Chief Executives, Medical Directors and Directors of Nursing as well as relevant clinicians. The questionnaire was also circulated to London Cancer North and East and London Cancer Alliance West and South. A single response was requested from each NHS Trust or organisation. The questionnaire sought views about the optimal number of PTCs; the age range served by a children's PTC; critical service co-locations; optimal number of POSCUs; the level of care provided by POSCUs; outreach support to POSCUs from the PTCs; governance arrangements between PTCs and POSCUs; and structures for patient / parent engagement.

5.6.2 In total, 22 responses were submitted from NHS Trusts and organisations in London. A report which analyses these responses can be found in Appendix 3. (A questionnaire response was also received from East Kent NHS Foundation Trust which was considered by the Review Panel separately but is not included in the report as the Trust is located outside London).

5.6.3 Responses to the questionnaire were considered and discussed at multiple Review Panel meetings. Due to limits on the amount of text which could be submitted for particular questions online, some respondents provided supplementary written information, which was also considered by the panel.

5.6.4 Following a request for further information about the GOSH/UCLH PTC model of care, Dr Hargrave submitted written information, agreed by both parties, which was considered by the Review Panel at its fifth meeting.

5.6.5 David Probert, Director of Strategic Development, ULCH, provided information, following a request, in relation to Proton Beam Therapy development at UCLH, in particular:

- Activity modelling for PBT patients (children and young people), including initial and potential increase in activity as indications for PBT are widened, for referrals within and outside London.
- Potential impact of PBT on support services for children and young people at UCLH (in patient, anaesthetic and play specialist resources etc.).

This submission was considered, for information purposes, by the Review Panel at its fifth meeting.

5.6.6 A letter was submitted to the Review Panel from a number of POSCU clinicians in London, highlighting their concerns about the reconfiguration of paediatric oncology services. These concerns derived from proposals made earlier in 2014 from a document published by the London Children's SCN Paediatric Oncology Pathway Group. The letter and a response from the Chair were considered by the Review Panel at its fifth meeting.

5.7 Data

5.7.1 A request was submitted to Specialised Commissioning (London region), as the sole commissioner of paediatric oncology services in London, to provide PTC and POSCU activity data over a three year period. A template of information requested by the Review

Panel was circulated to PTCs and POSCUs in London. These submissions were considered at the third Review Panel meeting.

5.7.2 Due to issues with interpretation of the activity data provided, a further data activity request was sent via Specialised Commissioning (London region) to PTCs and POSCUs to complete. The information submitted was discussed and considered at the fourth and fifth Review Panel meetings.

5.8 Engagement with children, young people and families

5.8.1 Activities undertaken by the Strategic Clinical Network prior to the commissioning of the external review were shared with the Review Panel at its third meeting. This included a summary of two parents' meetings facilitated by the Royal College of Paediatrics and Child Health (RCPCH) and attended by 26 parents, and an online survey with responses received from 21 parents and 8 children / young people, further supplemented with 8 face to face meetings.

Key messages included the need for: robust communication between professionals; equity of service provision across all POSCUs; skilled staff and information available at all times; high quality information for families about service provision; monitoring of performance at POSCUs with active sharing of good practice; optimal provision of clinical resources; and improved shared care for 16 – 18 year olds.

5.8.2 A further engagement event was initiated by the Review Panel and took place on 17 January 2015 (11:00-13:00) in London. 27 adults and 10 children attended the event, eight aged 7-11 and two aged 14-18. A further 13 people registered for the event but were unable to attend.

An invitation letter was sent to NHS Trusts, clinicians and CLIC Sargent staff to circulate to patients, families and carers affected by children's cancer. Those who previously took part in engagement activities during the London Children's SCN Oncology Pathway Group process were also invited.

Registration for the event reached capacity two days before the event. Those who registered an interest but were unable to attend the event were offered the opportunity to provide written feedback.

5.8.3 The event was facilitated by The Association for Young People's Health (AYPH) and was attended by the Professor Mike Stevens, Chris Gibbs, Tracy Parr and Andy Martin who provided an overview of the work of the review.

5.8.4 The workshop element was split into two sessions, one for adults and one for children and young people. There were four discussion areas discussed by the adults:

- Which services should be located at the same site?
- What is shared care and what are the ideal shared care arrangements?
- What are the key issues surrounding transition to adult services?
- What other improvements should be made to children's cancer care in London?

Children and young people discussed and developed their ultimate children and young people's cancer services.

5.8.5 A summary report from the event was considered by the Review Panel at their fifth meeting and can be found in Appendix 4.

Key messages from the participants included the need:

- for better communication, information and record keeping;
- for high quality and consistent services as near to home as possible;
- for families to be supported with good facilities, good information and good practical support;
- to minimise / eliminate transfer for care between different hospital sites;
- for consistent oversight of each child throughout their treatment;
- for continuity of care by skilled staff from PTC to POSCU to community services;
- for age appropriate care;
- for seamless transition across all services involved in a child / young person's care.

6 THE PRINCIPAL TREATMENT CENTRE (PTC) MODEL OF CARE

6.1 Background

6.1.1 **PTC development elsewhere:** There has been a steady trend towards ensuring the delivery of all components of the paediatric care required by children with cancer on one site at other PTCs within NHS England.

6.1.2 **The size of the current service:** Data were provided by the existing PTCs in response to a request from the Review Panel about the number of new patients seen each year. This is generally accepted as a measure of the comparable size of paediatric oncology services. ‘New patients’ were defined as NHS patients, aged 0-15 years, newly diagnosed with cancer (i.e. as per cancer registration standards) seen at each PTC per year. Data were requested for three consecutive years (and could be provided either for financial years 2011-12; 2012–13; 2013–14 or for calendar years 2011; 2012; 2013) (Appendix 5).

Figures provided by the GOSH/UCLH PTC suggest an average of approximately 230 new patients are seen each year, and those from RMH/SGH, approximately 180 new patients each year. They did not distinguish London patients from those resident outside London.

Data from the National Registry of Childhood Tumours (NRCT) collected between 2006 and 2011[17] suggest annual averages for GOSH/UCLH of 243 and for RMH/SGH of 144 new patients per year. The NRCT figures will include all patients registered by the PTC (i.e. not just cases resident in London) but will include children only to the age of 14 (to the 15th birthday). There is, therefore, a degree of discrepancy between the two sets of data, more particularly for RMH/SGH. In essence, however, the total work load, defined as new patient referrals, for children’s PTC services in London lies close to 400 new patients per year.

In comparison, data from NRCT show that only four other PTCs in NHS England returned average registrations of over 100 new patients/year (Birmingham 187, Cambridge 126, Manchester 124, Bristol 110). These comparisons confirm the size of the paediatric oncology service currently provided by the London PTCs and for which future plans are required.

6.1.3 **The influence of PTC size on patient outcomes:** There are no data which support the influence of centre size (defined as numbers of new patients seen per year) on patient outcome assessed as survival. This has been addressed within the UK Children’s Cancer and Leukaemia Group (CCLG) in the past, largely in the context of determining whether there is evidence that an optimal lower threshold can be determined for the size of a PTC, i.e. whether smaller centres have less favourable outcomes than larger centres.

A paper from the Childhood Cancer Research Group at the University of Oxford was issued to the CCLG governance group in February 2009[18] which explored links between

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[17] National Cancer Intelligence Network. (2012) *National Registry of Childhood Tumours Progress Report 2012*.

[18] Childhood Cancer Research Group. (2009) *Survival by CCLG centre for children aged <15 at diagnosis, 2002-2006.*

centre size and observed *vs.* expected deaths. No centre within the United Kingdom showed evidence for a consistently higher number of observed *vs.* expected deaths across major disease subtypes. The document also makes clear that important confounders exist in such analyses where events are, numerically, too small to provide high statistical certainty.

6.1.4 **Characteristics of the RMH/SGH PTC:** Much of the previous attention given to the issue of PTC services in London has focused on the 'South Thames' PTC model of care, currently delivered as a joint service between the Royal Marsden Hospital (RMH), Sutton, and St George's Hospital (SGH), Tooting. These hospitals are 7.8 miles apart (AA Route Planner).

Concerns about the South Thames joint PTC model had been raised following previous clinical incidents and were addressed in detail in a report from the National Clinical Advisory Team (NCAT), published in 2011[19]. The Review Panel has reviewed this report in detail.

The NCAT report stated that whilst, in the short to medium term, the existing collaboration developed to deliver a 2-site PTC between RMH and SGH was the only viable option, five possible options for a longer term solution should be considered. However, the NCAT team concluded that *"In the longer term we think the most advantageous long term solution is to re-provide the whole paediatric oncology Principal Treatment Centre clinical activity on the site of a children's specialised services hub in South Thames, alongside other essential services as set out in the 'Safe and Sustainable'[20] recommendations".*

The report also placed specific emphasis on the necessity to ensure that bone marrow transplantation in South Thames *"should be on a site that can offer immediate critical care support as set out in 'Safe and Sustainable' ".*

The Review Panel understands that no steps have been taken to meet either of these recommendations and believes that this raises a serious concern about commitment to change structures in order to address patient safety issues.

The continuing fragmentation of paediatric specialist service support for the RMH/SGH PTC is illustrated by the following configurations: Level 3 paediatric critical care (PICU) services are provided on three sites - at SGH, King's College Hospital (King's College Hospital NHS Foundation Trust) and at the Evelina London Children's Hospital (Guy's and St Thomas' NHS Foundation Trust). Paediatric neurosurgery is undertaken on two sites - at King's College Hospital and SGH. Cardiac and renal support for patients at RMH is provided at the Evelina.

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[19] National Clinical Advisory Team. (2011) *South London Paediatric Oncology – NCAT Review Report*.

[20] Department of Health. (2008) *Commissioning Safe and Sustainable Specialised Paediatric Services: A Framework of Critical Inter-Dependencies.*

"Families shared the shock of being transferred and what a scary and stressful experience this had been. For many it meant losing time, continuity of care and familiarity of setting"

Summary comment from the engagement event for patients, families and carers held on 17 January 2015 (See Appendix 4)

6.1.5 **Characteristics of the GOSH/UCLH PTC**: The 'North Thames' PTC also operates on two sites, GOSH and UCLH. These sites are 1.3 miles apart (AA Route Planner). The nature of the 2-site relationship has not been subject to prior external review.

The GOSH/UCLH PTC model of care splits the care of patients in the paediatric age range between the two sites at about the age of 13 years. Current arrangements were set out in a paper provided to the Review Panel in January 2014[21]. There is no on-site Level 3 paediatric critical care (PICU) at UCLH and any children under 13 years requiring this are transferred to GOSH whilst those aged 13 – 15 years (to 16th birthday) are admitted to the UCLH ITU. In addition, cardiac, renal and neurosurgical services for children aged 13 – 15 years treated at UCLH are based at GOSH.

On the basis of this information, the Review Panel does not believe that the component of the children's PTC provided at UCLH meets the essential on site service co-locations defined in chapter 7 of this report.

6.1.6 **Paediatric Critical Care Utilisation:** Data about paediatric critical care utilisation submitted by the two current PTCs were incomplete and no data were provided by RMH about transfers out for level 3 paediatric critical care / PICU. However, data given in the NCAT report suggest that there were, on average, 20 - 25 transfers out of RMH for PICU support each year. This contrasts with a figure of less than 10 PICU admissions per year provided by GOSH.

The NCAT report also quoted data which suggested that between 25 - 35% of patients undergoing stem cell transplantation (SCT) at RMH require transfer off site for paediatric critical care support. Data from a published international meta-analysis[22] suggest a median 17% (range 7 – 29%) admission rate of SCT patients to intensive care units, derived from 13 published reports including paediatric data over the period 1980 - 2005.

The Review Panel accepts that early recognition of the need for critical care support is appropriate but believes that the lack of such facilities on site will result in unnecessary transfer for some patients who might otherwise be managed on the paediatric oncology ward with critical care oversight.

6.1.7 **Age definitions** for the delivery of paediatric services and the interface with TYA services are further discussed in chapter 10 of this report.

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[21] Great Ormond Street Hospital for Children NHS Foundation Trust and University College London Hospital NHS Foundation Trust. (2015) *Summary of Joint GOSH/UCLH PTC Model of Care for Paediatric Oncology Patients < 16 years of age.*

[22] Naeem et al. Review: Transfer of the hematopoietic stem cell transplant patient to the intensive care unit: does it really matter? *Bone Marrow Transplant* (2006) 37, 119-133.

6.1.8 **Work done by the London Children's Strategic Clinical Network Paediatric Oncology Pathway Group**: The group published two papers relevant to PTC care. In the first, describing the case for change[23], there are no specific recommendations about PTC configuration although reference is made to a) work done to strengthen joint governance between the two sites offering joint PTC services in South Thames and b) the necessary critical co-dependencies for PTC services.

A second paper, which exists only as a draft, specifically addressed the PTC model of care[24]. Three options for the future were presented for consideration. In summary, these were: 1) the status quo; 2) two PTCs located to "decrease fragmentation and optimise tertiary pathways"; and 3) a single 'pan London' PTC. No preferred option was provided and subsequent discussion between the Review Panel Chair and Dr Hargrave and Dr Chisholm clarified that the Pathway Group's thinking behind the single 'pan London' PTC option should be interpreted as a 'dispersed' PTC model by which a single PTC operated on different sites and across different provider Trusts according to clinical risk and patient need.

6.1.9 **Current Patient Pathway:** The Review Panel considered the possible patient pathways that might apply within the current service configuration. The following scenario (Example Pathway 1) illustrates the possible management of a patient with a brain tumour under current arrangements in South Thames.

Example Pathway 1: A 6 year old girl is seen at her local hospital in South London (also the site of a Level 1 POSCU) with a history of headache, ataxia and early morning vomiting. Imaging confirms the presence of a brain tumour. She is referred directly to the paediatric neurosurgical service at King's College Hospital where she undergoes surgery to remove the tumour. A diagnosis of high risk medulloblastoma is established. She is seen post operatively by a paediatric oncologist visiting from the Royal Marsden Hospital (RMH). Eight days after surgery she is discussed by the South Thames paediatric neuro oncology MDT based at RMH: the neurosurgical team participate by remote link from King's. She is transferred to RMH a week later where her further care (neuro rehabilitation, stem cell harvesting and planning for radiotherapy) is initiated. Early in her radiotherapy treatment she develops neurosurgical complications and is transferred back to King's where she undergoes shunt insertion. One week later she is returned to RMH where, after reassessment by the paediatric radiation oncologist, she is able to recommence radiotherapy early the following week. In view of her neurological rehabilitation needs and nutritional state she cannot be discharged home at the end of radiation therapy. This support continues as an inpatient and chemotherapy is started six weeks after completion of radiotherapy but an episode of sepsis requires urgent transfer to St George's Hospital for paediatric critical care assessment. She requires monitoring but stabilises and does not need additional support. Five days later she is transferred back to RMH to continue her chemotherapy.

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[23] NHS England London Children and Young People Strategic Clinical Network. (2014) *London Paediatric Cancer Service Model – Case for Change.*

[24] NHS England London Children and Young People Strategic Clinical Network. (2014) *Draft Proposed Model of Care. London Paediatric Oncology Principal Treatment Centre (PTCs).*

6.2 Option Appraisal

6.2.1 The Review Panel concluded, first, that neither of the current London PTC services (both of which are delivered across two sites involving separate NHS Trusts) meet the necessary critical co-location requirements for the optimal delivery of PTC care as defined in chapter 7 of this report; and second, that no professional consensus about the future configuration of PTC care in London had yet been reached. The panel therefore considered five options for the optimal delivery of children's PTC care in London.

6.2.2 **Option 1: the status quo**. This implies that, apart from optimising governance and organisational arrangements between the sites constituting the current GOSH/UCLH and RMH/SGH PTCs, and implementing a rationalisation of POSCU services as recommended by this review (chapter 9), the sites of delivery of PTC care would not change.

6.2.3 **Option 2: two PTCs co-located with all necessary paediatric services.** This option had already been discussed in the NCAT Report in respect of the RMH/SGH PTC (section 6.1.4).

In response to an online questionnaire sent out by the Review Panel in November 2014 (Appendix 3), 16/22 organisations felt that the current number of PTCs providing care in London was optimal for the future. The questionnaire did not, however, refer to other options and nor did it specify PTCs co-located with all necessary services.

6.2.4 **Option 3: a single 'Pan London' PTC located on a single site with all necessary paediatric services.** This option would require the development of a single site offering the complete range of paediatric services requiring co-location with the PTC (as defined by the Review Panel in chapter 7).

6.2.5 **Option 4: a single 'Pan London' PTC delivering care across a number of sites in London.** This option presents the concept of a 'dispersed PTC' with the delivery of PTC care at different sites according to clinical need and perceived risk (section 6.1.8).

6.2.6 **Option 5: an increase in number of PTCs in London.** The Review Panel did not think that any proposal to increase the number of PTCs currently offering care in London represented any advantage in terms of the quality of patient care and would result in costly duplication of many services. On that basis, this option was not considered further.

6.2.7 In considering its detailed response to options 1 - 4, the Review Panel acknowledged both the complexity of the factors contributing to an optimal model for PTC care and the challenge it felt it had been given to propose 'future proof, visionary and radical' recommendations in order to achieve world class services for children with cancer in London.

6.2.8 The Review Panel placed particular emphasis on certain conclusions reached in its deliberations on age considerations (discussed in chapter 10) and on the appropriate co-location of paediatric services to support PTC care (as detailed in chapter 7).

The key principles adopted by the Review Panel in its assessment of these various options include:

- All children and young people newly diagnosed with cancer between the ages of 0 and 15 years (i.e. to their 16th birthday) should be treated at a children's PTC providing services as defined in chapter 7, and within an age appropriate environment. From 16 to 18 years it is expected that young people newly diagnosed with cancer would be referred to a TYA PTC.
- All PTCs are expected to meet the requirements set out in current peer review standards[25].
- On site co-location of a children's PTC with other paediatric speciality services is explicitly prioritised over on site co-location with radiotherapy facilities and other cancer services.
- A children's PTC must have support from an on-site Level 3 paediatric critical care facility (PICU).
- On site co-location with paediatric neurosurgery is essential for the delivery of a paediatric neuro oncology service.
- Nationally, allogeneic stem cell transplantation (SCT) is not undertaken by every PTC but, when provided for malignant disease, it should only be provided within a paediatric oncology PTC.

6.2.9 Based on these key principles, the Review Panel supported the conclusion (also made in the NCAT report) to dismiss Option 1 (status quo) as this would fail to address the key issue of critical service co-location.

6.2.10 The Review Panel considered the possibilities created by Option 4 ('dispersed' PTC model) but were concerned about the concept of one PTC operating on several sites and across different provider organisations. Specifically, if this option does not satisfy co-location requirements at all sites of care, it provides no advantages over Option 1. If all sites of care are able to satisfy the co-location requirements, the Review Panel believes there would be an unacceptably complex pathway of services, with additional challenges for governance and duplication of resources. Furthermore, feedback from parents has highlighted specific concerns about minimising transfers to other sites for care.

The Review Panel was not convinced that this model of care offered advantages over the status quo and decided not to consider it further.

6.2.11 The Review Panel recognised that the implementation of Option 2 (two PTCs co-located with all necessary paediatric services) would require re-location of children's PTC services away from RMH to another site in line with the co-location recommendations identified in chapter 7. This is in line with the previous NCAT report recommendations. Implementation of this option would also require an adjustment to the provision of PTC services between GOSH and UCLH to ensure that care for children to the age of 16 years is provided by the necessary co-located paediatric services.

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[25] NHS England National Peer Review Programme. (2014) *Manual for Cancer Services: Children's Cancer Measures. Version 1.0.*

6.2.12 The Review Panel's principal concerns about Option 3 (a single site PTC) relate to the size of the service change that would result, and the feasibility of achieving the necessary investment required.

The Review Panel reviewed the literature for research providing insights into the relationship between treatment centre size and patient outcomes. Very limited publications are available and most data confirm the dominant effect of recruitment of children to clinical trials over the importance of treatment centre size. Historical analyses undertaken by the Childhood Cancer Research Group at the University of Oxford for the UK Children's Cancer and Leukaemia Group (and its predecessor, UK Childhood Cancer Study Group) have not shown a consistent relationship between PTC size (defined as new patients per year) and patient survival.

The Review Panel also considered examples of international models of care and recognised that the single PTC model is being developed in the Netherlands for a national population of approximately 16 million on the site of an existing children's hospital offering the full range of paediatric care.

6.2.13 The Review Panel concludes that only two options represent valid possibilities for the future model of care for PTC services in London – Option 2 and Option 3.

In order to further assess the relative merits of each, the Review Panel undertook a separate SWOT analysis for both options. An agreed summary of the responses offered by the Review Panel is provided in appendices to this report - Appendix 6 addresses Option 2 (the two PTC model) and Appendix 7 addresses Option 3 (the single PTC model). The results highlight the balance of risk in any decision taken about a future model of care.

6.2.14 The Review Panel wishes to emphasise that neither PTC configuration would succeed unless its recommendations to reconfigure the POSCU network (chapter 9) are also implemented.

Based on experience elsewhere in the UK, it estimates that up to 50% of current clinical activity at the existing PTCs could be transferred to Level 3 POSCUs where almost all routine chemotherapy and supportive care can be delivered. Core activity at a PTC would then focus on diagnosis, stabilisation and treatment planning for newly diagnosed and relapsed children; surgery; interventional and complex radiological and therapeutic techniques; oversight for children undergoing radiotherapy; care of high risk patients – specifically, infants and those requiring high dose / complex therapies, including allogeneic and autologous stem cell transplant procedures; and early phase clinical trials. It is clear that the complexity and length of stay of patients treated at the PTC will increase. Further modelling is required to accurately define the resources required to deliver such care.

6.3 Review Panel's Conclusions

6.3.1 The Review Panel remains concerned that delivery of Option 2, with the maintenance of two PTCs, may not address existing differences in service delivery and patient experience even if co-location with all appropriate services is achieved on both sites. Furthermore, two PTCs will continue the duplication of staff and resources necessary to provide a comprehensive service. The Review Panel also envisage a risk of asymmetric development between the two PTCs which may also result in lack of equitable access to some aspects of care. The persistence of two PTCs also creates greater complexity in standardising and managing governance and clinical relationships with POSCUs.

6.3.2 The Review Panel sees Option 3 (a single PTC) as the more visionary alternative and, subject to the necessary investment, carefully managed implementation and strong clinical leadership, believe this offers substantial potential for the delivery of the world class service deserved by the children of London.

6.3.3 The risks associated with delivery of the service on a single site were discussed by the Review Panel. This would reflect the same provision as for the rest of the UK where there is only one PTC for a given location. The provider organisation would need to ensure there are suitable business continuity plans in place to ensure that the service can be continued regardless of disruption to staff, location or supplies.

6.3.4 Regardless of the decision on the optimal number of PTCs, the Review Panel believes that the level of activity relating to allogeneic stem cell transplantation for children with malignant disease justifies a decision to undertake such procedures at only one PTC in London. The data provided suggest approximately 35 such procedures are undertaken between both current PTCs each year. Centralisation of this aspect of the service would consolidate expertise, maximise opportunities for innovation and research, avoid duplication of facilities and support the training and retention of staff with the appropriate skills.

6.3.5 The Review Panel is concerned about the fragmentation of paediatric neurosurgical services for children with brain and spinal tumours, currently provided on 3 sites in London, and the need for this to be provided at the children's PTC, ensuring full integration into a London paediatric neuro oncology service.

6.3.6 Whilst the Review Panel is mindful that its recommendations may be subject to demands for a better evidence base with regard to, for example, survival (see also section 6.1.3), it is clear that such evidence may not always be available. It nevertheless believes that service outcomes are also importantly represented by consideration of patient / parent experience and by evidence of fragmentation in the delivery of the care pathway. In order to illustrate this point, the patient pathway given in section 6.1.9 is reproduced here as envisaged within the new PTC model of care:

Example Pathway 2: A 6 year old girl is seen at her local hospital (also the site of a Level 3 POSCU) with a history of headache, ataxia and early morning vomiting. Imaging confirms the presence of a brain tumour. She is referred directly to the paediatric neurosurgical service at the children's PTC where she undergoes surgery to remove the tumour. A diagnosis of high risk medulloblastoma is established. There are joint consultations, pre and post operatively, with her parents by the paediatric oncologist and the paediatric neurosurgeon. Eight days post operatively she is discussed by the paediatric neuro oncology MDT. Plans for her further care (neuro rehabilitation, stem cell harvesting and planning for radiotherapy) are agreed and initiated immediately after that meeting. Early in her radiotherapy treatment she develops neurosurgical complications and undergoes shunt insertion. Paediatric oncology review is provided on site, including assessment by the paediatric radiation oncologist during a routine clinical session at the PTC. Daily assessment of progress by the oncology and neurosurgery teams, and her rapid clinical improvement, facilitate recommencement of radiotherapy after one week. In view of her neurological rehabilitation needs and nutritional state she cannot be discharged home at the end of radiation therapy. This support continues as an inpatient and chemotherapy is started six weeks after completion of radiotherapy but an episode of sepsis requires paediatric critical care assessment. This is provided on the oncology ward where she is monitored but stabilised and does not require PICU admission. Chemotherapy continues after a short delay.

6.4 Review Panel's Recommendations

6.4.1 The Review Panel recommends that the optimal model for the future delivery of PTC care for children with cancer in London is the creation of a single PTC, located on a single site with co-location of all necessary paediatric services as defined in chapter 7.

6.4.2 Allogeneic stem cell transplantation for children with malignant disease in London should be only undertaken only on one site - at the children's PTC.

6.4.3 Paediatric neurosurgery for children with brain tumours in London should only be undertaken by the neurosurgical service co-located with the children's PTC as part of an integrated London paediatric neuro oncology service.

6.4.4 POSCU reorganisation with delivery of Level 3 care must be fully implemented within the time line required in chapter 9 prior to the creation of the single PTC.

7 REQUIREMENTS FOR CLINICAL SERVICE CO-LOCATION AT A PRINCIPAL TREATMENT CENTRE (PTC)

7.1 Background

7.1.1 A key element in providing a specification for the optimal model of care at a Principal Treatment Centre (PTC) lies in the definition of the relationship between a paediatric oncology service and those other clinical services on which the care of children with cancer depends.

7.1.2 Many of these services may need to be accessed frequently, sometimes in an urgent manner. Support from other services may not be required frequently but may nevertheless be required urgently. Furthermore, given the overall complexity of care required by many children with cancer, and the burden this places on children and their families, every effort should be made to ensure that all services likely to be required for their care and support are accessible without delay or travel to other hospital sites.

> ***"Everything a child might need in a hurry should be on the same site"*.**
>
> Summary comment from the engagement event for patients, families and carers held on 17 January 2015 (See Appendix 4)

7.1.3 Unlike some other paediatric sub specialities, paediatric oncology can be described as a net 'user' of other services as it is a service that rarely (if ever) provides support to children whose care lies principally under the direction of other clinical specialities. It is clear, therefore, that children with cancer have a wide range of needs requiring access to other clinical services, many of which justify co-location.

7.1.4 The key reference on critical inter-dependencies in paediatric services is the report on 'Commissioning Safe and Sustainable Specialised Paediatric Services' published in 2008[26].

7.2 Review Panel's Conclusions

7.2.1 The Review Panel considered, in detail, the 'Safe and Sustainable' report.

In his introduction, Professor Edward Baker, the Project Chair, stated *"Historically, specialised paediatric services have developed in different ways across the country and have not been planned in a co-ordinated manner. It is no longer possible to safely sustain this diverse and sometimes fragmented pattern of service provision"*.

In a response to the Framework, Professor Sir Mike Richards, then national Clinical Director for Cancer, commented *"It (the Framework) therefore enables us to focus on patients and not just their condition. It also recognises the importance of safety and sustainability, and demonstrates that we cannot continue with 'more of the same' if we are to achieve our world-class ambitions"*.

The Review Panel endorses these views.

7.2.2 The Review Panel interprets the term 'co-location' as meaning the provision of two or more services on the same site. The Review Panel further recognises that the definition of

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[26] Department of Health. (2008) *Commissioning Safe and Sustainable Specialised Paediatric Services: A Framework of Critical Inter-Dependencies.*

'site' might also be open to interpretation. In this report, therefore, the term 'same site' is defined as the provision of a service within the same building or group of buildings in a configuration that does not require ambulance or similar transport in order to allow a child within the PTC to access the service in question.

This definition of 'site', therefore, does not allow the delivery of a service at another location, albeit within the boundaries of the same organisation, if this requirement cannot be met.

The Review Panel believes that best care can be provided only if a PTC is sited at a hospital able to provide all other age appropriate services considered necessary for the care of children with cancer and defined in Appendix 8 to this report as requiring "Essential co-location on the same site".

7.2.3 In addition, the Review Panel expects that any hospital providing paediatric care in London will also be expected to comply with the recently published London acute care standards for children and young people[27].

Although Accident and Emergency is a service which forms a major component of acute children's care, the Review Panel does not consider that this is an essential requirement for co-location at a hospital hosting a paediatric oncology PTC.

7.2.4 The Review Panel believes that the existing fragmentation of paediatric specialist services in London creates a challenge to the achievement of the ambitions intended by the publication of the 'Safe and Sustainable' report on a scale unlike that which may exist elsewhere in the United Kingdom, and which must be addressed.

7.2.5 The Review Panel believes that the 'Safe and Sustainable' report did not address all of the co-location requirements for a paediatric oncology service. For example, relationships between paediatric oncology and radiotherapy, and between paediatric oncology and services for TYA with cancer are not addressed.

The Review Panel therefore also considered a draft document detailing work undertaken by the NHS England Paediatric Cancer Services Clinical Reference Group[28] that addresses co-location requirements for a paediatric oncology service. This work supplements the NHS England service specification for paediatric oncology produced by the same group[29] but has not, it is understood, yet been formally endorsed.

The Review Panel felt that these additional documents do not provide sufficiently specific recommendations to support a detailed service specification and that, in particular, the description applied to the provision of radiotherapy is unclear and may largely reflect the status quo (for example the statement "The radiotherapy service for children and adolescents must be at the specified site(s) agreed by the CCN").

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[27] NHS England London Children and Young People Strategic Clinical Network. (2014) *Draft London acute standards for children and young people*.

[28] NHS England Paediatric Oncology Clinical Reference Group. (2014) *Paediatric Cancer Services Co-location Summary. Draft.*

[29] NHS England Paediatric Oncology Clinical Reference Group. (2013) *E04/S/a 2013/14 NHS Standard Contract for Paediatric Oncology.*

7.3 Review Panel's Recommendations

7.3.1 The Review Panel has constructed a framework defining specific recommendations for service co-location at a paediatric oncology PTC. This is an amended version of that provided in the 'Safe and Sustainable' report and includes all services identified in that report with the addition of other services with which paediatric oncology has an important relationship.

7.3.2 In undertaking this work, the Review Panel recognises that the London acute care standards for children and young people also mandate the provision of services generic to the care of all acutely unwell children (for example, diagnostic laboratory and radiology services). Some services in this category have also been incorporated into the Review Panel's recommendations both because of their particular relevance to the care of children with cancer and also to provide a comprehensive specification of services essential to the delivery of care at and for a PTC.

7.3.3 In drawing up this framework, the Review Panel recognises that it is necessary to make a judgement about some aspects of an ideal service configuration, i.e. whether it is possible to achieve a service model which incorporates all essential and desirable relationships on one site.

The Review Panel has therefore explicitly prioritised the on site co-location of a paediatric oncology PTC with other paediatric speciality services over on site co-location with radiotherapy facilities and other cancer services. In doing so, however, the Panel wishes to emphasise the significant benefits of a strong relationship between paediatric oncology and other aspects of cancer care, in particular with TYA cancer services (further discussed in chapter 10), with new drug development and with basic cancer research (chapter 12). However, the Review Panel does not believe that any requirement for geographical co-location to support these relationships can be allowed to override the importance of ensuring that every child with cancer requiring care at a PTC is treated in a comprehensively resourced hospital providing all clinical services as defined in Appendix 8.

7.3.4 The Review Panel also recognises that unless radiotherapy can be provided on the same site as the PTC (using the definition given in section 7.2.2), appropriate paediatric facilities and staffing must be provided at the radiotherapy facility, particularly with regard to the safe administration of paediatric anaesthesia and the provision of in-patient isolation facilities (chapter 8).

7.3.5 The framework is identified by a coloured key which uses the following definitions:

🟥	Essential co-location with PTC on the same site (as defined in section 7.2.2)
🟧	Desirable co-location with PTC on the same site
🟫	Desirable co-location with PTC on the same site but where it is recognised that this may not be feasible and that arrangements may need to be made to support access for children to this service elsewhere
🟨	On site support from this clinical service may be needed but service co location on the same site is not required
🟩	No on site service relationship is required
🟦	National / Supra regional service. Access is via agreed pathways (as for all PTCs in NHS England)

8 RADIOTHERAPY

8.1 Background

8.1.1 Radiotherapy forms an important component of the treatment of some children and young people with cancer. Whilst it contributes to cure, it is also a form of treatment particularly associated with unwanted, long term and potentially serious consequences for future health.

8.1.2 The planning and delivery of radiotherapy is technically complex. Treatment is usually delivered on a daily basis over a period of several weeks and requires the immobilisation of the patient for the duration of each treatment fraction. Some forms of unsealed source radionuclide treatment and brachytherapy (although the latter is infrequently used at present in a paediatric setting in the UK) require in-patient hospitalisation in isolation facilities to avoid environmental contamination. These requirements create particular challenges for the delivery of radiotherapy to children.

8.1.3 It is generally held that approximately 25 - 30% of all children with cancer require radiotherapy as part of their treatment. This is usually delivered with curative intent but the use of radiotherapy is also important for some children in a palliative setting.

Data provided to the Review Panel (Appendix 5) indicate that approximately 170 children undergo radiotherapy between the two PTCs in London each year. This represents a larger fraction of the average number of new patient referrals per year (n= 400) than would be expected. Both figures are likely to include patients aged <16 years from outside London who are also managed at the London PTCs. It is possible that the figures may also include some patients referred from elsewhere in the UK, or abroad. These data will not, however, include the proportion of patients already referred out of the country for Proton Beam Therapy (see sections 8.2.1 – 8.2.3). Approximately 25% require treatment under general anaesthesia (GA).

8.1.4 The Good Practice Guide for Paediatric Radiotherapy was published in 2012[30]. This is a comprehensive guide to all aspects of the assessment, planning, delivery and follow up of radiotherapy for children and young people in the United Kingdom and forms the core of practice guidance for all paediatric radiotherapy services within NHS England.

8.1.5 Guidance about radiotherapy in the NHS England Paediatric Oncology service specification[31] is as follows:

"The radiotherapy service for children and adolescents must be at the specified site(s) agreed by the CCN. The named radiotherapy service should offer a comprehensive range of radiotherapy and access to radionuclide therapy services required for children with cancer. The majority of paediatric PTCs do not have specialised facilities for delivering

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[30] The Royal College of Radiologists, Society and College of Radiographers, Children's Cancer and Leukaemia Group. Good Practice Guide for Paediatric Radiotherapy. London: The Royal College of Radiologists, 2012

[31] NHS England Paediatric Oncology Clinical Reference Group. (2013) *E04/S/a 2013/14 NHS Standard Contract for Paediatric Oncology.*

paediatric radionuclide therapy currently and therefore this is referred on to a specialist centre.

The maintenance and development of the service is critically dependent not just on 'adult' radiotherapy equipment and adequate staffing including clinical oncologists, radiographers and physicists, but also on paediatric oncology support on (from) the PTC site, paediatric nursing and play specialists and paediatric anaesthesia.

Currently children requiring Proton Beam Therapy (PBT) will need to be referred to the nationally commissioned service accessed through PBT panel for treatment outside the UK. Proton Beam Therapy services will be nationally commissioned within the UK from 2018."

8.1.6 National peer review measures for paediatric cancer services[32] state that:

"The CCNCG should agree a policy specifying that:

1. *Radical courses of radiotherapy for children and/or all radiotherapy treatment needing sedation or general anaesthesia should only be delivered in a single, named radiotherapy department for the CCN and only under the care of a clinical oncologist who is a core member of the PTC diagnostic and treatment MDT.*
2. *Palliative courses of radiotherapy for children not needing sedation or general anaesthesia may be delivered in any radiotherapy department in the CCN under the care of any clinical oncologist, provided the proposed course is discussed with a core consultant member of the PTC diagnostic and treatment MDT prior to the treatment."*

8.1.7 Together this guidance highlights several issues of critical importance in providing recommendations for the optimal future delivery of paediatric radiotherapy in London, namely:

- The delivery of radiotherapy to children and young people is complex and highly specialised. It should only be provided at designated centres closely linked to a children's PTC under the supervision of appropriately trained staff.
- Significant specialised paediatric support is required in radiotherapy departments to assist children to receive such treatment, and to support their families.
- Changes in the availability of radiotherapy techniques, notably the introduction of Proton Beam Therapy (PBT) and its future availability in the United Kingdom[33], will have an impact on current paediatric radiotherapy provision. Since 2008, the NHS has funded patients to go abroad for PBT in the absence of this facility in the UK.

8.2 The impact of the introduction of Proton Beam Therapy

8.2.1 Evidence from Dr Nicky Thorp, who served as an adviser to the Review Panel in relation to paediatric radiotherapy, suggests that the introduction of two PBT facilities to the United Kingdom (expected by 2018), one of which is being commissioned at UCLH, will have a major impact on the referral flow of all paediatric radiotherapy within NHS England.

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[32] NHS England National Peer Review Programme. (2014) *Manual for Cancer Services: Children's Cancer Measures. Version 1.0.*

[33] Department of Health. (2009) *A Framework for the Development of Proton Beam Therapy Services in England.*

8.2.2 This will result from a) the internal referral of patients currently going abroad for PBT in line with current referral guidance[34] and b) the possibility that the current referral guidance will be extended to cover other indications.

8.2.3 It is therefore possible that the great majority of paediatric radiation therapy, and nearly all paediatric radical radiotherapy, will be undertaken at PBT centres in the future. This will have a collateral effect on the retention of skills and resources for delivery of paediatric radiotherapy elsewhere.

8.3 Review Panel's Conclusions

8.3.1 The Review Panel recognises the highly specialised nature of paediatric radiotherapy and the complexity of its delivery. It supports the current requirement for service provision only at designated centres and wishes to re-emphasise the close nature of the relationship between the radiotherapy department and the children's PTC.

8.3.2 Whilst the Review Panel suggests the ideal situation is one in which paediatric radiotherapy facilities are co-located with the children's PTC, it recognises the logistical limitations on achieving this and has (as stated in section 7.3.3) "explicitly prioritised the on site co-location of a paediatric oncology PTC with other paediatric speciality services over on site co-location with radiotherapy facilities and other cancer services".

> **"We need the ability to stay on site for radiotherapy if needed but radiotherapy on a different site is fine if it is accessible and easy to get to"**
>
> Summary comment from the engagement event for patients, families and carers held on 17 January 2015 (See Appendix 4)

8.3.3 The Review Panel has also made clear its views about the critical requirement for appropriate paediatric facilities and staffing to be provided at the radiotherapy facility, particularly with regard to the play specialist support, safe administration of paediatric anaesthesia and the provision of in-patient radio isotope isolation facilities (section 7.3.4).

> **"Play specialists are important for radiotherapy"**
>
> Summary comment from the engagement event for patients, families and carers held on 17 January 2015 (See Appendix 4)

8.3.4 The Review Panel accepts the view that the commissioning of PBT at UCLH will have a substantial impact on referral practice for the delivery of radiotherapy to children within and beyond London. It has sought advice from UCLH about the activity modelling being undertaken in relation to PBT (section 5.6.5) and wishes to emphasise the scale of the challenge in relation, to work force issues and staff training in order to meet the predicted demand.

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[34] NHS National Specialised Commissioning Team. (2011) *Guidance for the Referral of Patients Abroad for NHS Proton Treatment. Version 2.3.*

8.4 Review Panel's Recommendations

8.4.1 The Review Panel recommends that all forms of radiotherapy for children should be centralised on one site in London and, given the previously agreed development of Proton Beam Therapy, it envisages that UCLH is the only site at which paediatric radiotherapy should be undertaken in the future.

8.4.2 In addition to the resources available from the children's PTC, in order to meet the requirements for supporting children who may require on-site inpatient care during radiotherapy and / or the delivery of concurrent chemotherapy and supportive care, the Trust delivering the paediatric radiotherapy service must be supported with resources that provide Level 3 POSCU care (including Level 2 paediatric critical care) in addition to those (play specialist, nursing and paediatric anaesthesia) required to deliver safe radiotherapy to children.

8.4.3 Centralising paediatric radiotherapy on one site must be supported by the further development of accommodation and other facilities for children and their families, many of whom will not require hospitalisation but who will nevertheless need to be resident away from their home for several weeks at a time. This will include adequate facilities for day care and outpatient review.

8.4.4 Given the current size of the paediatric radiotherapy service in London, and its likely future expansion, the Review Panel strongly recommends that specific efforts are made to establish a major research programme linked to paediatric radiation therapy.

9 THE PAEDIATRIC ONCOLOGY SHARED CARE UNIT (POSCU) MODEL OF CARE

9.1 Background

9.1.1 Shared care is a well-established component of paediatric oncology care in the United Kingdom although it is implemented to differing degrees of complexity (Levels of Care) within the different services provided across NHS England.

9.1.2 Shared care was actively promoted within the NICE Improving Outcomes Guidance (IOG) (2005)[35] under the overarching principle of "age-appropriate, safe and effective services as locally as possible, not local services as safely as possible". Section 3, page 105 stated: *"For most patients it will be appropriate and necessary for some elements of care to be provided by their local hospital, rather than their principal treatment centre, in a 'shared care' arrangement. The local hospital may or may not provide specialist cancer services and the responsible team may be from paediatric or adult services, depending on age and the nature of condition."*

The core components of shared care were defined in the NICE IOG as follows:

- Coordinated care supported by appropriate structures and process
- A named consultant in the principal treatment centre who takes overall clinical responsibility for care, and a named consultant who takes responsibility at the local level
- An identified nursing lead at the non-principal treatment site
- An identified pharmacist lead at the non-principal treatment site
- Robust two-way systems of communication
- Age-appropriate environment
- Written guidelines to support the level of care agreed
- Education and training programmes for staff in all settings
- Arrangements for unexpected admissions
- Identified contacts for families
- Identified funding

9.1.3 Further work by the DH Advisory Group on the Implementation of IOG for Children and Young People with Cancer[36] developed the concept of 'levels' of activity for shared care, defining a three step model for increasing complexity of care from Level 1 (least complex) to Level 3 (most complex).

These levels of care were subsequently incorporated into peer review measures for children's cancer services[37] and have been defined for a POSCU in terms of what types of

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[35] NICE. (2005) *Improving Outcomes in Children and Young People with Cancer. The Manual.*

[36] This group was initiated in 2005 and jointly chaired by the National Directors for Cancer and for Children. Its Terms of Reference that stated its overall remit as: *"To facilitate collaboration, promote mutual understanding between the Department of Health, the voluntary sector, patient and professional groups and advise the National Cancer Director on the implementation of NICE's guidance on improving outcomes for children and young people with cancer"*. The group was discontinued in 2012.

[37] NHS England National Peer Review Programme. (2014) *Manual for Cancer Services: Children's Cancer Measures. Version 1.0.*

clinical activity may be undertaken with the corresponding requirements for staff and facilities.

9.1.4 Shared care is identified within the model of care defined by the NHS England Clinical Reference Group for Paediatric Oncology: this further suggests that there should be a trend towards increasing the number of POSCUs operating at Level 2/3 and decreasing those operating only at Level 1[38].

9.1.5 There is no evidence that survival is compromised when care is delivered within a service model incorporating a significant commitment to shared care[39].

9.2 Shared care in London: current situation

9.2.1 Shared care is established within the current model of care implemented by both PTCs in London. In total, shared care is delivered on 17 sites within London (11 linked to the GOSH/UCLH PTC and 6 to the RMH/SGH PTC). A map is provided in figure 1.

In addition, there are 16 sites outside London which offer POSCU services linked to the London PTCs (6 with GOSH/UCLH and 10 with RMH/SGH).

9.2.2 The shared care levels defined within peer review measures have been agreed for use within London[40] (given in Appendix 9 to this report). At present, no POSCU in London fulfils criteria for Level 3 service delivery, and the majority operate at Level 1.

9.2.3 Information was requested by the Review Panel from all organisations hosting POSCU services in London; 16/17 responded. Data was sought for the number of new patients with cancer, aged 0-16 years, referred on to any PTC, whether or not they subsequently returned for shared care at that POSCU. The data were requested per year for three consecutive years (data could be provided either for financial years 2011-12; 2012–13; 2013–14 or for calendar years 2011; 2012; 2013) (Appendix 5).

An average total of 277 new patients per year were identified through POSCUs. This contrasts with approximately 400 new patients per year reported via the two PTCs (section 6.1.2). The PTC total will include patients' resident outside London whilst the figure derived from the POSCUs is likely to be close to the number of children resident in London who are diagnosed with cancer each year.

The average annual number of new patients per year varied from 7 to 33 (median 17) between the POSCUs. Five (31%) POSCUs had an average of >20 new patient per year and 5 (31%) had fewer than 15 per year.

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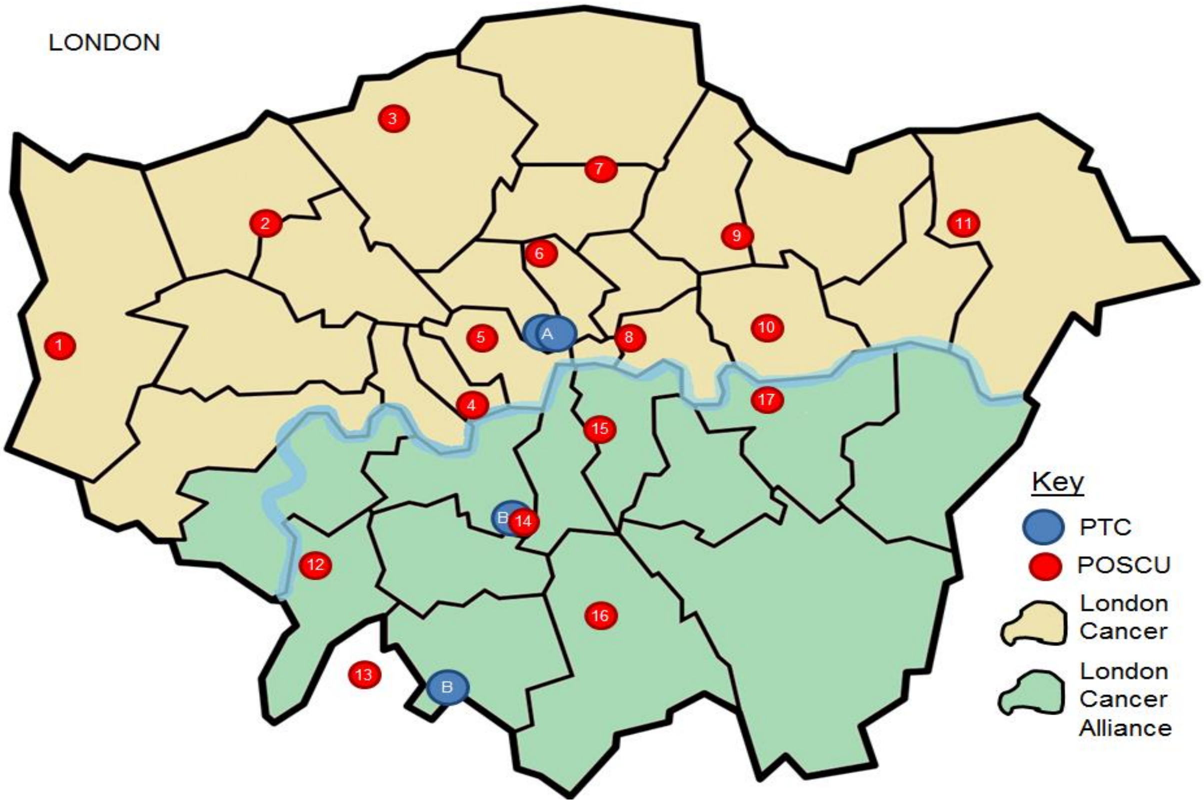
[38] NHS England Paediatric Oncology Clinical Reference Group. (2013) *E04/S/a 2013/14 NHS Standard Contract for Pediatric Oncology.*

[39] National Cancer Intelligence Network. (2013) *Shared Care and Survival.*

[40] NHS London Specialised Commissioning Group. (2012) *Pan Thames Paediatric Oncology Shared Care model for Patients aged 0 to 18 years. A Discussion Paper.*

Figure 1



Key

Existing PTCs in London:

A - Great Ormond Street Hospital for Children NHS Foundation Trust and University College London Hospitals NHS Foundation Trust

B - The Royal Marsden NHS Foundation Trust (Sutton) and St George's University Hospitals NHS Foundation Trust

Existing POSCU Hospitals in London (All Level of Care = 1 except where shown):

1 - The Hillingdon Hospitals NHS Foundation Trust
2 - Northwick Park Hospital (London North West Healthcare NHS Trust)
3 - Barnet Hospital (Royal Free London NHS Foundation Trust)
4 - Chelsea and Westminster Hospital NHS Foundation Trust
5 - St Mary's Hospital (Imperial College Healthcare NHS Trust) (L2)
6 - The Whittington Hospital NHS Trust
7 - North Middlesex University Hospital NHS Trust
8 - The Royal London Hospital (Barts Health NHS Trust) (L2)
9 - Whipps Cross University Hospital (Barts Health NHS Trust)
10 - Newham University Hospital (Barts Health NHS Trust)
11 - Queen’s Hospital, Barking, Havering and Redbridge University Hospitals NHS Trust
12 - Kingston Hospital NHS Foundation Trust
13 - Epsom Hospital, Epsom and St Helier University Hospitals NHS Trust
14 - St George's University Hospitals NHS Foundation Trust (L2)
15 - King's College Hospital NHS Foundation Trust (L2)
16 - Croydon University Hospital (Croydon Health Services NHS Trust)
17 - Queen Elizabeth Hospital (Lewisham and Greenwich NHS Trust)

9.2.4 An analysis has been undertaken of concerns / serious concerns raised within the peer review self-assessment reports at 13 of the 17 POSCUs in London[41]. The findings include issues about staffing, other resources including clinical environment, documentation, staff training, MDT membership and support.

Almost all (18/21, 86%) of organisations responding to an on line questionnaire sent out by the Review Panel in November 2014 indicated that they did not believe that current governance arrangements between PTCs and POSCUs were adequate (Appendix 3)

9.2.5 Feedback from parents / patients using the service includes reflections on a need to address, amongst other issues, improvements in communication between PTCs and POSCUs and to ensure the consistent availability to families of appropriately trained staff and out of hours advice[42].

> **"Improving the quality of care is really important - services should be at the level of the best POSCUs even if this means having fewer POSCUs"**
>
> Summary comment from the engagement event for patients, families and carers held on 17 January 2015 (See Appendix 4)

9.2.6 Currently, although 20/22 organisations responding to the on line questionnaire agreed that PTCs should provide outreach support, including clinics, to all POSCUs, no clinical outreach services are provided at POSCUs in London by medical staff from either PTC, although there is clinical support from nursing staff.

9.2.7 In response to the same questionnaire, 17/18 responding organisations indicated that fewer POSCUs are required to provide optimal care for children with cancer in London. Despite this, only 9/22 agreed that most / all POSCUs should operate at Level 3. The Review Panel believes that an important reason for not supporting the development of Level 3 POSCUs may lie in a concern that current resources could not support this.

9.2.8 As both PTCs in London currently undertake shared care with designated POSCUs outside London in East of England (part of) and in Kent, Surrey and Sussex, it is recognised that changes to service configuration in London will have an impact on those relationships. This is a matter of current discussion between the Specialised Commissioners in London and colleagues in the other areas.

9.3 POSCU configuration: the case for change

9.3.1 The London Children's Strategic Clinical Network Paediatric Oncology Pathway Group has documented its views about changes to the model of shared care in London[43]. These views were reiterated at a meeting of the Review Panel with representatives of both PTCs and their shared care networks on 13.11.14.

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[41] NHS England London Children and Young People Strategic Clinical Network. (2014) *London POSCU Peer Review documentation (self-assessment reports) summary of concerns.*

[42] NHS England London Children and Young People Strategic Clinical Network. (2014) *Patient and parent engagement summary.*

[43] NHS England London Children and Young People Strategic Clinical Network. (2014) *Paediatric Oncology Pathway Group – Proposed POSCU Model of Care.*

9.3.2 The key element of the Pathway Group's recommendations was the proposal to reduce (by at least 50%) the number of POSCUs providing care to children with cancer in London and to increase the level of care they each offer. It was suggested that POSCUs should be expected to manage a minimum of 25 – 30 new patients a year and that the age range for patients under their care should extend to the 19th birthday.

9.3.3 The justification for these proposals was principally focused on the opportunity to improve clinical care and patient experience. It derived from an 'economy of scale' position with the belief that this shift would increase the size, skills and experience of teams working in Level 2 and 3 POSCUs and facilitate communication and staff training, with expected benefits to patients and families. The importance of robust shared governance and appropriate clinical outreach by PTC staff was also identified. The recommendations did not specify service co-locations for shared care but referred to work then currently underway within the London Children's SCN to define standards for all children's acute services[44] with which any Trust offering POSCU care would need to comply.

9.3.4 The Pathway Group's recommendations also included reference to standards for governance, outreach, documentation, workforce and training. The Group proposed an addendum to the NHS England Service Specification listing additional clinical standards for POSCUs in London[45].

9.3.5 The barriers identified to the implementation of these proposals included the need to: redefine patient pathways; ensure recruitment, retention and training of staff with appropriate experience and competencies; establish effective governance structures; address research governance challenges relating to clinical trials; and manage the interface with TYA services.

9.4 Review Panel's Conclusions

9.4.1 The Review Panel supports the approach promoted by the Paediatric Oncology Pathway Group and believes that the existing configuration of POSCU care in London is fragmented and difficult to manage. It accepts that many of the individual POSCUs are too small to ensure that staff resources, knowledge and skills are easily maintained.

9.4.2 The Review Panel agrees that a significant reduction in the number of POSCUs participating in children's cancer care in London is necessary, with a concomitant increase in the level of care provided by those that remain.

9.4.3 The Review Panel believes that this shift will deliver safer patient care and better patient experience provided the reconfiguration is accompanied by a carefully managed programme of service development necessary to ensure that staffing, capacity, resources, training, governance, policies and documentation are all optimised. This must include a parallel augmentation in the capacity and spread of community nursing support. The

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[44] NHS England London Children and Young People Strategic Clinical Network. (2014) *Draft London acute standards for children and young people*.

[45] NHS England London Children and Young People Strategic Clinical Network. (2014) *London Region Paediatric Oncology Shared Care Services Clinical Standards - Proposed addendum to NHS England Service Specification E04/S/A Paediatric Oncology.*

Review Panel understand that the London CYP SCN is reviewing the development of community services for children in London as a priority for 2015/16.

> **“Make better use of community nurses. They can be worth their weight in gold. Nursing teams who are positive, energetic, go out of their way to be flexible, helpful and find a way to make things work – this has to be part of the organisational culture”**
>
> Summary comment from the engagement event for patients, families and carers held on 17 January 2015 (See Appendix 4)

9.4.4 The Review Panel believes that the resulting shift in patient care from PTCs to high level POSCUs, delivered according to agreed pathways, is also an essential component in safeguarding the future viability of the PTC itself (see section 6.2.14).

9.4.5 The Review Panel is aware that, at present, neither PTC in London provides full care for patients from its immediate local population. This has given rise to situations where some patients are required to attend a POSCU further away from their home than the PTC. The Review Panel believes that this inappropriate and that patients living in close proximity to the PTC should be able to receive all their care at the PTC.

9.5 Review Panel’s Recommendations

9.5.1 **Designation of POSCU hospitals:** The Review Panel believes that the key element to POSCU reconfiguration is a reduction in numbers of POSCUs in London, all delivering Level 3 care.

The selection of Trusts to host POSCUs will need to be determined by commissioners utilising a number of factors including geography, size of local population, accessibility (including average travel times), and the availability of co-located acute paediatric services which meet the SCN’s standards for all Trusts providing acute children’s services. This must include the on site provision of Level 2 Paediatric Critical Care (PCC), previously known as high dependency care[46].

In taking all such issues into consideration, and despite the specific recommendations of the Paediatric Oncology Pathways Group (section 9.3.2), the Review Panel does not feel it appropriate to set a minimum size for an individual POSCU, a metric generally defined as the number of new patients with conditions eligible for cancer registration (i.e. patients ‘new to cancer’) seen each year for treatment and support. However, based on the data with which it has been provided (Appendix 5), the Review Panel recommends that no more than 9 POSCUs of approximately equal size would be sufficient to meet needs if all of these units ultimately deliver care at Level 3 (section 9.5.2). In addition, a small number of patients who live close to the PTC should receive all their care at the PTC and would not be referred to a more distant POSCU.

The Review Panel recognises that patients requiring oncological surgery, radiotherapy, allogeneic stem cell transplantation, Level 3 critical care, infants and others requiring particularly complex or specialised forms of care would need to receive this at the PTC,

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[46] Royal College of Paediatrics and Child Health. (2014) *High Dependency Care for Children – Time to Move On*.

but emphasises that Level 3 POSCUs should be able to deliver nearly all elements of routine chemotherapy and supportive care (section 6.2.14).

The Review Panel wishes to emphasise that all patients must be referred to, and seen at, a PTC at the time of first diagnosis. Care at the most appropriate POSCU would then be negotiated and delivered according to the care plan proposed and agreed by the relevant diagnostic and treatment MDT.

9.5.2 **Levels of Care:** The Review Panel does not see a useful role for the continuing presence of a Level 1 POSCU and believes that, although the necessary development will need to be managed incrementally, there is also relatively little advantage in POSCUs delivering Level 2 care except as an interim step towards achieving Level 3 status.

Further detail of levels of POSCU care is provided in Appendix 9. The Review Panel does not believe there is current evidence to support the proposal made by the Pathway Group (section 9.3.4) to modify the nationally agreed standards for shared care.

9.5.3 **Age limits:** The Review Panel accepts that any attempt to ‘cap’ paediatric oncology shared care at age 16 years may adversely affect the quality of care available to patients in the 16 – 19 year age bracket. On that basis the Review Panel agrees with the recommendations of the Paediatric Oncology Pathway Group (section 9.3.2) that there should be provision at each Trust hosting a POSCU to support shared care for patients with cancer to the age of 18 years (i.e. up to the patient’s 19th birthday). This is discussed further in relation to the interface with TYA services in chapter 10 but two key recommendations apply.

First, that clear pathways must be developed before and beyond the age of 16 years to ensure transition to TYA or adult cancer services in accordance with patient preference and clinical need.

Second, that all children and young people are cared for in age appropriate accommodation.

9.5.4 **Resources:** All POSCUs should be funded to meet current peer review requirements for Level 3 shared care in order to successfully initiate a planned programme of development in resources, capacity and staff training to achieve Level 3 status as per the timescales set out in section 9.5.9.

9.5.5 **Networks and Governance:** A single London CYP Cancer Network should be established (this is further discussed in chapter 11) which will be responsible (with Specialised Commissioning) for monitoring all Trusts providing POSCU care. The London CYP Cancer Network will also be responsible for implementing a governance framework to secure and monitor agreed clinical and corporate responsibilities between PTC and POSCUs in relation to patient care. Central to this are three key recommendations.

First, that there should be a written Service Level Agreement held by POSCUs which will address, amongst other items: communication; documentation; management of complaints; reporting of clinical incidents; management of clinical trials; mandatory training; shared policies; and publication of reports. Each POSCU would also contribute to an annual report for the service, coordinated by the PTC.

Second, a single patient / parent forum should be created as part of the feedback and oversight arrangements between the PTC and all POSCUs.

> **"Who governs the care we get and makes ultimate decisions? How are things monitored, managed and policed?"**
>
> Summary comment from the engagement event for patients, families and carers held on 17 January 2015 (See Appendix 4)

Third, work is required to ensure integrity of the patient pathway across traditional boundaries, from PTC to POSCU to community services, and back again.

9.5.6 **Outreach:** Each patient must have a named consultant responsible for oversight of his / her care throughout each stage of the patient's journey. The organisation of this will require designated consultants to be linked to individual POSCUs for appropriate groups of patients (a logical subdivision would be for this to be organised separately for leukaemia, neuro oncology and solid tumours).

The designated consultants should undertake clinics jointly with POSCU staff (at the POSCU) at intervals of no less than once in every 4 months. The purpose of these clinics is not only to direct patient care but also to contribute to the support and training of staff at the POSCU, and to reassure patients of close collaboration across the whole team.

The complementary role of paediatric oncology outreach nurses must be recognised for their links with POSCU nursing staff and children's community nursing teams and in relation to their expertise in offering clinical advice, training and support.

> **"We want a named consultant, immediate access to skilled clinicians and to maintain relationships with clinicians who have cared for us …."**
>
> Summary comment from the engagement event for patients, families and carers held on 17 January 2015 (See Appendix 4)

9.5.7 **Communication:** The Review Panel believes that communication by medical staff should, wherever possible, operate from consultant to consultant, particularly in relation to decisions about key issues such as treatment plans, evaluation of response and management of significant toxicities. The named PTC consultant and POSCU lead clinician should be jointly responsible for the quality and frequency of communication between the PTC and POSCU with regard to each patient's care. This responsibility extends to procedures that ensure any significant communication about a patient which occurs between other members of staff on either site is reported to the responsible consultant(s) in a timely manner.

Arrangements should be agreed and implemented to ensure that POSCU staff have access to the relevant MDT at the PTC as required.

9.5.8 **Training / Staff Education:** In addition to organisational responsibilities for its own staff, all Trusts hosting a POSCU will be responsible for agreeing an annual education and training plan with the PTC and the London CYP Cancer Network to maintain and develop staff skills and knowledge.

9.5.9 **Timescale:** The Review Panel is conscious both that uncertainty resulting from the commissioning of this review (and previous inquiries) may have limited POSCU development within the existing network structures, and that upgrading all POSCUs to function at Level 3 will take time. It recommends that the full reconfiguration of all POSCU services in London should be completed (i.e. with the delivery of Level 3 care) within 3 years from a formal decision to provide such care at the agreed sites.

9.5.10 **Commissioning:** The Review Panel wishes to emphasise that whilst treating children for cancer in a POSCU setting may offer an opportunity for saving against the cost of providing the same care at a PTC, such patients nevertheless require greater resource compared to most other patients in an acute paediatric service. It is therefore important that funding to each POSCU is incremented from the time of its designation (section 9.5.4) and thereafter follows the activity seen at an appropriate tariff in order to adequately support the Trusts offering POSCU care.

10 AGE CONSIDERATIONS AND INTERFACE WITH SERVICES FOR TEENAGERS AND YOUNG ADULTS WITH CANCER (TYA)

10.1 Background

10.1.1 The Terms of Reference for the Review Panel direct its attention to paediatric oncology services yet the definition of 'paediatric' is not standard and the age range to which this descriptor applies varies within clinical practice and across public policy. There are often good reasons for such variability as the needs of children and young people vary not only by age but also in relation to developmental stage. The implications of this for the approach required to care were summarised by Professor Sir Ian Kennedy as follows:

"It seems so obvious it hardly needs to be said: just as children differ from adults in terms of their physiological, psychological, intellectual and emotional development, so they differ in their healthcare needs. They experience and see the world differently. Children are in a constant state of growth and development which creates particular needs and demands which are of a different order from those affecting adult patients. Their relative physical and emotional immaturity, in comparison with adults, has implications both for the treatment which they receive and the physical environment in which they are cared for."[47]

10.1.2 The National Service Framework for Children, Young People and Maternity Services[48], published in 2004, described its age coverage by this statement: *"The NSF covers all babies, children and young people, and child/children is frequently used as shorthand to cover all under-19s" and it went on to state: "However, the agencies have different statutory responsibilities for children and young people of different age ranges, and services need to be commissioned and provided accordingly. The aim of this NSF is to improve the age-appropriateness of services and base this around the needs of the individual young person and their family, including, in particular planning appropriately for transition to adulthood. This may mean that some children receive services from children's services providers for a longer period than others."*

10.1.3 The Guidance for Improving Outcomes in Children and Young People with Cancer[49], published in 2005 applies to all children and young people aged from birth to 24 years of age (i.e. to the 25th birthday). This publication established, for the first time, the importance of the relationship between cancer services for children and those for teenagers and young adults. The Guidance included an important statement in relation to the place of care for young people:

"All care for children and young people under 19 years old must be provided in age-appropriate facilities. Young people of 19 years and older should also have unhindered access to age-appropriate facilities and support when needed. All children and young people must have access to tumour specific or treatment-specific clinical expertise as required."

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[47] HM Government. *(2001) Bristol Royal Infirmary Inquiry, Learning from Bristol: The report of the public inquiry into children's heart surgery at the Bristol Royal Infirmary 1984 -1995).*

[48] Department of Health. (2004) *National Service Framework for Children, Young People and Maternity Services.*

[49] NICE. (2005) *Improving Outcomes in Children and Young People with Cancer. The Manual.*

10.1.4 The wider recognition of the particular needs of teenagers and young adults with cancer has led to the development of specific approaches to their care in age appropriate settings. The flexibility required at the interface between care for children and care for TYA has been described in guidance for professionals published by the Teenage Cancer Trust in 2012[50], as follows:

"The information presented in this document relates to teenage and young adult patients diagnosed with cancer between the ages of 16 and 24 years treated within Principal Treatment Centres, TYA Designated Hospitals or District General Hospitals (DGH) across the UK. For some younger teenagers (aged 13-15 years) parts of this Blueprint of Care will also be relevant and healthcare professionals should use their judgement following individual patient assessment on the application of the practice principles and guidance in such younger patients."

10.1.5 Clinical Reference Groups (CRGs), working within one of six national programmes of care, advise NHS England on the strategic delivery of specialised services. Their work includes the production of service specifications (setting key standards of delivery for a service) and clinical commissioning policies (clinical criteria for access to specific services based on sound clinical evidence).

Two CRGs have been established by NHS England to address cancer care for children and TYA. The service specifications published by these two groups indicate that the Paediatric Oncology service specification[51] relates to the provision of specialist cancer care for children and teenagers aged 0 to 15 years (i.e. to the 16th birthday) and that the TYA service specification[52] applies to the provision of specialist cancer care for teenagers and young adults aged 16 – 24 years. Both documents refer to the possibility of older teenagers (to 19th birthday) being treated within a children's service if wished. The TYA specification makes reference to younger teenagers (aged 13 – 15 years) being treated in a TYA service if compatible with local agreements for both children's and TYA PTCs. This specific point is not addressed in the paediatric specification.

10.2 Review Panel's Conclusions

10.2.1 The Review Panel has discussed, at length, the various age thresholds defined in the publications discussed above, and their implications for its recommendations for the future of paediatric oncology services in London. It recognises there is no agreed single definition of the upper age limit for paediatric services; that there is variability in the interface between paediatric and TYA oncology services; and that the needs of young people are determined by developmental stage as well as chronological age.

10.2.2 The Review Panel believes that all children and young people newly diagnosed with cancer between the ages of 0 to 16th birthday (hereafter referenced as 0 - 15 years) in London should be treated under the direction of a children's PTC. This should be located in a hospital providing all the necessary services (as defined in chapter 7) and their care

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[50] Teenage Cancer Trust. (2012) *A Blueprint of Care for Teenagers and Young Adults with Cancer.*

[51] NHS England Paediatric Oncology Clinical Reference Group. (2013) *E04/S/a 2013/14 NHS Standard Contract for Paediatric Oncology.*

[52] NHS England Teenage and Young Adult Cancer Clinical Reference Group. (2013) *B17/S/a 2013/14 NHS Standard Contract for Cancer: Teenagers and Young Adults.*

should be provided in an age appropriate environment. Supportive care for all patients aged 0 – 15 years should be provided by paediatric services with appropriate co-location status as shown in Appendix 8.

10.2.3 It further believes that patients aged 16 to 18 years can be cared for well in age appropriate accommodation co-located with either paediatric or adult services but expects that all such young people would be referred to, and cared for under the direction of a London TYA PTC. All PTCs (children's and TYA) should be co-located with critical care facilities able to treat all patients in the age range covered by the PTC.

10.2.4 From 19 to 24 years, all young people should be discussed by the TYA MDT but can choose whether or not they wish to be referred to the TYA PTC or treated within designated TYA facilities.

10.2.5 The Review Panel recognises that individual care planning is required between paediatric and TYA services over arrangements for the ongoing care of young people who become 16 years old during treatment or who relapse and require re-treatment after previous care at the children's PTC. This implies there will need to be flexibility about continuing to care for some patients aged 16 – 18 years at the children's PTC, pending transition to TYA care.

> **"Transition may happen at different times for different young people. It would help to have clear age ranges for paediatric, TYA and adult services but with patient choice and flexibility on timing"**
>
> Summary comment from the engagement event for patients, families and carers held on 17 January 2015 (See Appendix 4)

10.2.6 Patients from the paediatric service who become eligible for aftercare should be transferred to a TYA environment once they have reached the age of 16 years, even if it is agreed that the paediatric team will continue to provide care.

10.2.7 The Review Panel recognises a particular concern about shared care opportunities for young people aged 16 – 18 years (i.e. to the 19th birthday).

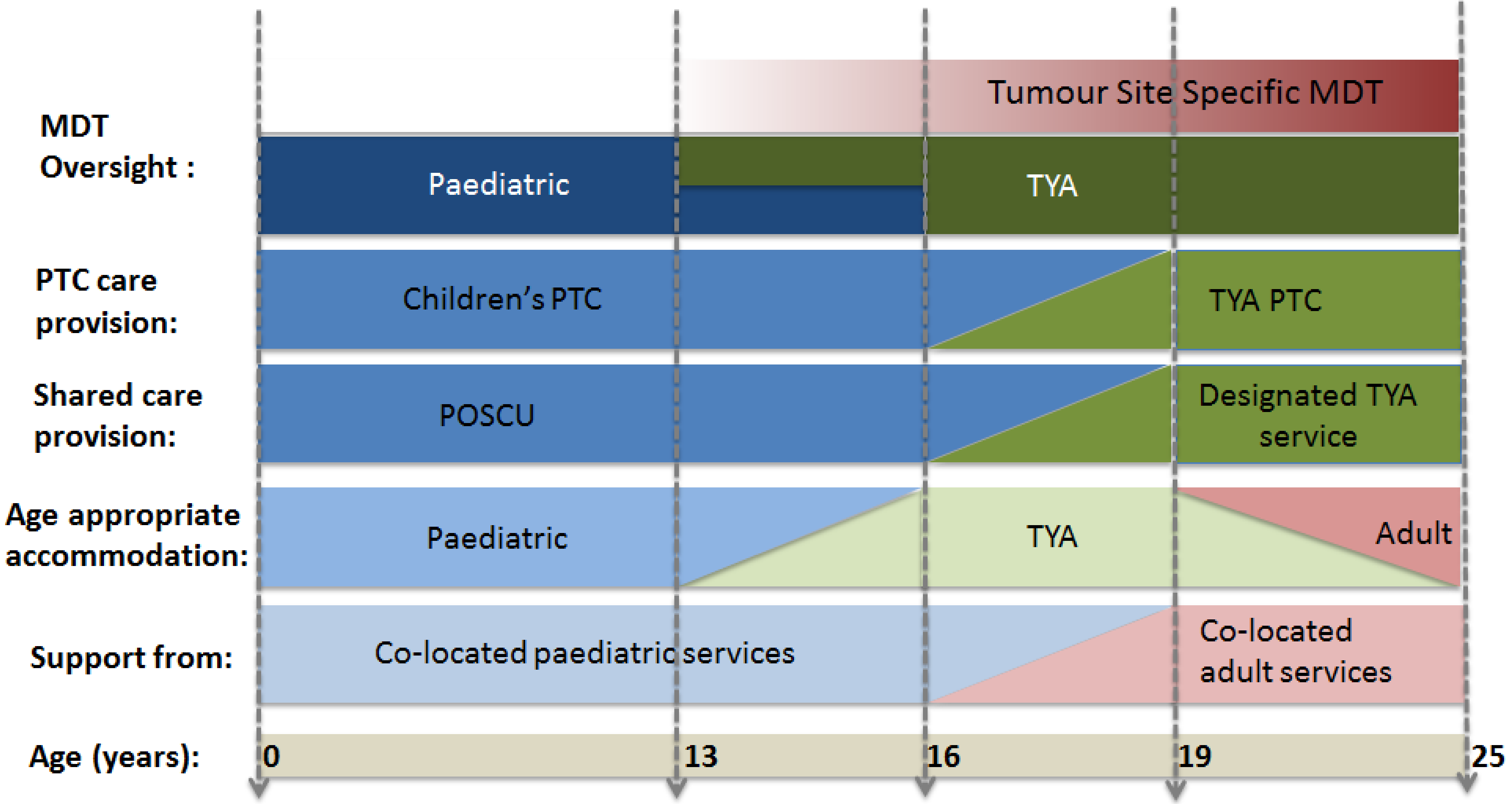
Data provided to the Review Panel indicate that only one third of the 17 current POSCUs were able to provide care beyond the age of 15 years (Appendix 10). Such variability presumably relates to local Trust policies about upper age limits for paediatric services and to the availability of age appropriate facilities for young people over the age of 16 years. It nevertheless highlights the inequity that exists in the opportunities for those under 19 years to receive some of their treatment closer to home. Only 4/17 Trusts hosting POSCU services in London are also TYA designated centres, illustrating a significant lack of cohesion in the provision of shared care services to serve the CYP population in London.

10.3 Review Panel's Recommendations

10.3.1 The Review Panel has agreed a diagram (figure 2) which represents its view of the complexity of the interface between children's, TYA and adult cancer services and emphasises the importance of integrated service planning between paediatric and TYA services in London. This is addressed further in chapter 11. Explanatory notes follow in sections 10.3.2 – 10.3.6.

Figure 2

Age related interfaces in the care of CTYA with cancer



10.3.2 **MDT Oversight:** All newly diagnosed children aged 0 – 15 years should be discussed at the paediatric oncology MDT. Those aged 13 – 15 may, according to local policy, also benefit from discussion at the TYA MDT: this is illustrated by the horizontal line dividing the age band between 13 and 16 years in the diagram.

All children with specific diagnoses may also require discussion by a tumour site specific MDT: for example, a 14 year old with colorectal cancer or a 12 year old with thyroid cancer. In the same way, whilst young people diagnosed at age 16 years or over are properly discussed at the TYA MDT, they will also require discussion at the relevant tumour site specific MDT. This may, in certain circumstances, mean discussion at a paediatric MDT: for example; an 18 year old with rhabdomysarcoma may be usefully discussed by the paediatric MDT as well as the sarcoma MDT, as would the (rare) situation of a patient aged 16 years with a Wilms' tumour.

10.3.3 **PTC Care Provision:** All newly diagnosed children aged 0 – 15 years should be referred to a children's PTC. Whilst the Review Panel agrees with the NHS England CRG Service Specifications that an older teenager (from 16 years to 19th birthday) may be treated within a children's service, if compatible with local agreements for both children's and TYA PTCs, it recommends that, wherever they are managed in relation to age appropriate accommodation, children aged 0 – 15 should receive oversight from the children's PTC with on site co-location of paediatric support services.

10.3.4 **Shared Care Provision:** The age structure for children and young people receiving shared care should reproduce that applying to PTCs. All children aged 0 - 15 years should be treated within a POSCU. Young people from 16 years to 19th birthday may be treated either within a POSCU or within a TYA designated service.

10.3.5 **Age Appropriate Accommodation:** Recognition of the evolving needs of children at different ages and developmental stages should always influence the provision of accommodation. Whilst it may not always be feasible to separate, for example, babies and toddlers from school age children, age appropriate accommodation is a requirement for all those aged 13 years or older. This may be provided in paediatric, TYA or adult run services. Where young people from 16 years to 19th birthday elect to be treated within a children's PTC or at a POSCU, this requires the provision of TYA appropriate accommodation.

10.3.6 **Service co-location:** All children aged 0 – 15 years requiring support from other clinical services should receive this from children's services co-located with the children's PTC as defined in chapter 7. The Review Panel does not accept that it is appropriate for children aged 13 – 15 years to receive care in adult services.

Support for young people aged 16 years to 19th birthday may come from either paediatric or adult services subject to the principles of co-location defined in section 10.2.3.

10.3.7 **Relationship with TYA services:** The Review Panel recommends that POSCUs should, wherever possible, be co-located with a TYA Designated Service and that there should, in future, be greater cohesion in the design of shared care networks between children's and TYA PTCs.

11 GOVERNANCE AND NETWORK STRUCTURE

11.1 Background

11.1.1 The NICE Improving Outcomes Guidance (IOG)[53] states (page 103) that PTCs should have 'defined clinical governance structures' and later refers (page 114) to the responsibility of all Trusts undertaking elements of care for children and young people with cancer to identify clinical leadership with overall responsibility for the delivery of the service and for the maintenance of policies and governance structures.

11.1.2 National Peer Review documentation[54] not only provides a detailed framework for the operation of both PTCs and POSCUs but also includes a set of measures in relation to the coordinating and oversight functions of the Children's Cancer Network.

11.1.3 The commissioning of this external review was prompted by concerns around incidents involving the quality and safety of paediatric oncology services in London (see full Terms of Reference – Appendix 1).

11.1.4 The Terms of Reference for the previous NCAT review[55] of the South Thames service, requested following concerns about safety and sustainability as a result of a reported clinical incident, also included a specific reference to recommendations for changes to governance arrangements.

11.1.5 The Case for Change[56] published by the London Paediatric Oncology Pathway Group included the following statement amongst a list of key drivers for change in the design and implementation of a new service model for paediatric oncology in London: "A robust and transparent shared governance system, with clear responsibilities is required across the whole patient pathway (i.e. community, POSCU and PTCs)".

This was further emphasised in proposals for changes to the model of care for POSCUs[57].

11.1.6 Almost all (18/21, 86%) of organisations responding to an on line questionnaire (Appendix 3) sent out by the Review Panel in November 2014 indicated that they did not believe current governance arrangements between PTCs and POSCUs are adequate.

All respondents who indicated their dissatisfaction with current governance arrangements provided written comments in response to a supplementary question inviting suggestions about how these might be strengthened. A total of 71 suggestions or comments were offered (Appendix 11). Additional responses, representing similar views, came from supplementary written information received by the Review Panel.

11.1.7 The NCAT report highlighted the complexity of patient pathways and the uncertainty and stress this had caused for patients and families. Reports from patient engagement events

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[53] NICE. (2005) *Improving Outcomes in Children and Young People with Cancer. The Manual.*

[54] NHS England National Peer Review Programme. (2014) *Manual for Cancer Services: Children's Cancer Measures. Version 1.0.*

[55] National Clinical Advisory Team. (2011) *South London Paediatric Oncology – NCAT Review Report*.

[56] NHS England London Children and Young People Strategic Clinical Network. (2014) *London Paediatric Cancer Service Model – Case for Change.*

[57] NHS England London Children and Young People Strategic Clinical Network. (2014) *Paediatric Oncology Pathway Group – Proposed POSCU Model of Care.*

held by the Strategic Clinical Network in 2014[58], including that commissioned by the Review Panel in January 2015 (Appendix 4), consistently demonstrate a concern to see: improved communication and information given to families; assured access to high quality and consistent care at all times, regardless of the place of care within the network; minimised fragmentation of care across different sites; and consistent contact with the responsible clinical team, which has up to date knowledge of patient progress throughout treatment.

> **"(We want) consistent and high quality services at and across the centres that work with our family that are defined / accredited / monitored and changes made when needed. Improving the quality of care is really important…."**
>
> Summary comment from the engagement event for patients, families and carers held on 17 January 2015 (See Appendix 4)

11.2 Review Panel's Conclusions

11.2.1 The Review Panel recognises that improvements to governance arrangements were implemented at the RMH/SGH PTC following the recommendations of the NCAT review. It has not assessed further progress made in response to that report beyond reviewing the steps reported in an update to the Recommendations and Action Plan published in May 2012[59].

11.2.2 Both PTCs in London currently operate across two sites and between two separate organisations. As the NCAT report commented, the IOG does not specifically address a model within which PTC function was shared between two organisations.

The Review Panel agrees with a statement in the NCAT report that *"this type of model adds the complexity of having to develop an additional layer of structure to ensure that organisations jointly sharing the PTC role also share responsibilities for the whole patient pathway".*

11.2.3 The Review Panel recognises the high level of dissatisfaction about current governance arrangements between PTCs and POSCUs expressed by those representing organisations who contribute to the current model of care. It also recognises the wish of those leading the current services to improve communication and governance between PTCs and POSCUs and accepts that the large number of current POSCUs is one barrier to achieving this (section 9.4.1).

11.2.4 The Review Panel is clear that professionals involved in the current services have ideas for improvements to the model of care which have not yet been addressed (Appendix 3) and believes that clinical commitment and clear leadership are paramount for the way forward.

11.2.5 The Review Panel accepts that there is evidence for continuing dissatisfaction amongst some parents / patients about arrangements within the current services, many of which relate to communication and to clarity about responsibility for care.

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[58] NHS England London Children and Young People Strategic Clinical Network. (2014) *Patient and parent engagement summary.*

[59] National Clinical Advisory Team. (2012) *South London Paediatric Oncology Review: Recommendations and Action Plan.*

11.2.6 The Review Panel has already highlighted (section 10.3.7) the complexity of age inter relationships across CYP care and has emphasised the importance of integrated service planning between paediatric and TYA services in London in the future.

11.3 Review Panel's Recommendations

11.3.1 Steps to introduce more effective communication and better governance structures between PTCs and POSCUs should be initiated as soon as possible and should not wait for the service reconfiguration recommended in this report.

11.3.2 The Review Panel recommends the creation of a single network for all children's and young people's cancer services in London. The London CYP Cancer Network would operate across all Children's and TYA PTCs, POSCUs and TYA Designated Hospitals.

The Review Panel believes that this will offer leadership, authority and consistency in managing the service reconfiguration recommended in this report. It will also create opportunities for cohesive planning across the CYP age span; provide greater authority in driving improvements to governance, communication and training; ensure a single focus for the development of a robust interface with young people and their families; offer a single point of communication with NHS structures and with the leadership of adult cancer services in London.

11.3.3 The Review Panel recommends that a transitional clinical director should be appointed to provide clinical leadership to the process of reconfiguration.

12 RESEARCH AND TRAINING

12.1 Research

12.1.1 Clinical research is a priority for the NHS. The NHS Constitution[60] states *"The NHS aspires to the highest standards of excellence and professionalism ….. through its commitment to innovation and to the promotion, conduct and use of research to improve the current and future health and care of the population".* The government's Plan for Growth[61] identifies innovation as a key driver of long-term growth in the healthcare sector and key to the NHS improvement agenda. Clinical research is a major driver of innovation and central to NHS practice for maintaining and developing high standards of patient care. Patients themselves value research because they know that by participating in high quality research they benefit from access to new treatments, interventions and medicines. Yet, lack of funding, time, expertise and resources are all commonly perceived by health professionals to be the main barriers to clinical research with the consequence that research may then rely upon enthusiastic individuals working in relative isolation to champion the research cause.

12.1.2 The challenges to research in child heath have been well described in a recent report by the RCPCH Commission on Child Health Research[62]. The report focuses on evidence for a decline in children's research capacity in the UK and highlights areas for strategic attention including: education, training and guidance; the need for robust partnerships with young people and their families; promotion of a collaborative, strategic approach to help organisations work together to overcome obstacles to progress, maximise impact, sharpen the focus on children's research, and maintain momentum; better infra-structure; creation of capacity; and addressing potential barriers to the delivery of research that may arise within NHS organisations. Although the report identifies children's cancer as an exemplar in relation to the organisation and delivery of clinical trials, paediatric oncology departments across the UK share the same challenges of resource, capacity and leadership.

12.1.3 The London Health Commission's report[63] reinforces the aspiration to maximise science, discovery and innovation and highlights the considerable, internationally competitive, skills and resources already available in biomedical research in London.

12.1.4 The Panel has explicitly prioritised the on-site co-location of a children's PTC with other children's speciality services over on site co-location with radiotherapy facilities and other cancer services. It does not believe that this negates the very significant benefits of existing relationships between paediatric oncology in London and other aspects of cancer care or the importance of cancer research in paediatric oncology, including new drug development programmes. However, the Panel does not accept that a requirement for geographical co-location to support such relationships can be allowed override the importance of ensuring every child with cancer is treated in a comprehensively resourced children's PTC providing all necessary clinical services for children.

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[60] Department of Health. (2013) *The NHS Constitution for England.*

[61] HM Treasury. (2011) *The Plan for Growth.*

[62] Royal College of Paediatrics and Child Health. (2012) *Turning the Tide: Harnessing the power of child health research.*

[63] London Health Commission. (2014) *Better Health for London*.

12.1.5 The Panel believes that the creation of a single, large PTC in London offers a unique opportunity for maximising capacity for clinical and translational research which should have a profound and beneficial impact on the leadership and delivery of research in paediatric oncology, both nationally and internationally.

12.1.6 The Panel recognises that the reconfiguration of the service across a single PTC and a network of Level 3 POSCUs offer opportunities to develop and evaluate innovative IT based solutions to new models of care, in line with the intentions of the NHS Five Year Forward View[64] and Better Health for London[65].

12.2 Training

12.2.1 The mandate from the government to Health Education England[66], articulates the importance of effective and high quality education and training to ensure that NHS staff are "available in the right numbers with the right skills, values and competencies to deliver both excellent clinical outcomes together with patient-centred care".

12.2.2 Feedback from parents / patients using the current service includes reflections on a need to address, amongst other issues, improvements in communication between PTCs and POSCUs and to ensure the consistent availability to families of appropriately trained staff and out of hours advice. Staff education and training is key to the delivery of this.

> **"We would like better core skill training in paediatric cancer. Communication and listening skills of staff are really important."**
>
> Summary comment from the engagement event for patients, families and carers held on 17 January 2015 (See Appendix 4)

12.2.3 Care for children with cancer is demanding, technically challenging and often very complex. The Panel believes that the advantages it has described in relation to the opportunities for research apply equally to the education and training of staff. It asserts that the creation of a single, large PTC in London offers a similar opportunity for creating a world leading centre for staff training in children's cancer care.

12.3 Review Panel's Recommendations

12.3.1 The proposed London CYP Cancer Network should appoint both an Associate Director for Research and an Associate Director for Education to work with the transitional clinical director to drive, direct and enhance opportunities for research and training across the network of care.

12.3.2 Plans for the commissioning of a single PTC for London must protect, and further develop, existing high quality research. This must be approached from a multiprofessional perspective and include a strategy to safeguard appointments of clinical academic staff, provide clinical

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[64] NHS England. (2014) *Five Year Forward View*.

[65] London Health Commission. (2014) *Better Health for London*.

[66] Department of Health. (2013) *Delivering high quality, effective, compassionate care: Developing the right people with the right skills and the right values. A mandate from the Government to Health Education England: April 2013 to March 2015.*

and non-clinical research support staff and ensure that the necessary patient care facilities are available within which clinical research can be optimally delivered.

12.3.3 The PTC and the London CYP Cancer Network will take joint responsibility for ensuring that research governance agreements are effected across the network of care so that children participating in clinical trials can receive POSCU care.

12.3.4 The PTC will develop and publish a 5 year strategic plan for research and will ensure that relationships with research teams collaborating with both current PTCs are critically reviewed and protected in the transition to a single PTC.

12.3.5 The Panel recommends that specific efforts are made to establish a major research programme linked to paediatric radiation therapy

12.3.6 Plans for the commissioning of a single PTC for London within a network of Level 3 POSCUs must be supported by a strategy to educate and train staff across the network to ensure the delivery of high quality care. This must be approached from a multiprofessional perspective and include appointments of clinical teaching staff.

12.3.7 Early implementation of a plan to recruit and train staff to Level 3 POSCU standard will be required in order to achieve the target for designated POSCUs functioning at Level 3 within 3 years. A parallel programme must be offered to London children's community nurses to support children with cancer in the community.

12.3.8 All Trusts hosting a POSCU will be responsible for agreeing an annual training plan with the PTC, and with the London CYP Cancer Network, to maintain and develop staff skills and knowledge.

12.3.9 The London CYP Cancer Network will report on research and training activity in its annual reports.

13 NEXT STEPS

Subject to review and endorsement by the London Clinical Senate, and a commissioning decision by NHS England on the recommendations, the NHS England (London region) Specialised Commissioning Team will be responsible for required consultation on the proposals.

Implementation of the agreed recommendations would be taken forward following consultation. The Review Panel suggests that three phases to the Implementation process will be required and that while these are sequentially dependent on each other, there are opportunities for early progress and some overlap between phases will be necessary to ensure that progress is maintained.

An agreed communication plan will be required to ensure that all stakeholders are informed about decisions being taken, the reasons for those decisions and the timeframe within which they will be implemented.

13.1 Phase 1 - Implementation Planning

13.1.1 During this phase the infrastructure required to deliver implementation of change will be established.

13.1.2 Having received the report NHS England (London region) will establish a formal programme implementation board, terms of reference and governance arrangements.

13.1.3 A transitional clinical director will be appointed to provide clinical leadership to the process.

13.1.4 A plan of work incorporating programme milestones will be drawn up to include:

- Development of options for delivery of the required model
  - Undertake detailed financial and activity modelling
  - Workforce modelling
  - Access and travel times
  - Undertake equality impact assessment
- Determining configuration of providers to deliver model of care
  - Agreement of criteria on which decision making will be based
- Commence engagement with Clinical Commissioning Groups (CCGs), Health Overview and Scrutiny Committees (HOSCs), providers, patients and public
- Establish and undertake the appropriate procurement process, including:
  - Informal expressions of interest
  - Formal tenders to provide services
  - Establishment of expert external panel to assess tenders
  - External assessment of bids against agreed criteria of quality, safety, co-location
  - Determination of option(s) for service delivery
- Develop outline business case for future model
- Engagement with CCGs, HOSCs, patients and public and other stakeholders around options leading to potential public consultation
- Further determination of requirements for
  - Workforce
  - Facilities

    - IT
    - Other enabling services
- Describe commissioning arrangements

13.2 Phase Two – Consultation

13.2.1 Having assessed potential providers against the required service delivery criteria, there will be a period of consultation. This will be based on the expected degree of change as has been identified in the procurement process.

13.2.2 There may be a single option or more than one option identified following the submission of tenders to deliver the service. These will be collated into one or more options around which engagement and consultation will be undertaken. Each will be assessed for their ability to deliver the model in relation to the key issues of quality, safety and critical co-dependencies. Other issues will be considered for each option, such as the impact on specific communities and travel times. Mitigation strategies will be described within the assessment.

13.2.3 Engagement and consultation around the option(s) will be undertaken with relevant bodies such as CCGs, HOSCs, patients and public. The degree of consultation required will depend on the size of change proposed in the option(s).

13.2.4 The business case will be refined according to the proposed option(s).

13.2.5 Having considered the responses to the proposed option(s) the programme implementation board will make a decision to proceed with a particular configuration of provision.

13.2.6 A full business case will be drafted based on the selected option.

13.3 Phase 3 - Implementation assurance

13.3.1 Once an option for the configuration of services has been agreed, a number of steps will be put into place to ensure delivery of the required service.

13.3.2 A timetable for delivery will be drawn up in conjunction with providers. This will include milestones for the delivery of level 3 POSCU, PTC and radiotherapy service provision.

13.3.3 The transitional clinical director will work in conjunction with the Specialised Commissioning Team to undertake regular assurance visits to providers and ensure there is timely progress for delivery of the following to the required standard:

- Workforce
- Facilities
- Infrastructure
    - Governance
    - Protocols
    - Effective participation in network

13.3.4Regular reporting of progress in delivering the new service model will be made to the programme implementation board.

Requirements for ongoing monitoring of clinical quality and safety following implementation will be determined though this period.

14 ACKNOWLEDGEMENTS

The Review Panel is especially appreciative of the contributions made by children, young people, parents and other family members who provided their views and experiences about children's cancer services in London both at the Engagement Event arranged by the Panel which took place on 17 January 2015, and at similar events held earlier in 2014, the reports of which were made available for its consideration. It would also like to thank the Royal College of Paediatrics and Child Health and the Association for Young People's Health who facilitated these events.

We are grateful to all those who submitted information and data to the review and to the London Children and Young People Strategic Clinical Network and NHS England (London region) for their support during the process.

15 LIST OF APPENDICES

Appendix 1: London Paediatric Oncology Review - Expert Panel - Terms of Reference

Appendix 2: Document register – Information considered by the Review Panel

Appendix 3: Questionnaire analysis report

Appendix 4: Engagement event summary report

Appendix 5: Activity data

Appendix 6: Summary of Review Panel’s SWOT analysis for Option 2 (two PTCs)

Appendix 7: Summary of Review Panel’s SWOT analysis for Option 3 (a single ‘Pan London’ PTC)

Appendix 8: Framework for defining co-location of services supporting a PTC

Appendix 9: Levels of POSCU care

Appendix 10: Information submitted by Dr Rachel Hough and Dr Louise Soanes – POSCU age limits

Appendix 11: Responses from professionals to a question about how governance arrangements between PTCs and POSCUs might be strengthened

APPENDIX 1

London Paediatric Oncology Review - Expert Panel - Terms of reference

Introduction

NHS England (London) is commissioning an externally-led review to determine the most appropriate model of care provision for paediatric oncology services in London. The scope will include the model of care for Principal Treatment Centres (PTCs) and Paediatric Oncology Shared Care Units (POSCUs). This has been prompted by concerns around incidents involving the quality and safety of these services.

Objectives

The review panel will make recommendations on the following:

- the critical interdependencies which should be delivered to achieve best value care pathways and best outcomes for children;
- the model of shared care and optimal number of PTCs that would best serve the population of children both within and outside London;
- the number of POSCUs and their level based on the model agreed for PTCs (taking into account activity that could be delivered close to home in a POSCU).

The review will not describe sites to deliver the services. The model will be used by NHS England commissioners to identify and commission providers able to fulfil the criteria for the model.

Governance

The review panel will be accountable to the NHS England (London) Paediatric Oncology Programme Board which provides overall direction and management of the paediatric oncology services review programme through to implementation. The London Children's Strategic Clinical Network will act as secretariat to the panel review.

The London Clinical Senate will critically examine the recommendations from review panel and give independent advice on:

- whether it feels the process through which the model of care has been developed was robust;
- whether it agrees with the recommendations from the review (on each of the four issues set out above);
- any issues where the review team has been unable to reach a recommendation;
- any issues where the Senate's recommendations differ from those of the review team.

Membership

Panel members have been identified as demonstrating the following:

- an appropriate level of knowledge and / or expertise in the delivery of paediatric oncology services in the NHS and / or in the commissioning of such services.
- appropriate professional qualifications, sufficient standing and good character.
- no existing, direct relationship with any of the current paediatric oncology service provider in London that could reasonably constitute a conflict of interest.
- no other circumstances that could reasonably constitute a conflict of interest.

- ideally, experience of similar reviews.

The expert panel will be identified to represent the following constituencies:

- Paediatric oncology (including leukaemia and stem cell transplantation)
- Paediatric nursing
- Paediatrics and child health (including paediatric oncology shared care)
- Patient advocacy
- NHS commissioners

In addition, the Medical Director for NHS England (London) will identify a Chair of the expert panel having regard to the need for the Chair to have appropriate experience, standing and independence from any current London provider of paediatric oncology.

The role of the Chair will be to:

- ensure that the review process is delivered with sufficient probity, impartiality and rigour;
- manage each panel meeting to deliver the required outputs;
- bring to the attention of the Medical Director for NHS England (London) and Programme Lead for the London Children's Strategic Clinical Network any relevant issues about process that become apparent during the period of the review;
- represent the panel at relevant NHS England (London) meetings of the NHS England (London) Clinical Senate Council and Paediatric Oncology Programme Board as required.

Process

In advance of the review, the panel will receive from the London Children's Strategic Clinical Network information including:

- Organisational structure within London Children's Strategic Clinical Network
- London Paediatric Oncology Service – Case for Change
- Proposed POSCU Model of Care – recommendations from the Paediatric Oncology Pathway Group
- POSCU Standards
- Draft PTC Model of Care -– recommendations from the Paediatric Oncology Pathway Group
- London Clinical Senate advice template
- National Clinical Advisory Team reviews
- Peer review reports and measures
- Commissioning safe and sustainable specialised paediatric services: a framework of critical inter-dependencies
- Paediatric Cancer Services Clinical Reference Group (CRG) service specifications and co-dependencies
- Stakeholder engagement reports (including parents, patients and clinicians)
- Recommendations from stakeholders
- NICE Improving outcomes in children and young people with cancer
- National Cancer Intelligence Network reports

Further information from other parties including the London Cancer Alliance and London Cancer will be requested and considered.

The product of the review will be a panel report which will comprise the panel's recommendations based on the objectives above.

Confidentiality

All information received by the panel will be regarded as confidential and will not be disclosed to other parties unless with the express agreement of NHS England (London).

Public announcements

The panel will not make any public announcements unless with the express agreement of NHS England (London).

Impartiality and probity

The panel will not discuss any aspect of the review process or the outcomes of the review process with officers or representatives of any London or associated paediatric oncology provider or other parties.

Members of the panel will immediately inform the Chair if a conflict of interest or potential conflict of interest becomes apparent.

APPENDIX 2

Document register – Information considered by the Review Panel

Document title	**Status**	**Author**	**Year**
Meeting 14/10/14			
Agenda – London Paediatric Oncology Panel Review Meeting 14 October 2014	Final	NHS England (London region)	2014
London Paediatric Oncology Review Panel - Terms of Reference	Draft	NHS England (London region)	2014
PTCs and POSCUs (map)	Draft	NHS England (London region)	2014
Guidance on Cancer Services - Improving Outcomes in Children and Young People with Cancer - The Manual	Final	NICE National Institute for Health and Clinical Excellence	2005
Manual for Cancer Services - Children's Cancer Measures Version 1.0	Final	NHS England - National Peer Review Programme	2014
European Standards of Care for Children with Cancer	Final	SIOP Europe - Jolanta Kwasniewska's Foundation	2009
Commissioning Safe and Sustainable Specialised Paediatric Services - A Framework of Critical Inter-Dependencies	Final	Department of Health	2008
Supra-regional referral patterns of childhood cancer patients	Final	NCIN – National Cancer Intelligence Network	2013
Short-term survival of children with Cancer	Final	NCIN – National Cancer Intelligence Network	2013
Shared Care and Survival	Final	NCIN – National Cancer Intelligence Network	2013
NRCT Progress Report 2012	Final	NRCT – National Registry of Childhood Tumours	2012
NCAT South London Paediatric Oncology Review - Report	Final	National Clinical Advisory Team (NCAT)	2011
NCAT South London Paediatric Oncology Review - Recommendations and Action Plan	Final	National Clinical Advisory Team (NCAT)	2012
Pan Thames POSCU Model of Care for patients aged 0 to 18 years	Final draft	NHS – London Specialised Commissioning	2012
E04/S/a 2013/24 NHS Standard Contract for Paediatric Oncology - Service Specification	Final	NHS England	2013

Paediatric Cancer Services Colocation Summary	Draft	NHS England	2014
London POSCU Peer Review self-assessment documentation - Summary of concerns	Final	NHS England (London region)	2014 (Data 2012)
Peer Review - GOSH PTC Core self-assessment Report	Final	NHS National Cancer Peer Review	2012
Peer Review - GOSH Solid Tumour MDT self-assessment report	Final	NHS National Cancer Peer Review	2012
Peer Review - GOSH Neuro-oncology MDT self-assessment report	Final	NHS National Cancer Peer Review	2012
Peer Review - GOSH Haematology MDT self-assessment report	Final	NHS National Cancer Peer Review	2012
Peer Review - GOSH Late Effects MDT self-assessment report	Final	NHS National Cancer Peer Review	2012
Peer Review - RMH PTC Core self-assessment report	Final	NHS National Cancer Peer Review	2012
Peer Review - RMH Solid Tumour MDT self-assessment report	Final	NHS National Cancer Peer Review	2012
Peer Review - RMH Neuro-oncology MDT self-assessment report	Final	NHS National Cancer Peer Review	2012
Peer Review - RMH Haematology MDT self-assessment report	Final	NHS National Cancer Peer Review	2012
Peer Review - RMH Late Effects MDT self-assessment report	Final	NHS National Cancer Peer Review	2012
Advice request - London Clinical Senate Paediatric Oncology	Final	NHS England (London region)	2014
London Paediatric Oncology Case for Change	Final draft	NHS England (London region)	2014
Paediatric Oncology Pathway Group - Proposed London POSCU Model of Care	Final draft	NHS England (London region)	2014
Paediatric Oncology Pathway Group - Proposed London POSCU Standards	Final draft	NHS England (London region)	2014
Paediatric Oncology Pathway Group - Proposed London PTC Model of Care	Final draft	NHS England (London region)	2014
Patient and parent engagement summary	Final	NHS England (London region)	2014

POSCU Leads meetings summary	Final	NHS England (London region)	2014
Meeting 13/11/14			
Agenda - London Paediatric Oncology Panel Review meeting 13 November 2014	Final	NHS England (London region)	2014
Final draft minutes - London Paediatric Oncology Panel Review 14 October 2014	Draft	NHS England (London region)	2014
London Paediatric Oncology Review Panel - Terms of Reference	Final	NHS England (London region)	2014
PTCs and POSCUs (map)	Final	NHS England (London region)	2014
Conflict of Interest form part a	Final	NHS England (London region)	2014
Conflict of Interest form part b	Final	NHS England (London region)	2014
Better Health for London (London Healthcare Commission)	Final	London Health Commission	2014
NICE support for commissioning for children and young people with cancer	Final	NICE National Institute for Health and Clinical Excellence	2014
Children and young people with cancer - NICE quality standard 55	Final	NICE National Institute for Health and Clinical Excellence	2014
Paediatric oncology review process prior to establishment of London Children's SCN paediatric oncology pathway group	Final	Dr Julia Chisholm and Dr Darren Hargrave	2014
London Children's SCN Paediatric Oncology Pathway Group - Progress	Final	Dr Julia Chisholm and Dr Darren Hargrave	2014
North and South Thames - Vision for future of paediatric oncology services - Presentation	Final	Dr Julia Chisholm and Dr Darren Hargrave	2014
Senate Council process	Final	NHS England (London region)	2014
London CYP Strategic Clinical Network - Update to Paediatric Oncology External Review presentation	Final	NHS England (London region)	2014
Report template	Draft	NHS England (London region)	2014
Critical Inter-Dependencies template	Final	NHS England (London region)	2014
Submission from North Thames Children's Cancer Network			
North Thames Children's Cancer Network – Documentation for London Paediatric	Final	North Thames Children's Cancer Network	2014

Oncology Review			
1.1. North Thames Children’s Cancer Network Annual Report 2014 (part 1 and 2)	Final	North Thames Children’s Cancer Network	2014
1.2. North Thames Children’s Cancer Network Self-Assessment 2014	Final	North Thames Children’s Cancer Network	2014
1.3. North Thames Children’s Cancer Network Core PTC Self-Assessment 2014	Final	North Thames Children’s Cancer Network	2014
1.4. North Thames Children’s Cancer Network Haematology MDT Self-Assessment 2014	Final	North Thames Children’s Cancer Network	2014
1.5. North Thames Children’s Cancer Network Oncology MDT Self-Assessment 2014	Final	North Thames Children’s Cancer Network	2014
1.6. North Thames Children’s Cancer Network Neuro-oncology MDT Self-Assessment 2014	Final	North Thames Children’s Cancer Network	2014
1.7. North Thames Children’s Cancer Network Late Effects MDT Self-Assessment 2014	Final	North Thames Children’s Cancer Network	2014
1.7. North Thames Children’s Cancer Network Late Effects MDT Self-Assessment 2014	Final	North Thames Children’s Cancer Network	2014
1.8. North Thames Children’s Cancer Network Community Chemotherapy Self-Assessment 2014	Final	North Thames Children’s Cancer Network	2014
1.9. North Thames Children’s Cancer Network Last External Peer Review Report 2012	Final	North Thames Children’s Cancer Network	2012
1.10. North Thames Teenage and Young Adult Cancer Network Coordinating Group Self-Assessment 2014	Final	North Thames Teenage and Young Adult Cancer Network Coordinating Group	2014
1.11. North Thames Teenage and Young Adult Cancer Network Coordinating Group Annual Report 2014	Final	North Thames Teenage and Young Adult Cancer Network Coordinating Group	2014
2.1. North Thames Children’s Cancer Network Operational Policy 2014	Final	North Thames Children’s Cancer Network	2014
2.2. North Thames Children’s Cancer Network Coordinating Group Terms of Reference/ constitution 2012	Final	North Thames Children’s Cancer Network Coordinating Group	2012
2.3. North Thames Teenage and Young Adult Cancer Network Coordinating Group Constitution 2013	Final	North Thames Teenage and Young Adult Cancer Network Coordinating Group	2013
2.4. Supportive Care Protocol 4th Edition	Final	Great Ormond Street Hospital for Children NHS Foundation Trust, The Royal Marsden NHS Foundation Trust, University College London	2014

		Hospitals NHS Foundation Trust, London Cancer North and East and London Cancer Alliance West and South	
2.5. Commissioning Safe and Sustainable Specialised Paediatric Services - A Framework of Critical Inter-Dependencies	Final	Department of Health	2008
2.6. Commissioning Safe and Sustainable Specialised Paediatric Services - A Framework of Critical Inter-Dependencies (North Thames Network)	Final	North Thames Children's Cancer Network	2014
3.1. North Thames Children's Cancer Network Service Level Agreement POSCU	Final	North Thames Children's Cancer Network	Not known
3.2. North Thames Teenage and Young Adult Cancer Network Coordinating Group Governance Framework	Final	North Thames Teenage and Young Adult Cancer Network Coordinating Group	Not known
3.3.1. Princess Alexandra Hospital POSCU Plan (31 May 2012)	Final	NHS London Specialised Commissioning Group	2012
3.3.2. London Specialised Commissioning Group Letter Princess Alexandra Hospital 22.06.2012	Final	NHS London Specialised Commissioning Group	2012
3.3.3. Princess Alexandra Hospital POSCU Plan (14 September 2012)	Final	NHS London Specialised Commissioning Group	2012
3.3.4. Princess Alexandra Hospital POSCU Compliance Review Meeting (12 December 2012)	Final	Great Ormond Street Hospital for Children NHS Foundation Trust	2012
3.3.5. Princess Alexandra Hospital Action Plan Progress	Final	The Princess Alexandra Hospital NHS Trust	2013
3.3.6. West Essex Clinical Commissioning Group Letter (8 February 2013)	Final	West Essex Clinical Commissioning Group	2013
3.3.7. POSCU Care at Princess Alexandra Hospital (20 February 2013)	Final	Great Ormond Street Hospital for Children NHS Foundation Trust	2013
3.3.8. North Thames Children's Cancer Network Coordinating Group Letter Princess Alexandra Hospital POSCU (13 March 2013)	Final	North Thames Children's Cancer Network Coordinating Group	2013
4.1. United Kingdom Children's Cancer Study Group Center Survival Data 2010 (last time figures sent)	Final	United Kingdom Children's Cancer Study Group	2010
4.2. National Childhood Cancer Registry data 2012	Final	United Kingdom Children's Cancer Study Group	2012
4.3. Survival Outcomes GOSH non-BMT	Final	Great Ormond Street Hospital for Children NHS Foundation Trust	2014

4.4. GOSH BMT annual data 2013	Final	Great Ormond Street Hospital for Children NHS Foundation Trust	2014
4.5. GOSH Prescribing Errors data 2014	Final	Great Ormond Street Hospital for Children NHS Foundation Trust	2014
4.6. National Cancer Research Network Children’s Cancer and Leukaemia North Thames trial recruitment 2012 to 2013	Final	National Cancer Research Network	2013
4.7. Children Peer Review 2012-2013 National Comparison	Final	London Cancer North and East	2013
5.1. North Thames Children’s Cancer Network Work plan 2014-15	Final	North Thames Children’s Cancer Network	2014
5.2. North Thames Teenage and Young Adult Cancer Network Coordinating Group Work plan 2014	Final	North Thames Teenage and Young Adult Cancer Network Coordinating Group	2014
6.1. North Thames Children’s Cancer Network Patient/ Parent Survey 2013	Final	North Thames Children’s Cancer Network	2013
6.2. North Thames Children’s Cancer Network Patient/ Parent Survey Quantitative 2013	Final	North Thames Children’s Cancer Network	2014
6.3. North Thames Children’s Cancer Network Patient/ Parent Survey Thematic Analysis 2013	Final	North Thames Children’s Cancer Network	2014
6.4. North Thames Children’s Cancer Network Parent feedback from Patient/ Parent Survey 2013	Final	North Thames Children’s Cancer Network	2014
6.5. North Thames Children’s Cancer Network Action Plan following Patient/ Parent Survey 2013	Final	North Thames Children’s Cancer Network	2014
6.6. NHS England (London region) Patient and Parent Engagement Summary 2013-14	Final	NHS England (London region)	2014
6.7. NHS England (London region) POSCU Leads Engagement Event Summary 2014	Final	NHS England (London region)	2014
6.8. North Thames Children’s Cancer Network Parents Council Terms of Reference 2013	Final	North Thames Children’s Cancer Network	2013
Submission from South Thames Children’s Cancer Network			
ce for: London Paediatric Oncology Review Expert Panel	Final	South Thames Children’s Cancer Network	2014
Children’s Cancer Multidisciplinary Team Operational Policy	Final	London Cancer Alliance West and South	2014

Details of the Children, Teenagers and Young Adult pathway group can be found at: http://www.londoncanceralliance.nhs.uk/information-for-healthcare-professionals/pathway-groups/children,-teenagers-and-young-adults/ Protocols and guidelines for tumours can be found at: http://www.londoncanceralliance.nhs.uk/information-for-healthcare-professionals/forms-and-guidelines/lca-forms,-protocols-and-guidance/ Shared policies and protocols for children's cancer can be found: http://www.londoncanceralliance.nhs.uk/information-for-healthcare-professionals/forms-and-guidelines/south-east-london-cancer-network/childrens-and-young-people/	Final	London Cancer Alliance West and South	2014
London Cancer Alliance West and South Annual Report 2013-14	Final	London Cancer Alliance West and South	2014
Contribution from children's and TYA pathway group towards LCA annual report	Final	London Cancer Alliance West and South	2014
LCA implementation plan paediatrics and TYA 2014-15	Final	London Cancer Alliance West and South	2014
London Cancer Alliance West and South Children's Cancer Multidisciplinary Team Annual Report	Final	London Cancer Alliance West and South	2014
London Cancer Alliance West and South Teenage and Young Adult Annual Report	Final	London Cancer Alliance West and South	2014
London Cancer Alliance West and South Teenage and Young Adult Operational Policy	Final	London Cancer Alliance West and South	2014
Supportive Care Protocol 4th Edition	Final	Great Ormond Street Hospital for Children NHS Foundation Trust, The Royal Marsden NHS Foundation Trust, University College London Hospitals NHS Foundation Trust, London Cancer North and East and London Cancer Alliance West and South	2014
LCA Neutropenic Sepsis Audit 2014 Presentation	Final	London Cancer Alliance West and South	2014
Family Held Record	Final	Great Ormond Street Hospital for Children NHS Trust, The Royal Marsden NHS Trust and The University College London Hospital NHS Trust	2014
LCA Brain/CNS Cancer Clinical Guidelines	Final	London Cancer Alliance West and South	2014

Referral diagnostic and staging protocols	Final	South Thames Children's Cancer Network Group	2014
South Thames Children's Cancer Network Group - Clinical Management Protocols	Final	South Thames Children's Cancer Network Group	2014
PTC list of approved regimens Leukaemia - 2014	Final	Joint Paediatric Oncology Chemotherapy (JPOC) Committee - South Thames Children's Cancer Network Group	2014
PTC list of approved regimens Lymphomas - 2014	Final	Joint Paediatric Oncology Chemotherapy (JPOC) Committee - South Thames Children's Cancer Network Group	2014
PTC list of approved regimens Solid Tumours - 2014	Final	Joint Paediatric Oncology Chemotherapy (JPOC) Committee - South Thames Children's Cancer Network Group	2014
PTC list of approved regimens Brain Tumours - 2014	Final	Joint Paediatric Oncology Chemotherapy (JPOC) Committee - South Thames Children's Cancer Network Group	2014
South Thames Children and TYA Clinical Feedback Report and Actions from January 2014	Final	London Cancer Alliance West and South	2014
Policy for Prevention of the Use of Chemotherapy Regimens not on the Agreed Network list	Final	Joint Paediatric Oncology Chemotherapy (JPOC) Committee - South Thames Children's Cancer Network Group	2014
Policy on unsafe chemotherapy workload	Final	Joint Paediatric Oncology Chemotherapy (JPOC) Committee - South Thames Children's Cancer Network Group	2014
Pan London Guidelines for the safe prescribing, handling and administration of systemic anti-cancer treatment drugs	Final	NHS North West London Cancer Network, UCL Partners Academic Health Science Partnership, NHS North Central London and West Essex Cancer Commissioning Network, NHS North East London Cancer Network, South West London Cancer Network and NHS South East London Cancer Network	2011
Pan London Cytotoxic Chemotherapy Workbook 1	Final	The Royal Marsden NHS Foundation Trust, Great Ormond Street Hospital for Children NHS Foundation Trust and University College London Hospitals NHS Foundation Trust	2014
Pan London Cytotoxic Chemotherapy Workbook 2 (To be completed by staff working in Level 1 POSCU)	Final	The Royal Marsden NHS Foundation Trust, Great Ormond Street Hospital for Children NHS Foundation Trust and University College London Hospitals NHS Foundation Trust	2014

Pan London Cytotoxic Chemotherapy Workbook 2 (To be completed by staff working in Level 2 POSCU)	Final	The Royal Marsden NHS Foundation Trust, Great Ormond Street Hospital for Children NHS Foundation Trust and University College London Hospitals NHS Foundation Trust	2014
Pan London Cytotoxic Chemotherapy Workbook 2 (To be completed by staff working in Level 3 POSCU or PTC)	Final	The Royal Marsden NHS Foundation Trust, Great Ormond Street Hospital for Children NHS Foundation Trust and University College London Hospitals NHS Foundation Trust	2014
Information regarding Foundation Oncology Skills for Nurses working in Paediatric and Adolescent Cancer Care	Final	The Royal Marsden NHS Foundation Trust, Great Ormond Street Hospital for Children NHS Foundation Trust and University College London Hospitals NHS Foundation Trust	2011
Pan London Foundation Oncology Skills For Paediatric and Adolescent Nurses Working in a Haematology / Oncology Area - Competency assessment framework	Final	The Royal Marsden NHS Foundation Trust, Great Ormond Street Hospital for Children NHS Foundation Trust and University College London Hospitals NHS Foundation Trust	2010
Developing a Pan London Approach to Foundation Level Training for Nurses Caring for Children and Young People with Cancer	Final	The Royal Marsden NHS Foundation Trust and Great Ormond Street Hospital for Children NHS Foundation Trust	Not known
South Thames Children and TYA Quarterly Forum - 7 October 2013 - Minutes	Final	London Cancer Alliance West and South	2013
South Thames Children and TYA Clinical Forum - Feedback report and actions from January 2014	Final	London Cancer Alliance West and South	2014
South Thames Children and TYA Clinical Forum - Feedback report and actions from April 2014	Final	London Cancer Alliance West and South	2014
South Thames Children's Cancer Network Clinical Forum - Summary report and actions from June 2014	Final	London Cancer Alliance West and South	2014
Paediatric Oncology Shared Care Study Day - March 2014 - Agenda	Final	The Royal Marsden NHS Foundation Trust	2014
Paediatric Oncology Shared Care Study Day - March 2014 - Attendee Organisations	Final	The Royal Marsden NHS Foundation Trust	2014
The South Thames Retrieval Service clinical management guidelines can be found at: http://www.strs.nhs.uk/educationandguidelines/guidelines.aspx	Final	NHS South Thames Retrieval Service for children	2014

Oak Centre for Children and Young People 24 hour Communication Policy	Final	The Royal Marsden NHS Foundation Trust	2014
Oak Centre for Children and Young People audit of 24hr telephone advice line service	Final	The Royal Marsden NHS Foundation Trust	2014
National Clinical Advisory Team - South London Paediatric Oncology Review: Recommendations and Action Plan	Final	National Clinical Advisory Team (NCAT)	2012
The Royal Marsden NHS Foundation Trust and St. Georges Healthcare NHS Trust Joint Principal Treatment Centre Overarching Governance Policy	Final	The Royal Marsden NHS Foundation Trust and St. Georges Healthcare NHS Trust	2012
Operational Policy for Principal Treatment Centre Paediatric Oncology patients admitted to Pinckney ward at St George's Hospital	Final	St. Georges Healthcare NHS Trust	2014
Audit of Paediatric oncology principal treatment Centre (PTC) patients admitted to Pinckney ward at St George's hospital.	Final	The Royal Marsden NHS Foundation Trust	2012
Joint Paediatric Oncology PTC Clinical Governance Committee Terms of Reference	Final	The Royal Marsden NHS Foundation Trust and St. Georges Healthcare NHS Trust	2011
RMH/SGH Joint PTC Clinical Governance - Agenda - 8 September 2014	Final	The Royal Marsden NHS Foundation Trust and St. Georges Healthcare NHS Trust	2014
Joint RMH/SGH Clinical Governance Committee Meeting - Minutes - 12 May 2014	Final	The Royal Marsden NHS Foundation Trust	2014
Joint Paediatric Oncology Primary Treatment Centre Chemotherapy Group Terms of Reference	Final	The Royal Marsden NHS Foundation Trust and St. Georges Healthcare NHS Trust	2013
Joint Paediatric Oncology Primary Treatment Centre Chemotherapy Group - Agenda - 3 December 2012	Final	The Royal Marsden NHS Foundation Trust and St. Georges Healthcare NHS Trust	2012
Joint Paediatric Oncology Primary Treatment Centre Chemotherapy Group - Minutes - 11 November 2013	Final	The Royal Marsden NHS Foundation Trust and St. Georges Healthcare NHS Trust	2013
Children and Young People's Operational Group - Terms of Reference	Final	The Royal Marsden NHS Foundation Trust	2012
Children and Young People`s Operational Group - Agenda - 6 May 2014	Final	The Royal Marsden NHS Foundation Trust	2014
Children and Young People's Operational Group - Minutes - 1 April 2014	Final	The Royal Marsden NHS Foundation Trust	2014

St George`s Hospital/Royal Marsden Hospital Paediatric Oncology Operational Group - Terms of Reference	Final	The Royal Marsden NHS Foundation Trust	2012
St George's Hospital Paediatric Oncology Operational Group - Agenda - 13 October 2014	Final	The Royal Marsden NHS Foundation Trust	2014
St George's Hospital Operational Group - Minutes - 8 September 2014	Final	The Royal Marsden NHS Foundation Trust	2014
Paediatric Clinical Research Operational Meeting - Agenda - 16 October 2014	Final	The Royal Marsden NHS Foundation Trust	2014
Paediatric Clinical Research Operational Meeting - Minutes - 24 September 2014	Final	The Royal Marsden NHS Foundation Trust	2014
The Royal Marsden NHS Foundation Trust Shared Care Research Agreement	Final	The Royal Marsden NHS Foundation Trust	2012
Paediatric Oncology Shared Care Service Level Agreement	Final	The Royal Marsden NHS Foundation Trust, St. Georges Healthcare NHS Trust, Great Ormond Street Hospital for Children NHS Foundation Trust and University College London Hospitals NHS Foundation Trust	Not known
LCA Quality Assurance Framework 2014	Final	London Cancer Alliance West and South	2014
Letter regarding London Cancer Alliance Children's and TYA work programme - clarification of structures and accountability - March 2014	Final	London Cancer Alliance West and South	2014
Managing concerns and complaints - Policy and procedure	Final	The Royal Marsden NHS Foundation Trust	2013
Complaints and Concerns Policy and Procedures	Final	St. Georges Healthcare NHS Trust	2014
Cancer Services Risk Register Template	Final	The Royal Marsden NHS Foundation Trust	2014
Risk management policy	Final	The Royal Marsden NHS Foundation Trust	2014
Integrated Governance and Risk Management Committee (IGRM) - Terms of Reference	Final	The Royal Marsden NHS Foundation Trust	2014
Royal Marsden Hospital and St George's Hospital - Joint Principal Treatment Centre - Report for IGRM February 2014	Final	The Royal Marsden NHS Foundation Trust and St. Georges Healthcare NHS Trust	2014
Accident/incident and patient safety incident reporting policy Including serious incidents requiring investigation	Final	The Royal Marsden NHS Foundation Trust	2014

Investigation of incidents, complaints and claims policy	Final	The Royal Marsden NHS Foundation Trust	2014
Being open and duty of candour policy	Final	The Royal Marsden NHS Foundation Trust	2014
Adverse Incident Reporting Policy and Procedure	Final	St. Georges Healthcare NHS Trust	2014
Serious Incident Policy	Final	St. Georges Healthcare NHS Trust	2014
Executive Medication Safety Group - Terms of Reference	Final	The Royal Marsden NHS Foundation Trust	2014
Executive Medication Safety Group - Agenda - 27 October 2014	Final	The Royal Marsden NHS Foundation Trust	2014
Executive Medication Safety Group - Minutes - 23 September 2014	Final	The Royal Marsden NHS Foundation Trust	2014
Medicines Management Policy	Final	St. Georges Healthcare NHS Trust	2014
Care Quality Commission Royal Marsden Inspection Report 2013	Final	Care Quality Commission	2013
Care Quality Commission St George’s Healthcare NHS Trust Quality Report 2014	Final	Care Quality Commission	2014
Audit of transfer of paediatric oncology patients to paediatric intensive care unit (PICU)	Final	The Royal Marsden NHS Foundation Trust	2013
Transfer of paediatric oncology patients to paediatric intensive care unit 2013 presentation	Final	The Royal Marsden NHS Foundation Trust	2013
Minutes of PICU audit meeting - 3 March 2014	Final	The Royal Marsden NHS Foundation Trust	2014
Haematopoietic stem cell transplantation trends in children over the last three decades: a survey by the paediatric diseases working party of the European Group for Blood and Marrow Transplantation - Appendix CIC 218 Royal Marsden Hospital	Final	Bone Marrow Transplantation	2007
Commentary on Stem Cell Transplantation - NHS Specialist Commissioners Benchmarking Exercise for Stem Cell Transplantation CIC218 Royal Marsden Hospital Benchmark to UK Transplant Centre Data Returned to BSBMT	Final	The Royal Marsden NHS Foundation Trust	2014
Audit of allogeneic BMT patients 2013 presentation	Final	The Royal Marsden NHS Foundation Trust	2013
Acute Lymphoblastic Leukaemia Mortality and Serious Adverse Events Audit 2014	Final	The Royal Marsden NHS Foundation Trust	2014
National Reporting Learning System (NRLS) Acute Specialist Incident Review - 6	Final	The Royal Marsden NHS Foundation Trust	2013

monthly data			
Analysis of the outcome of children with newly diagnosed and relapsed medulloblastoma - presentation	Final	The Royal Marsden NHS Foundation Trust	2013
NRCT Progress Report 2012	Final	NRCT – National Registry of Childhood Tumours	2012
Hyperfractionated versus conventional radiotherapy followed by chemotherapy in standard-risk medulloblastoma: Results from the randomized multicenter HIT-SIOP PNET 4 Trial	Final	Journal of Clinical Oncology	2012
High-dose rapid and standard induction chemotherapy for patients aged over 1 year with stage 4 neuroblastoma: a randomised trial	Final	The Lancet	2008
Paediatric oncology surgery data 2011-13	Final	The Royal Marsden NHS Foundation Trust and St. Georges Healthcare NHS Trust	2014
Paediatric mortality data for 2012-14	Final	The Royal Marsden NHS Foundation Trust	2014
Peer Review - RMH PTC Core - Visit report	Final	NHS National Cancer Peer Review	2011
London Cancer Alliance - Children's Cancer Multidisciplinary Team MDT Work Programme 2014	Final	London Cancer Alliance West and South	2014
Peer Review - Internal Validation Report - South Thames Teenage and Young Adult Cancer Network Coordinating Group	Final	NHS National Cancer Peer Review	2011
Peer Review - External Validation Report - South Thames Teenage and Young Adult Cancer Network Coordinating Group	Final	NHS National Cancer Peer Review	2012
South Thames Teenager and Young Adult's Cancer Network Workplan 2012/13	Final	NHS London Specialised Commissioning Group	2012
Peer Review - Self Assessment Report – TYA PTC MDT	Final	NHS National Cancer Peer Review	2014
London Cancer Alliance - TYA PTC MDT Work Programme 2014	Final	London Cancer Alliance West and South	2014
POSCU Peer Review - 2013/14 CQUIN data	Final	The Royal Marsden NHS Foundation Trust	2014
Patient and parent engagement summary	Final	NHS England (London region)	2014
Young Inpatients Survey 2012 - The Royal Marsden NHS Foundation Trust -	Final	Picker Institute Europe	2012

Executive Summary			
Young Outpatients Survey 2012 - The Royal Marsden NHS Foundation Trust - Executive Summary	Final	Picker Institute Europe	2012
Picker survey 2012 Action Plan	Final	The Royal Marsden NHS Foundation Trust	2013
The Royal Marsden NHS Foundation Trust - Shared Care Pathways - qualitative research	Draft (v1.5)	Picker Institute Europe	2013
Summary of Appendix 2 - London Paediatric Oncology Services Review Programme Engagement Activity Undertaken by NHS England	Final	NHS England (London region)	2014
Family and Friends Report 2014	Final	The Royal Marsden NHS Foundation Trust	2014
A review of POSCU Paediatric Oncology Patient Experience Feedback - October 2014	Final	The Royal Marsden NHS Foundation Trust	2014
National Cancer Patient Experience Survey 2012-2013 - The Royal Marsden NHS Foundation Trust - Clinical Nurse Specialist analysis	Final	NHS England	2013
National Cancer Patient Experience Programme 2012-2013 National Survey - The Royal Marsden NHS Foundation Trust	Final	NHS England	2013
Picker staff survey 2nd Quarter analysis	Final	Picker Institute Europe	2014
Patient information: Introducing the Paediatric and Young Adults Psychological Service (PYAPPS)	Final	The Royal Marsden NHS Foundation Trust	2014
Children And Young People Oncology Outreach And Symptom Care Nurse Specialist (CYPOONs) Team - Annual Report 2013-14	Final	The Royal Marsden NHS Foundation Trust	2014
List of open/closed/pending trials	Final	The Royal Marsden NHS Foundation Trust	2014
Paediatric Drug Development at The Royal Marsden Hospital	Final	The Royal Marsden NHS Foundation Trust	2014
Oak Foundation Project Progress Report	Final	Oak Foundation	2014
Scientific achievements at ICR/RMH, an integrative translational research campus directly benefit cancer patients	Final	The Royal Marsden NHS Foundation Trust	2014

Paediatric Radiotherapy	Final	The Royal Marsden NHS Foundation Trust	2014
Children and Young People’s Unit - Clinician and Nursing Publications 2009-2014	Final	The Royal Marsden NHS Foundation Trust	2014
Children and Young People's Unit, Grant and Charitable Project Funding, 2009-2014	Final	The Royal Marsden NHS Foundation Trust	2014
Collection report of the press and public engagement activities of ICR employees involved in paediatric cancer research Oct 2014	Final	The Institute of Cancer Research	2014
Meeting 09/12/14			
Agenda - London Paediatric Oncology Panel Review Meeting 9 December 2014	Final	NHS England (London region)	2014
Final draft minutes - London Paediatric Oncology Panel Review 13 November 2014	Draft	NHS England (London region)	2014
London Paediatric Oncology Services Review Programme - Engagement Activity - Key Issues/Learning Points	Final	Chris Gibbs	2014
London CYP Strategic Clinical Network - Draft London acute standards for children and young people	Draft	NHS England (London region)	2014
High Dependency Care for Children - Time To Move On	Final	Royal College of Paediatrics and Child Health	2014
High Dependency Care for Children - Time To Move On - Appendices	Final	Royal College of Paediatrics and Child Health	2014
Neutropenic sepsis: prevention and management of neutropenic sepsis in cancer patients	Final	NICE National Institute for Health and Clinical Excellence	2012
Paediatric Oncology Services - London - Questionnaire results 5 December 2014	Final	NHS England (London region)	2014
Questionnaire response - GOSH/UCLH	Final	Great Ormond Street Hospital for Children NHS Foundation Trust and University College London Hospitals NHS Foundation Trust	2014
Questionnaire response - London Cancer North and East	Final	London Cancer North and East	2014
Letter from St. Georges Healthcare NHS Trust 2 December 2014	Final	St. Georges Healthcare NHS Trust	2014
Further information submitted by The Hillingdon Hospitals NHS Foundation Trust	Final	The Hillingdon Hospitals NHS Foundation Trust	2014
Questionnaire response - East Kent NHS Foundation Trust	Final	East Kent NHS Foundation Trust	2014
Critical Inter-Dependencies template overview	Final	NHS England (London region)	2014

London Paediatric Oncology Review - Draft POSCU Model of Care recommendations - draft	Draft	London Paediatric Oncology Review Panel	2014
London Paediatric Oncology Review - Draft Clinical Service Co-Location Requirements for PTC services in London	Draft	London Paediatric Oncology Review Panel	2014
PTC and POSCU activity data 2011-2014	Final	NHS England (London region)	2014
Meeting 08/01/15			
Agenda - London Paediatric Oncology Panel Review Meeting 8 January 2015	Final	NHS England (London region)	2014
Final draft minutes - London Paediatric Oncology Panel Review 9 December 2014	Draft	NHS England (London region)	2014
North Thames POSCUs and TYA Designated Centres	Final	Great Ormond Street Hospital for Children NHS Foundation Trust and University College London Hospitals NHS Foundation Trust	2014
South Thames POSCUs and TYA Designated Centres	Final	The Royal Marsden NHS Foundation Trust	2014
Questionnaire response - Barts Health NHS Trust	Final	Barts Health NHS Trust	2014
London Paediatric Oncology Review - Draft Clinical Service Co-Location Requirements for PTC services in London v0.2	Draft	London Paediatric Oncology Review Panel	2014
London Paediatric Oncology Review - Draft Clinical Service Co-Location Requirements for PTC services in London v0.3a	Draft	London Paediatric Oncology Review Panel	2015
London Paediatric Oncology Review - Draft Clinical Service Co-Location Requirements for PTC services in London v0.3b	Draft	London Paediatric Oncology Review Panel	2015
London Paediatric Oncology Review - Draft POSCU Model of Care recommendations - draft v0.2	Draft	London Paediatric Oncology Review Panel	2015
London Paediatric Oncology Review - Draft PTC Model of Care Recommendations	Draft	London Paediatric Oncology Review Panel	2015
London Paediatric Oncology Review - Draft Clinical Service Co-Location Requirements for PTC services in London v0.4a	Draft	London Paediatric Oncology Review Panel	2015
London Paediatric Oncology Review - Draft Clinical Service Co-Location Requirements for PTC services in London v0.4b	Draft	London Paediatric Oncology Review Panel	2015

PTC and POSCU activity data January 2015	Draft	NHS England (London region)	2015
Letter from North Thames and South Thames TYA Cancer Network Coordinating Groups	Final	North Thames and South Thames TYA Cancer Network Coordinating Groups	2015
B17/S/a 2013/14 NHS Standard Contract for Cancer: Teenagers and Young Adults - Section B Part 1 - Service Specifications	Final	NHS England	2013
Final draft minutes - London Paediatric Oncology Panel Review 13 November 2014 v0.2	Draft	NHS England (London region)	2015
Proton Overseas Programme National Clinical Reference Panel Report Nov 2014	Final	NHS England	2014
Guidance for the Referral of Patients Abroad for NHS Proton Treatment v2.3	Final	NHS Specialised Services	2011
A Framework for the Development of Proton Beam Therapy Services in England	Final	Department of Health	2009
Good practice guide for paediatric radiotherapy	Final	Children's Cancer and Leukaemia Group, Society and College of Radiographers and The Royal College of Radiologists	2012
Meeting 02/02/15			
Agenda - London Paediatric Oncology Panel Review Meeting 2 February 2015	Final	NHS England (London region)	2015
Final draft minutes - London Paediatric Oncology Panel Review 8 January 2015	Draft	NHS England (London region)	2015
Final draft minutes - London Paediatric Oncology Panel Review 9 December 2014 v0.2	Draft	NHS England (London region)	2015
Epsom and St Helier Hospitals NHS Trust POSCU MDT response to POSCU proposals in the London area - 31st March 2014	Final	Epsom and St Helier Hospitals NHS Trust	2014
Summary of Joint GOSH/UCH PTC Model of Care for Paediatric Oncology Patients < 16 years of age	Final	Great Ormond Street Hospital for Children NHS Foundation Trust and University College London Hospitals NHS Foundation Trust	2015
London Children and Young People's Cancer Services engagement event 17 January 2015 - Summary report	Final	Association for Young People's Health	2015
PTC and POSCU activity data January 2015 v0.2	Final	NHS England (London region)	2015
Paediatric Oncology Services - London - Questionnaire results January 2015	Final	NHS England (London region)	2015

Paed Onc Review Panel Collective Letter (RA) v1.4	Final	Dr Richa Ajitsaria, Dr Leena Karnik, Dr Olu Wilkey, Dr Madiha Elsawi, Dr Michele Afif, Dr Andrea Simmons, Dr Andrea Leigh, Dr Rakesh Ravi, Dr Rakesh Ravi, Dr Lynne Riley and Dr Sue Height	2015
London Paediatric Oncology Panel Review - Letter to Dr Ajitsaria and colleagues 23 January 2015	Final	NHS England (London region)	2015
SWOT analysis of one and two PTCs – Panel members combined	Final	NHS England (London region)	2015
Letter from UCLH regarding PBT - 29 January 2015	Final	University College London Hospitals NHS Foundation Trust	2015
London Paediatric Oncology Review - Draft PTC Model of Care Recommendations v0.2	Draft	London Paediatric Oncology Review Panel	2015
London Paediatric Oncology Review - Draft Clinical Service Co-Location Requirements for PTC services in London v0.5	Draft	London Paediatric Oncology Review Panel	2015
London Paediatric Oncology Review - Draft POSCU Model of Care recommendations - draft v0.3	Draft	London Paediatric Oncology Review Panel	2015
Age interfaces in care of CYTA	Draft	London Paediatric Oncology Review Panel	2015
Meeting 23/02/15			
Final draft minutes - London Paediatric Oncology Panel Review 8 January 2015	Draft	NHS England (London region)	2015
Draft London Paediatric Oncology Review Report	Draft	London Paediatric Oncology Review Panel	2015
Age interfaces in care of CYTA v0.2	Draft	London Paediatric Oncology Review Panel	2015
London Paediatric Oncology Review - Chapter 12 Research and Training v0.1	Draft	London Paediatric Oncology Review Panel	2015
Template for comments on London Paediatric Oncology Review Draft Panel Report	Final	NHS England (London region)	2015
Template for comments on London Paediatric Oncology Review Draft Panel Report - Panel members combined	Final	NHS England (London region)	2015
Other documentation considered			
Childhood Cancer – Cancer Statistics	Final	Cancer Research UK	2015
Five Year Forward View	Final	NHS England	2014

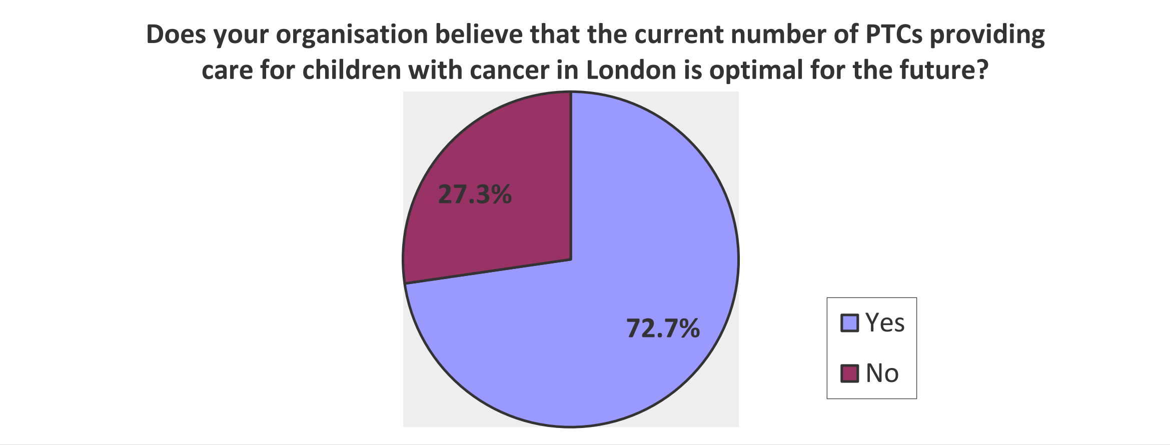
Children’s and young people’s project - London specialised children’s services: Guide for commissioners	Final	NHS Commissioning Support for London	2011
The Way Forward: Strategic Clinical Networks.	Final	NHS Commissioning Board	2012
Clinical Reference Groups for Specialised Services: A Guide for Stakeholders.	Final	NHS Commissioning Board	2013
Terms of Reference for the London Children and Young People SCN Oncology Pathway Group.	Final	NHS England	2013
Survival by CCLG centre for children aged <15 at diagnosis, 2002-2006.	Final	Childhood Cancer Research Group	2009
Bristol Royal Infirmary Inquiry, Learning from Bristol: The report of the public inquiry into children’s heart surgery at the Bristol Royal Infirmary 1984 -1995	Final	HM Government	2001
National Service Framework for Children, Young People and Maternity Services	Final	Department of Health	2004
A Blueprint of Care for Teenagers and Young Adults with Cancer	Final	Teenage Cancer Trust	2012
The NHS Constitution for England	Final	Department of Health	2013
The Plan for Growth	Final	HM Treasury	2011
Turning the Tide: Harnessing the power of child health research	Final	Royal College of Paediatrics and Child Health	2012
Delivering high quality, effective, compassionate care: Developing the right people with the right skills and the right values. A mandate from the Government to Health Education England: April 2013 to March 2015	Final	Department of Health	2013

APPENDIX 3

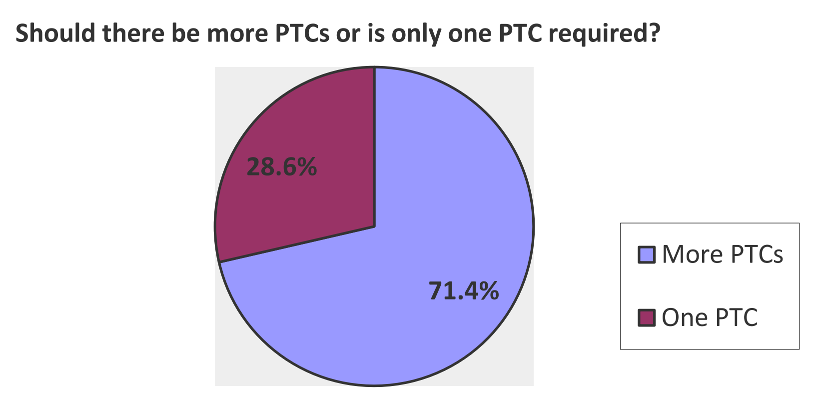
Questionnaire analysis report

Question 1 was information regarding organisation, name and contact details.

Q2. Does your organisation believe that the current number of PTCs providing care for children with cancer in London is optimal for the future?		
Answer Options	**Response Percent**	**Response Count**
Yes	72.7%	16
No	27.3%	6
	answered question	**22**
	skipped question	**0**

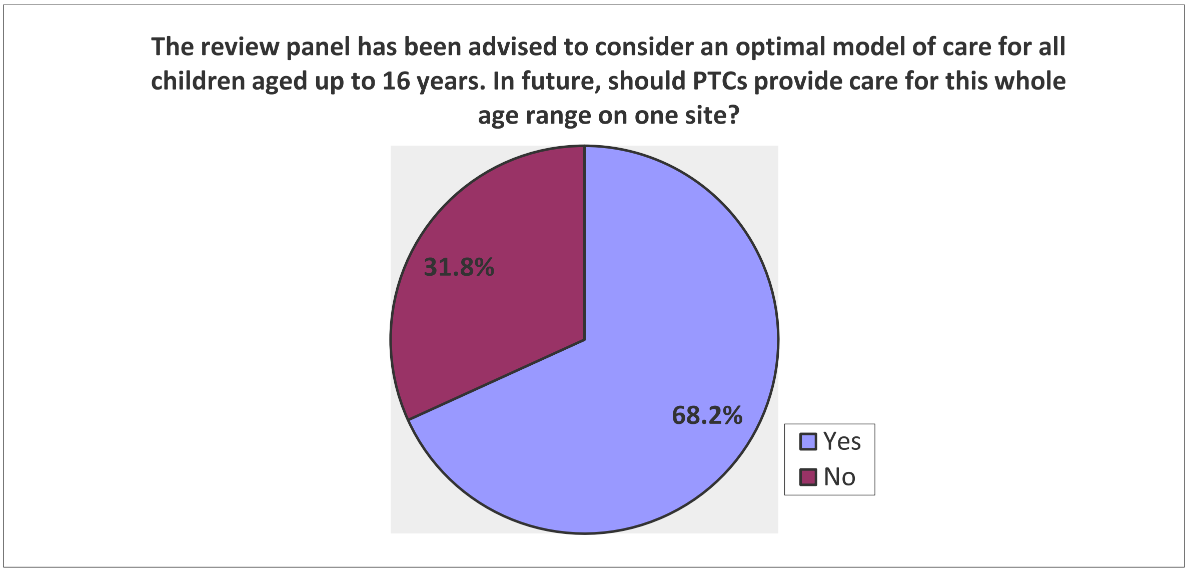


Q3. Should there be more PTCs or is only one PTC required?		
Answer Options	**Response Percent**	**Response Count**
More PTCs	71.4%	5
One PTC	28.6%	2
	answered question	**7**
	skipped question	**15**



Q4. The review panel has been advised to consider an optimal model of care for all children aged up to 16 years. In future, should PTCs provide care for this whole age range on one site?

Answer Options	**Response Percent**	**Response Count**
Yes	68.2%	15
No	31.8%	7
	answered question	**22**
	skipped question	**0**



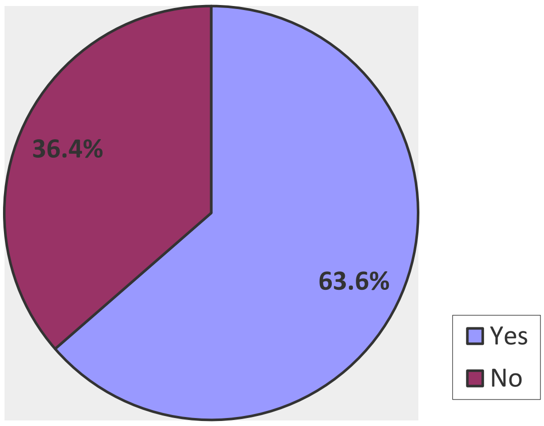
Q5. Please explain where your organisation feel the upper age point should lie and how the care of children over that age (and up to age 16 years) should be provided.

1. Ideally paediatric oncology services would cover patients aged 0-16 years and would be collocated with TYA and adult cancer services to ensure that expertise across the range of cancers is available to all patients and to facilitate smooth transition from paediatric to TYA and adult services. In South Thames our paediatric facility covers age 1-16 yrs, alongside TYA and adult services. We feel the small number of under 1s are best managed at the comprehensive tertiary children's service at GOSH.
2. The NICE IOG for Children and young People with Cancer and the NHS-England TYA service specification highlight that older children (i.e. 13-15 year olds) may benefit from treatment within a TYA cancer service. We support 13 years as a cut-off age as currently used in North Thames. Our service for these patients at UCLH is safe and younger teenagers benefit substantially from being co-located with other teenagers in all respects, including access to adult cancer expertise where adult cancers occur in younger patients. (please see email response for more details).
3. The review should encompass the full age range (0-18yrs) to provide a seamless transition with the services for young adults. Teenagers (13yrs+) have increasingly adult-type cancers and benefit from disease-specific expertise and TYA care and environment - their PTC service can be physically separate from paediatric service, providing age-appropriate acute care co-dependencies on both sites and MDTs are joined up. For shared care, a POSCU should be able to take adolescents up to the age of 18 yrs and those aged 19 yrs and above would receive care at a designated TYA service.
4. All children need to go to a place used to and able to cater for their age group needs. A network approach is best for age groups - under 1s and over 16s are special groups. Everything paediatrics recognises that 16 is not a good upper limit for care. Few units confine themselves to that age. Treatment lasts some time in oncology so provision must be made for a patient diagnosed at 16 to complete treatment under the same team. In summary it is not important that a PTC sees all ages, but it is important that the patient stays under one team for the duration of their treatment.
5. We do not think it is necessary for all children to be on one site, as long as the care provided is uniform and given in an age appropriate environment. It is well understood that young people have different needs to toddlers and children, so it is important they are looked after in an age appropriate environment. The crucial factor is that there should be capacity for all patients regardless of their age. I our opinion the upper age limit should be their 18th birthday, with a separate adolescent unit.
6. Up to age 18years with an agreed and flexible protocol in place between PTCs/POSCUs regarding patient choice and best location for the 16-18 years
7. 18 years

Q6. Children's cancer services have a range of critical co-dependencies with other paediatric services. These were set out in the DH document (2008): Commissioning Safe and Sustainable Specialised Paediatric Services: A Framework for Clinical Dependencies. Does your organisation believe that this document adequately defines the co-dependencies required for paediatric oncology services in the future?

Answer Options	**Response Percent**	**Response Count**
Yes	63.6%	14
No	36.4%	8
	answered question	**22**
	skipped question	**0**

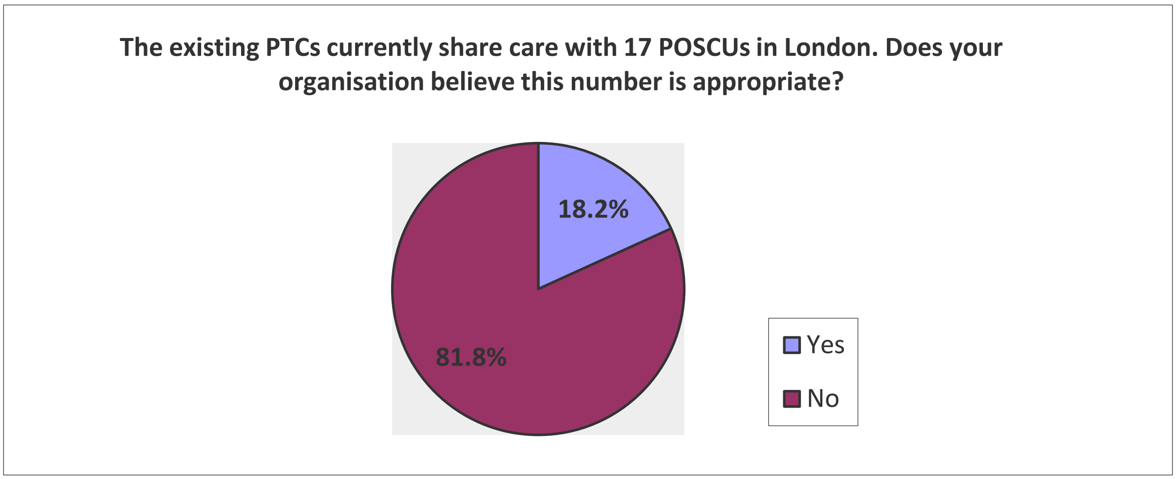
Children's cancer services have a range of critical co-dependencies with other paediatric services. These were set out in the DH document (2008): Commissioning Safe and Sustainable Specialised Paediatric Services: A Framework for Clinical Dependencies. Do



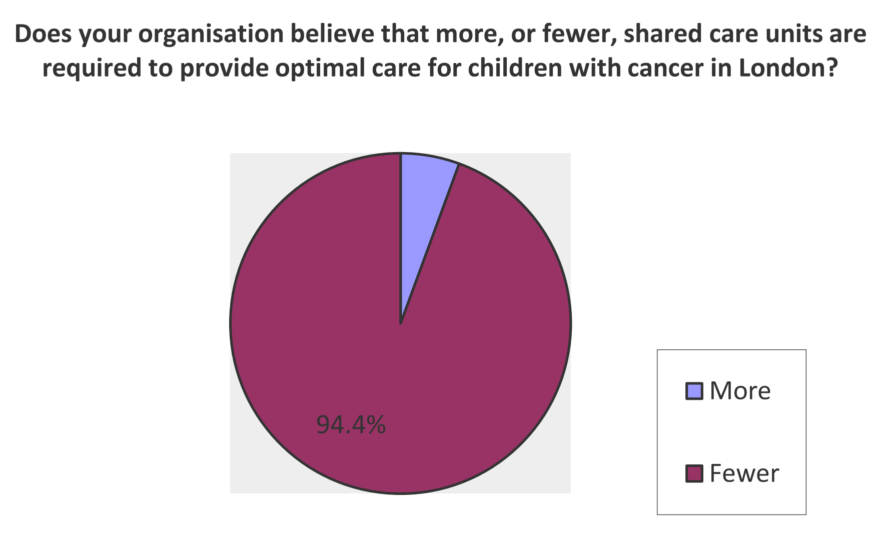
Q7. Please explain your organisation's reasoning and suggest how those requirements should be amended.

1. We agree with the critical co-dependencies at the PTC although some services such as ENT for paediatric airway management should be Red and other services which are currently designated at lower level should be higher i.e. Amber 3 for infectious diseases and renal. We also believe that there should be well-defined critical co-dependencies for level 2 and 3 POSCUs that ought to be taken into account in the service provision.
2. The DH document describes some critical interdependencies in paediatric oncology and other tertiary services but does not describe all areas of co-dependency. Its focus is on paediatric subspecialties and does not cover radiotherapy, palliative care, TYA, adult cancer, BMT where collocation with paediatric oncology benefits patients. In the South Thames model all tertiary paediatric services are available to children with cancer according to defined pathways across the network of tertiary paediatric care and patients benefit from collocation with these other services
3. We support the (2008): Framework for Clinical Dependencies, however have a few comments. A PTC must have definitive ("red"- on same site) co-locations with the specialties outlined for both Oncology and BMT. We also agree the importance of the other co-localities outlined in the document. However, we do believe that some childhood cancers could be provided on a site without these co-localities for some specific agreed lower risk diagnoses and for patients >13 years in a TYA unit supported by on-site paediatric services (as is the case at UCLH). [Please see email response for more details].
4. This review needs to take into account the particular specialist expertise and infrastructure needed to treat cancer in children and teenagers. Specialist radiotherapy is not listed in the critical co-dependencies document, yet the national proton beam therapy service will be located at UCLH and will need on-site paediatric oncology services. There are additional co-dependencies with adult cancer services (brachytherapy, unsealed source radiotherapy, certain adult surgical techniques and procedures, access to and expertise in using new drugs).
5. Neurosurgery is essential. Renal and Cardiology do not need to be immediately available, as long as the oncology unit is located with a PICU, which provides urgent haemofiltration and cardiac assessment (which they have to).
6. In the document shared care services were not being considered at all. All PTCs dealing with paediatric oncology should be linked to POSCUs providing safe local care to all patients. In consideration the shared care centres should not only provide clinical support for the medical condition but also adequate supportive services in the hospital and community.
7. The critical co-dependencies suggested for Paediatric Oncology do not include specialist paediatric radiology or paediatric orthopaedics (bone tumours) for which patients have to travel to yet another hospital (RNOH). In addition, some of the co-dependencies listed as desirable should be weighted more heavily - e.g. with increasing high dose chemotherapy and PBSCT, BMT on site, endocrinology for late effects etc.
8. We feel that it would be beneficial to have neurosurgery and BMT on-site (i.e. red category).

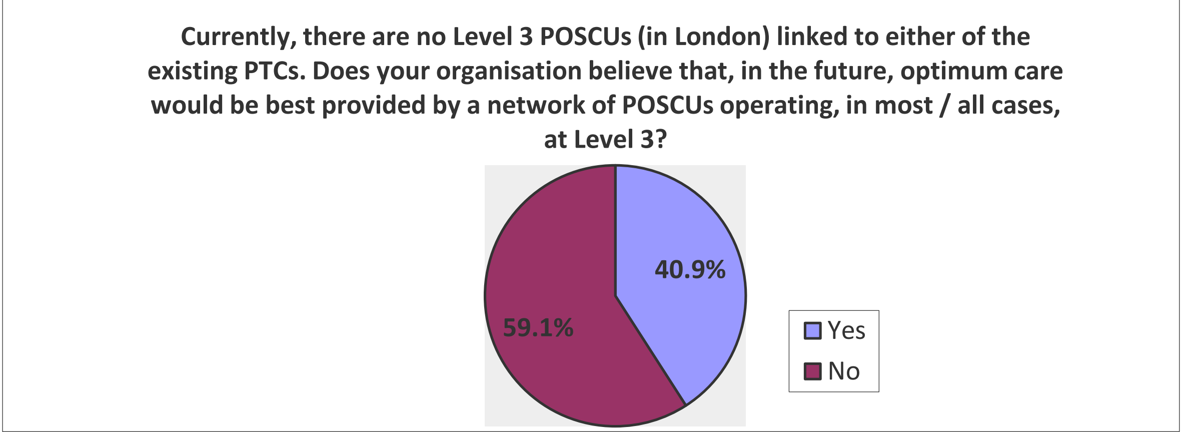
Q8. The existing PTCs currently share care with 17 POSCUs in London. Does your organisation believe this number is appropriate?		
Answer Options	**Response Percent**	**Response Count**
Yes	18.2%	4
No	81.8%	18
	answered question	**22**
	skipped question	**0**



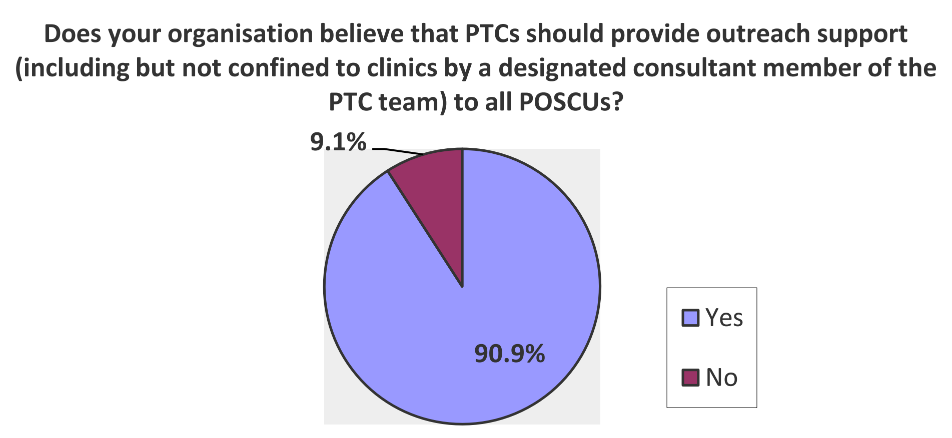
Q9. Does your organisation believe that more, or fewer, shared care units are required to provide optimal care for children with cancer in London?		
Answer Options	**Response Percent**	**Response Count**
More	5.6%	1
Fewer	94.4%	17
	answered question	**18**
	skipped question	**4**



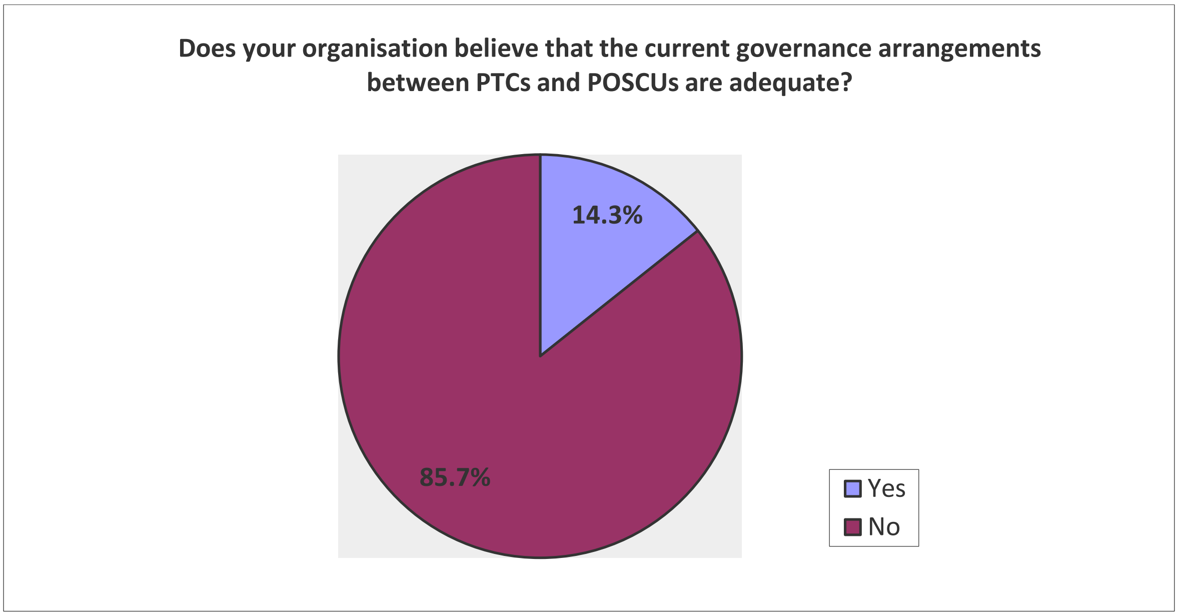
Q10. Currently, there are no Level 3 POSCUs (in London) linked to either of the existing PTCs. Does your organisation believe that, in the future, optimum care would be best provided by a network of POSCUs operating, in most / all cases, at Level 3?		
Answer Options	**Response Percent**	**Response Count**
Yes	40.9%	9
No	59.1%	13
	answered question	**22**
	skipped question	**0**



Q11. Does your organisation believe that PTCs should provide outreach support (including but not confined to clinics by a designated consultant member of the PTC team) to all POSCUs?		
Answer Options	**Response Percent**	**Response Count**
Yes	90.9%	20
No	9.1%	2
	answered question	**22**
	skipped question	**0**



Q12. Does your organisation believe that the current governance arrangements between PTCs and POSCUs are adequate?		
Answer Options	**Response Percent**	**Response Count**
Yes	14.3%	3
No	85.7%	18
	answered question	**21**
	skipped question	**1**



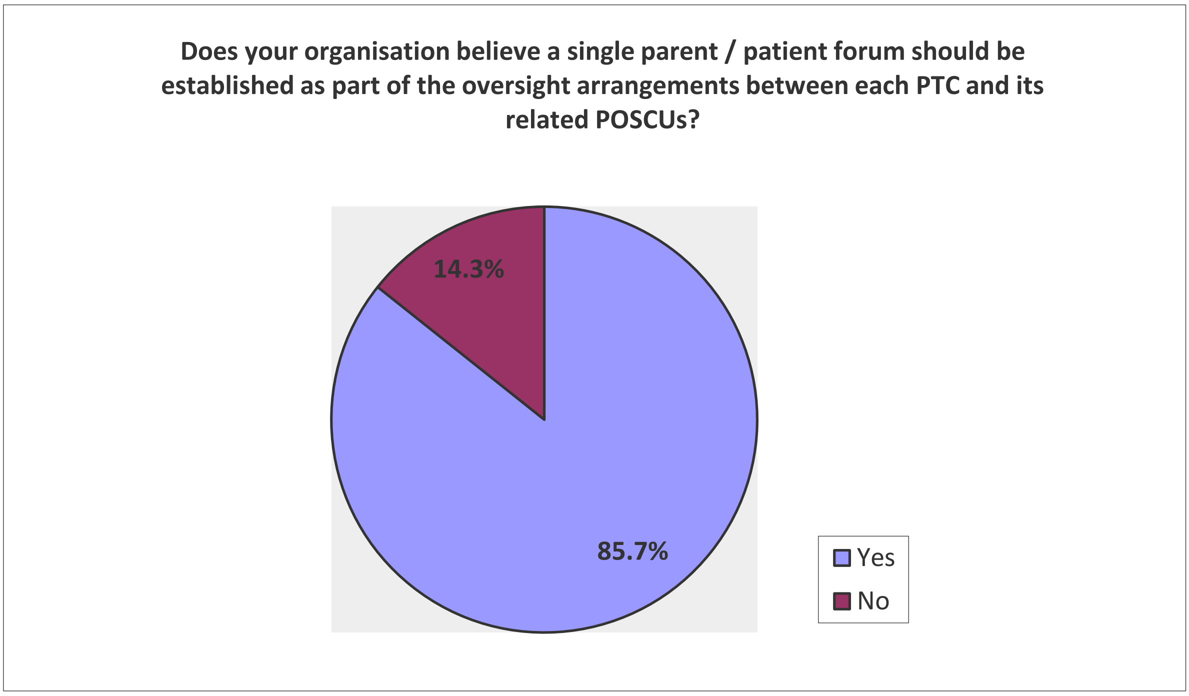
Q13. Please explain how these governance arrangements might be strengthened

1. There are no formal shared clinical governance arrangements between the clinical teams, hence no forum for investigation of clinical incidents/complaints regarding patients on shared care arrangements. There are no shared/virtual MDTs between PTC and POSCUs. There are different prescribing systems used, both paper and electronic, thus increasing the margin of error and causing practical problems. The patient information systems of the PTC and POSCUs do not communicate with each other.
2. Governance arrangements have been improved over the years. However there are still inadequacies particularly around the urgent care of sick children not yet requiring intensive care or children with unpredictable need (line blocks etc.)
3. Smaller number of POSCUs but with a larger Caseload. Lead PTC and named consultant for each POSCU; Common Data Sets leading to a single IT system/database; shared treatment protocols; Joint education and training; Central Audit programme local audit programme with common methodologies; Trials support; minimum staffing expectations for medical, nursing and administration; continuation of some form of peer review; sharing of incidents and a transparent shared risk register; hub and spoke model for service delivery and monitoring of KPIs;
4. Greater communication between the centres. Greater standardisation of care and ensuring that community services are included and not seen as an add on.
5. Since 2012 the ST PTC has proposed reduction in POSCU numbers to facilitate safe / excellent care and to facilitate improved joint governance. Governance should include: visits by PTC consultant(s)/nurses to POSCU; POSCU video links to MDTs; teaching and training; staff rotations; regular governance meets where incidents, complaints and risks shared research governance. In London we have wanted to develop Level 3 POSCUs but there has been funding shortfall to provide the necessary infrastructure. Any new model moving towards Level 3 POSCUs must address time lines, bed capacity and staffing
6. The complexity/acuity of patients moving between PTCS/ home/POSCUs is a particular challenge. Supportive Care Guidelines useful resource. Excellent communication is essential - dispense with Faxes, use secure email, no delayed discharge summaries from PTCs. Joint input from PTC/POSCU to complex inpatients needs consultant visit.
7. Single CCNCG for the whole of London. Governance- pan Network (e.g. mandatory shared incident reporting and governance meetings within the Network). A single point of referral into Pan Thames Paediatric service. Pan Thames shared care coordinating team. First-class electronic communication e.g. shared information server. A culture of working as a virtual single unit is vital to success E.g. joint PTC/POSCU MDT. Possibility for rotational training of medical nursing and AHP staff between PTC and POSCUs. Governance of clinical trials would be simplified and strengthened.
8. By integrating the PTC expertise with all referrals triaged through a single managed service, with appropriate shared information system and triage to the most appropriate PTC location according to patient age and clinical needs, joint appointments of staff between PTC and POSCU, integrated system for trial approval and data management, training schemes for

medical, nursing and AHP staff, single clinical governance reporting and shared learning from incidents and near misses, single long term follow up service supporting stratified follow up and empowered patients, families and primary care.

9. POSCUs should function as local outposts of the PTC, truly shared between the PTC and POSCU. at present they function as part of the DGH delivering low-intensity oncology care. Much of the risk in oncology care stems from poor day to day communication between PTC and POSCU.
10. Ensuring that named consultants in PTC are responsible for a number of POSCU and therefore developing good communication pathways from POSCU and PTC consultants as we had previously. A transparent shared governance system from diagnosis with an accountability structure and leads for each unit with good network arrangements .Clinical governance meeting which can have an educational and training emphasis involving multidisciplinary groups in both PTC and POSCU units which also used occur previously but with more of an educational slant .
11. There are some excellent governance strategies in place for paediatric oncology, in the form of national peer review and annual appraisal of the service; however, there is inadequate shared learning across the PTC and the POSCU. Most governance takes place ‘in-house’ within each individual ‘Trust’. We recommend strengthening these links across Trusts and the development of joint policies, which would include information governance.
12. The current structure needs improvement with a need for regular formalised meetings /incident reporting and communication issues regular logs.
13. Named link consultant at PTC to feedback governance issues and ensure actions from incidents carried through at both sites. Incident reporting systems for cross site incidents. Shared prescription charts to reduce transcription of prescriptions e.g. so PTC can prescribe GCSF and CCN administers it. Outreach nursing and pharmacy support. Outreach consultant support or POSCU consultant regularly attending PTC (improving communication). regular joint governance/audit meetings for shared learning (x1-2/yr)
14. Current arrangements are currently person/team dependent and require greater transparency and formalisation of the communication approach around bed accessibility for teenager care, solid tumours and brain tumours to ensure consistent and comprehensive communication between units in both directions especially
15. E prescribing would be of huge benefit.
16. Increase shared protocols; improve communication pathways; shared electronic records; joint clinical meetings
17. More formalised regular meetings between PTC and POSCUs that are accountable. Better communication between the two teams.
18. More collaborative working such as more consultant presence at the MDT, and clinic. More input from the clinical nurse specialists. Increased training opportunities across sites (locally and without excessive charges). More joint audits with feedback (such as feb neutropenic audit which hasn't yet been widely presented and patient satisfaction surveys).

Q14. Does your organisation believe a single parent / patient forum should be established as part of the oversight arrangements between each PTC and its related POSCUs?		
Answer Options	**Response Percent**	**Response Count**
Yes	85.7%	18
No	14.3%	3
	answered question	**21**
	skipped question	**1**



Q15. Please comment on any other key issues which should be addressed in defining an optimum specification for paediatric oncology services in London

1. Consider local demographics, bed availability in POSCU. Minimise risk and strengthen out of hours services, include additional staffing on site - additional junior doctors / trainees allocated by the deanery, CNSs pharmacy, radiology, pathology, haematology, play, therapies, social work, psychology / psychiatry, PICU, the need to access PTC if needed .Day care facility for additional chemotherapy. The need for the on-going supportive care currently well provided by the POSCUs,
2. POSCUs need robust MDT support with PTCs, better governance and information sharing. POSCU Consultants who either have grid training in oncology or equivalent (i.e. haematologists with RCPath qualifications) and the oncology CNSs are able to conduct oncology treatment and follow up clinics with no added benefit for the patients to have a PTC consultant present at the POSCU clinics. Development of level 3 services will need capital investment for infrastructure, electronic communication, as well as workforce planning. The provision of AHPs such as psychologists, psychotherapists, play specialists and social workers at POSCUs and the involvement of the 3rd sector in providing psychosocial and other support needs to be looked at across the board in paediatric oncology. Currently, the 3rd sector organisations have a very large presence in the PTCs and hardly any in POSCUs. Tariffs for systemic anticancer therapy as well as supportive care provided at POSCUs need to be transparent.
3. Consideration should be given to the now and the future- what is not optimum currently and what might be required over the next 10-20 years and beyond. Increasing complexity and expectations (family, clinicians and society) demand the most specialist and child specific infrastructure to be available when it is required not just when it can be provided. Children's cancer services should be built around the child and need to be able to look after the most challenging cases from start to finish. Currently this does not happen in South London as certain co-morbidities or complications automatically require the child and family to be moved outside the PTC often when the child is at the most vulnerable. All of the specialist services share a requirement for child specific infrastructure and a view should be taken as to how this might be achieved. Currently lack of provision is matched by duplication so the end result is at times both inadequate and wasteful.
4. Investment plan for skills and facilities; Geographical basis on decision making - reasonable travel time for patients. Network wide training; Palliative care / End of Life provision; bold decision making; links with strategic and local trust plans; patient/parent consultation;
5. In looking at oncology services the role of the community children's' nursing team should not be forgotten as it should be seen in partnership with the PTC, POSCU and the family.
6. The model must include the whole geographical area covered by the S and N Thames Children's Cancer Networks.
7. Bed capacity in POSCUS, Staffing and training, Psychology and social work funding at POSCUs, Pharmacy time and e-prescribing essential, Clinical trials infrastructure for POSCUs, CCNT and formal links with POSCUs + funding, TYA provision in POSCUS - beds/age range/staffing, Bed capacity at PTCS inadequate - transfers out of region for newly diagnosed patients, realistic

timescale for changes bearing in mind need for additional beds/ training/ recruitment to move from level 1 to 2 for existing POSCUs. A further written submission will follow since insufficient space to answer the question here,

8. We believe that a single PTC model is optimal for London, and if developed in partnership with the existing providers (GOSH/UCLH/RMH) would be the quickest, most efficient and cost effective way forward. This would build upon existing multi-professional expertise and create a truly world-class service and translational research capability. Based on the founding principles of NICE IOG i.e. age-appropriate, safe and effective services as locally as possible, not local services as safely as possible. We believe the service should be commissioned against CRG specification (incl. appropriate co-dependencies and co-locations adjusted for patient risk i.e. high-risk patients are treated in a PTC with a co-located PICU). This does not necessarily mean on a single site (e.g. as per North Thames model). Such a single PTC model can only be achieved by the development of level 3 POSCUs, which can safely accommodate large volumes of the less complex work currently performed in the PTCs, to increase capacity.
9. The numbers of patients requiring specific complex interventions is low, even for the population of London/South East (~16 million). GOSH/UCLH/RMH between them treat 360 patients/yr aged <15 yrs (NCIN annual report 2013), with surgery for renal tumours (21/yr), neuroblastoma (20/yr), soft tissue sarcomas (31/yr-only 3/yr bladder/prostate) optimally managed by single teams, with less complex care offered closer to home through shared care. Our international benchmarks will be Holland and Paris, who have already reorganised the most complex care to be discussed (Paris, 4 PTCs) or physically managed (Utrecht, NL) by single expert teams serving similarly sized populations. These will be our future quality benchmarks for outcomes.
10. Please see the response to Mr Huxter and Dr Mitchell from St George's Hospital.
11. Several issues that have to be considered. These include beds space and capacity in POSCUs that stay open particularly during the winter months as the oncology patients require cubicles and it will be difficult to ring fence cubicle particularly if not being used by oncology patients and any one time .Training staff to administer infusional chemotherapy and ensuring these competencies are maintained particularly with changeover of staff due to configuration of paediatric services
12. The key factors which we believe are important to consider are: bed capacity, including isolation facilities and an agreed level of high dependency care, geography and accessibility, i.e. local services for local people, but still delivered with expertise. There has to be adequate thought given to home-based care, both during treatment and where necessary at the palliative care stage. Adequate hospice provision/end of life care, psychological support services. Consideration of transitional care arrangements. Capacity of the organisation for teaching and training to develop staff and expand the service. Allied health professional support including pharmacy
13. London geography not to be underestimated! Travel for parents with ill children may prove a challenge for policy makers as it is quite different to other parts of UK. The aim is safety as close to home as possible. The importance of the provision of support to POSCUs during transition to ensure patient safety is paramount. Ideally for London there should be 3 POSCUs

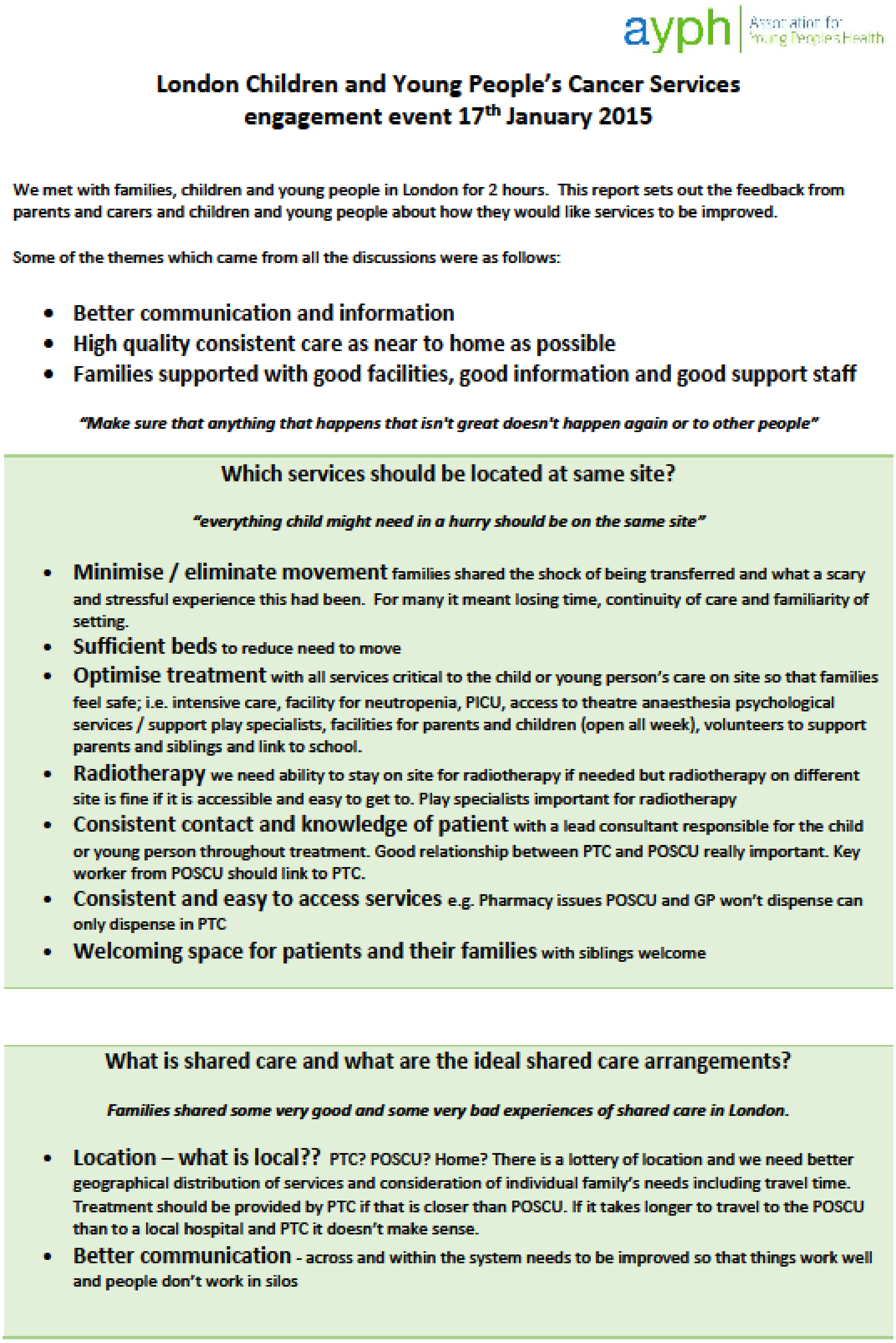
per geographical patch making a total of 12 with 2 functioning at level 2 and one at level 3. This is a good way of addressing all PTC and POSCU issues. Without additional financial resources /incentives the case for change of model of care would be a very hard task to achieve if at all. The ramifications of implementing the new model for London will produce geographical related risks is the number is halved as intended/planned.

14. A feasible model for paediatric oncology services in London would be 2 PTCs with relevant co-dependent services on-site. Fewer, but NOT half the number of POSCUs (removing those that fall way below the critical mass, assessing the impact on those that will remain) and moving initially to level 2 POSCUs with a view to some becoming level 3 in time with adequate infrastructure and staffing resource provided. "Safe care closer to home" must also include consideration of community nursing and provision for domiciliary low risk chemotherapy, currently a very patchy service. Consideration of POONs for each POSCU may help to provide some cross cover for day care work as well as specialist outreach nursing and avoidance of some hospital attendances.
15. Preventing the busier POSCUs from being over-burdened if numbers rise. Awareness that POSCU staff work within a wider general paediatric remit with consequent pressure on PA. Greater networked training for medical and nursing teams. PTC communication
16. We passionately believe in improving outcomes for children with cancer. As an integrated care organisation with a focus on the local communities we serve, having integrated pathways with community children services, hospital at home for children and Life force we are keen to secure Level 2 POSCU status. Teaching and training will be key to any specification and ideally multidisciplinary with a community focus. The interdependency with a paediatric HDU is important as is the ability to work well as part of a network with the PTC and any other POSCU. Travel time and accessibility will be key for parents and also the care closer to home for blood testing etc. which as in integrated care organisation and level 2 POSCU we believe we could be at the forefront of innovative delivery. Clinical relationships and innovation will be key to the future and a family focus as a core value.
17. POSCUs should all be at least level 2, there should be a critical minimum number of nurses for each POSCU, there should be a deputising arrangement for clinicians, there should be a critical number of patients to warrant a POSCU. There should be similar facilities for a level 3 POSCU as there are for a PTC, namely ITU and surgical and anaesthetic support. It facilities for e prescribing are desirable. Pharmacy deputising so that the service is not reliant on one individual. Sterile prep within the trust. If level two then ITU is not necessary but there should be one within the network. There should be appropriate support from psychology locally for each POSCU. Each POSCU should have ring fenced beds for oncology and adequate facilities.
18. Clinical capacity and staffing issues (including availability of specialist oncology nurses; impact on general paediatric services and their co-dependencies
19. Community nursing team that support families should be strengthened and should work across sites. Improve work force planning and co-ordination of this service across the network rather than per unit. Best practice tariff for example as that for Diabetes.

20. There should be more patient, family and public consultation as part of this process. It has been inadequate so far - and not accessible to most parents. The review and proposals should be evidence-based. If there is not the evidence available how do we know that we are moving to a better service? How will this be assessed and monitored? We feel that the modelling has not been done (or if done not been shared with us) to enable practical planning of services, beds, facilities, training etc. The proposed services should keep in mind the practical difficulties for the patients and their families in managing whilst their children are on treatment such as travel times, palliative care, other family members, local multidisciplinary support. Please refer to our response dated 31/3/14. I can send you another copy if needed.

APPENDIX 4

Engagement event summary report



ayph Association for Young People's Health

London Children and Young People's Cancer Services engagement event 17th January 2015

We met with families, children and young people in London for 2 hours. This report sets out the feedback from parents and carers and children and young people about how they would like services to be improved.

Some of the themes which came from all the discussions were as follows:

- Better communication and information
- High quality consistent care as near to home as possible
- Families supported with good facilities, good information and good support staff

"Make sure that anything that happens that isn't great doesn't happen again or to other people"

Which services should be located at same site?

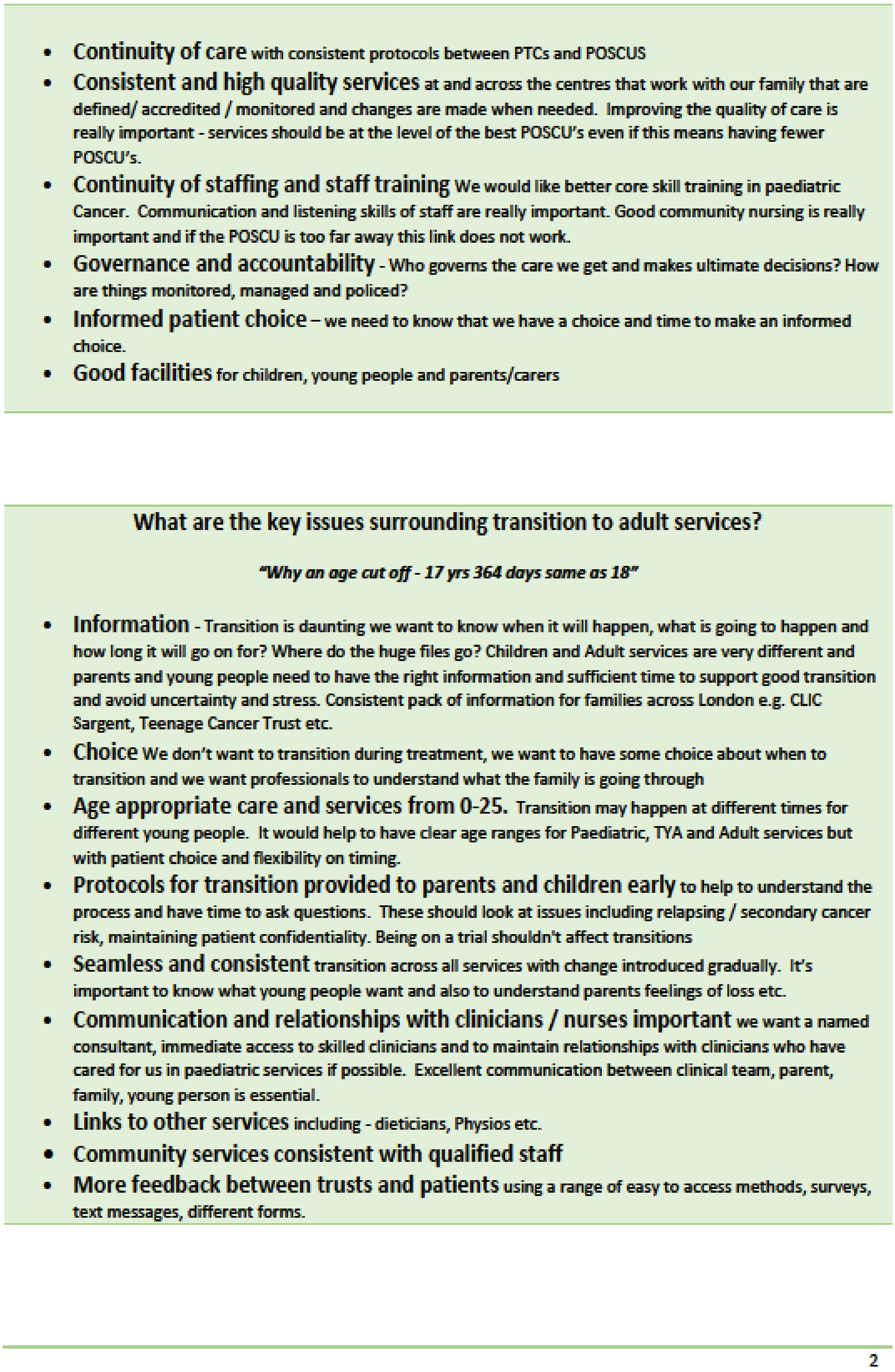
"everything child might need in a hurry should be on the same site"

- **Minimise / eliminate movement** families shared the shock of being transferred and what a scary and stressful experience this had been. For many it meant losing time, continuity of care and familiarity of setting.
- **Sufficient beds** to reduce need to move
- **Optimise treatment** with all services critical to the child or young person's care on site so that families feel safe; i.e. intensive care, facility for neutropenia, PICU, access to theatre anaesthesia psychological services / support play specialists, facilities for parents and children (open all week), volunteers to support parents and siblings and link to school.
- **Radiotherapy** we need ability to stay on site for radiotherapy if needed but radiotherapy on different site is fine if it is accessible and easy to get to. Play specialists important for radiotherapy
- **Consistent contact and knowledge of patient** with a lead consultant responsible for the child or young person throughout treatment. Good relationship between PTC and POSCU really important. Key worker from POSCU should link to PTC.
- **Consistent and easy to access services** e.g. Pharmacy issues POSCU and GP won't dispense can only dispense in PTC
- **Welcoming space for patients and their families** with siblings welcome

What is shared care and what are the ideal shared care arrangements?

Families shared some very good and some very bad experiences of shared care in London.

- **Location – what is local??** PTC? POSCU? Home? There is a lottery of location and we need better geographical distribution of services and consideration of individual family's needs including travel time. Treatment should be provided by PTC if that is closer than POSCU. If it takes longer to travel to the POSCU than to a local hospital and PTC it doesn't make sense.
- **Better communication** - across and within the system needs to be improved so that things work well and people don't work in silos

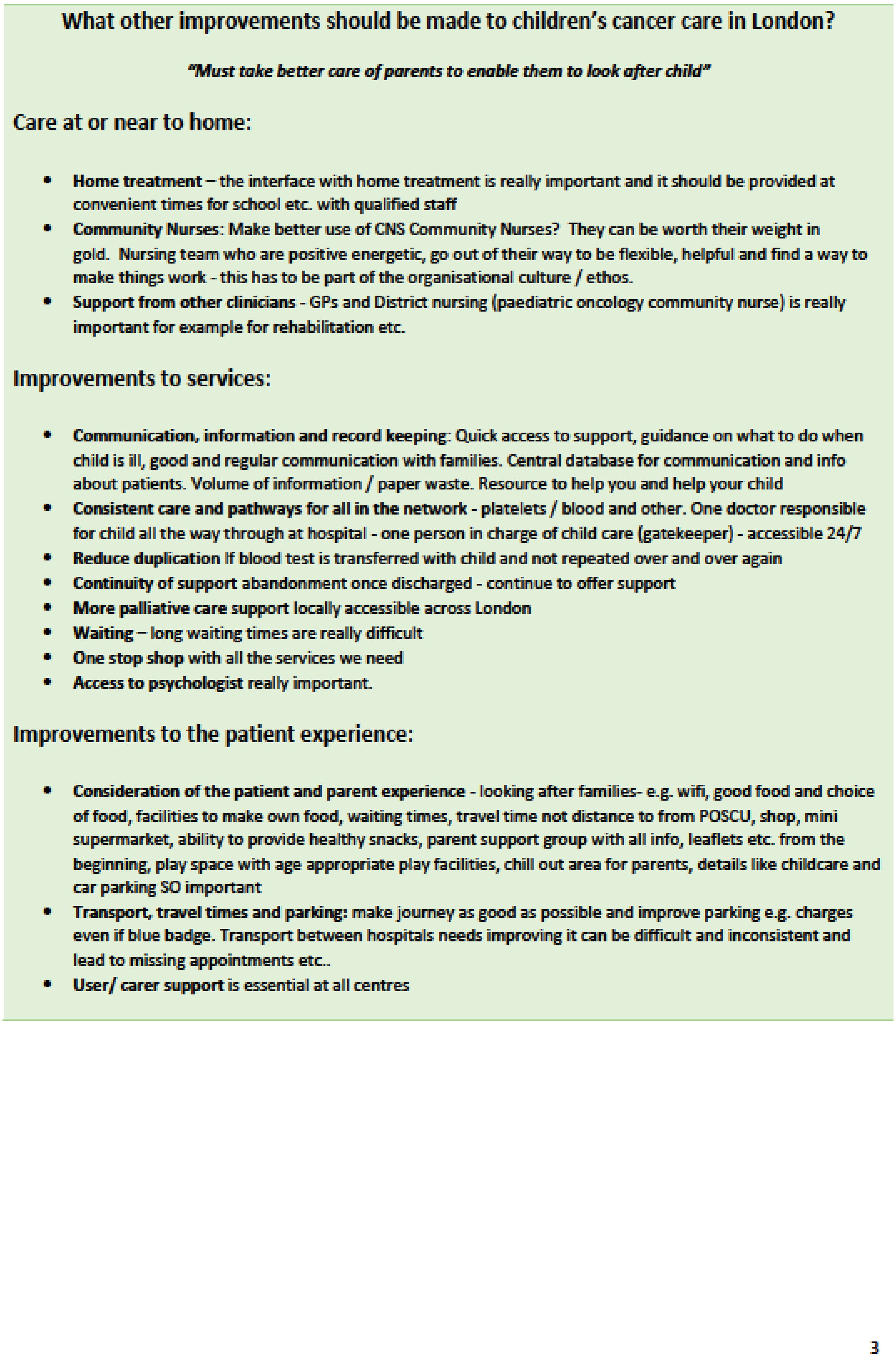


- **Continuity of care** with consistent protocols between PTCs and POSCUS
- **Consistent and high quality services** at and across the centres that work with our family that are defined/ accredited / monitored and changes are made when needed. Improving the quality of care is really important - services should be at the level of the best POSCU's even if this means having fewer POSCU's.
- **Continuity of staffing and staff training** We would like better core skill training in paediatric Cancer. Communication and listening skills of staff are really important. Good community nursing is really important and if the POSCU is too far away this link does not work.
- **Governance and accountability** - Who governs the care we get and makes ultimate decisions? How are things monitored, managed and policed?
- **Informed patient choice** – we need to know that we have a choice and time to make an informed choice.
- **Good facilities** for children, young people and parents/carers

What are the key issues surrounding transition to adult services?

"Why an age cut off - 17 yrs 364 days same as 18"

- **Information** - Transition is daunting we want to know when it will happen, what is going to happen and how long it will go on for? Where do the huge files go? Children and Adult services are very different and parents and young people need to have the right information and sufficient time to support good transition and avoid uncertainty and stress. Consistent pack of information for families across London e.g. CLIC Sargent, Teenage Cancer Trust etc.
- **Choice** We don't want to transition during treatment, we want to have some choice about when to transition and we want professionals to understand what the family is going through
- **Age appropriate care and services from 0-25.** Transition may happen at different times for different young people. It would help to have clear age ranges for Paediatric, TYA and Adult services but with patient choice and flexibility on timing.
- **Protocols for transition provided to parents and children early** to help to understand the process and have time to ask questions. These should look at issues including relapsing / secondary cancer risk, maintaining patient confidentiality. Being on a trial shouldn't affect transitions
- **Seamless and consistent** transition across all services with change introduced gradually. It's important to know what young people want and also to understand parents feelings of loss etc.
- **Communication and relationships with clinicians / nurses important** we want a named consultant, immediate access to skilled clinicians and to maintain relationships with clinicians who have cared for us in paediatric services if possible. Excellent communication between clinical team, parent, family, young person is essential.
- **Links to other services** including - dieticians, Physios etc.
- **Community services consistent with qualified staff**
- **More feedback between trusts and patients** using a range of easy to access methods, surveys, text messages, different forms.



What other improvements should be made to children's cancer care in London?

"Must take better care of parents to enable them to look after child"

Care at or near to home:

- **Home treatment** – the interface with home treatment is really important and it should be provided at convenient times for school etc. with qualified staff
- **Community Nurses**: Make better use of CNS Community Nurses? They can be worth their weight in gold. Nursing team who are positive energetic, go out of their way to be flexible, helpful and find a way to make things work - this has to be part of the organisational culture / ethos.
- **Support from other clinicians** - GPs and District nursing (paediatric oncology community nurse) is really important for example for rehabilitation etc.

Improvements to services:

- **Communication, information and record keeping**: Quick access to support, guidance on what to do when child is ill, good and regular communication with families. Central database for communication and info about patients. Volume of information / paper waste. Resource to help you and help your child
- **Consistent care and pathways for all in the network** - platelets / blood and other. One doctor responsible for child all the way through at hospital - one person in charge of child care (gatekeeper) - accessible 24/7
- **Reduce duplication** If blood test is transferred with child and not repeated over and over again
- **Continuity of support** abandonment once discharged - continue to offer support
- **More palliative care** support locally accessible across London
- **Waiting** – long waiting times are really difficult
- **One stop shop** with all the services we need
- **Access to psychologist** really important.

Improvements to the patient experience:

- **Consideration of the patient and parent experience** - looking after families- e.g. wifi, good food and choice of food, facilities to make own food, waiting times, travel time not distance to from POSCU, shop, mini supermarket, ability to provide healthy snacks, parent support group with all info, leaflets etc. from the beginning, play space with age appropriate play facilities, chill out area for parents, details like childcare and car parking SO important
- **Transport, travel times and parking:** make journey as good as possible and improve parking e.g. charges even if blue badge. Transport between hospitals needs improving it can be difficult and inconsistent and lead to missing appointments etc..
- **User/ carer support** is essential at all centres

3

THE ULTIMATE CHILDREN AND YOUNG PEOPLE'S CANCER SERVICE

Developed by children and young people on 17th January 2015 at NHS England consultation event facilitated by AYPH

Access to outdoor play area, disco room, indoor play area

Indoor games room (pool, table football, ping-pong plus video games in room with lower lighting near beds and a café area where families can eat together

Staff should be kind, understanding and joyful. There should be snacks and food that is better than at school!

Netflix! And sofas to sit and watch from

Places to sit with family and friends*

Extend the kitchen area

Softer covers and better pillows

Food not so sloppy – fresh fruit!

Simple tests (like bloods) at GP or closer to home

Reduced waiting times

Food we like: fish & chips, fajitas, pasta with meatballs and chicken korma. Also a life size stuffed animal petting zoo.

Welcoming reception with wifi, a pharmacy and a gift/snack shop. Young people friendly ambulances. A model space shuttle and space suits to try on in all sizes.

Drawing wall with art supplies and superhero paintings. Also a library and quiet reading/study area.

***typed suggestions on map from 14-18 year old group**

Evaluation and feedback

27 adults attended the event. 22 evaluation forms were completed by adults

20 people said that they felt that they had been listened to well or very well in answer to the question ***How well did you feel listened to at the event?*** Two people did not feel listened to well.

In answer to the question ***How well did the discussions cover the things that are important to you?*** 16 people said well or very well with 4 marking this question with an average score and 2 saying not well.

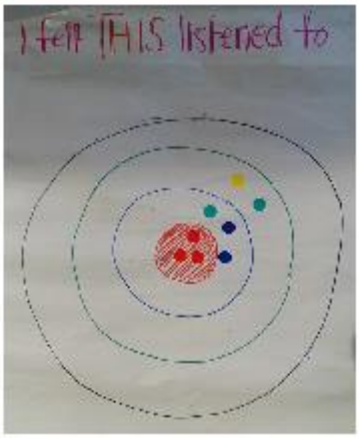
There were a range of other comments. Most noted that there was not enough time on the day with some saying they were worried that not all the points were being recorded. People welcomed the opportunity to meet with each other and share experiences and opinions about the services they received and their feelings about them.

People stressed the need for holistic care, good communication and effective community services. They also said that their children had enjoyed the session with one person saying that it was the first time their child had met with other children with cancer.

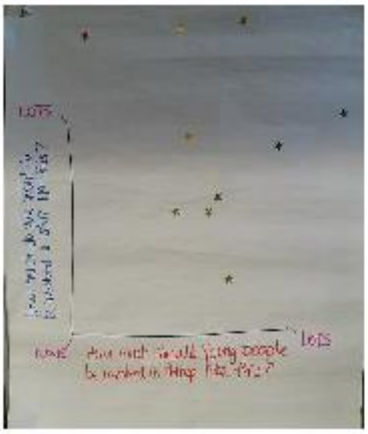
Feedback from children and young people

Ten children attended the event eight aged 7 – 11 and two aged 14-18. They completed an interactive evaluation showing how they had felt listened to see results below. In addition young people said that they had had a really good experience of care and would have liked all young people to experience the age appropriate setting and staff approach that they had had.

Target – the nearer the middle the more I felt listened to



Axis – how much should young people should be involved?



The event was facilitated by Emma Rigby and Lindsay Starbuck from the Association for Young People's Health and this report has been written by AYPH from the notes and discussions had on the day.

APPENDIX 5

Activity data

PTC activity data (patients aged 0-16 years)

Hospital Name	**Number of new patients (defined as NHS patients newly diagnosed with cancer i.e. as per cancer registration standards)**				**Total number of patients receiving RT**				**Total number patients receiving RT under GA**				**Patient undergoing allogeneic BMT**			
BY CALENDAR YEAR (Jan - Dec)	2011	2012	2013	2014	2011	2012	2013	2014	2011	2012	2013	2014	2011	2012	2013	2014
Great Ormond Street Hospital for Children NHS Foundation Trust	#	#	178	150	0	0	0	0	0	0	0	0	#	13	23	23

Hospital Name	**Number of new patients (defined as NHS patients newly diagnosed with cancer i.e. as per cancer registration standards)**				**Total number of patients receiving RT**				**Total number patient receiving RT under GA**				**Patient undergoing allogeneic BMT**			
BY FINANCIAL YEAR (Apr - Mar)	11-12	12-13	13-14	14-15*	11-12	12-13	13-14	14-15*	11-12	12-13	13-14	14-15*	11-12	12-13	13-14	14-15*
University College London Hospitals NHS Foundation Trust	74	64	63	#	112	108	106	72	28	23	23	18	6	5	4	6
The Royal Marsden NHS Foundation Trust	163	190	190	#	62	54	64	#	18	11	12	#	19	13	11	#

<u>Key</u>

data not provided

***** year to date to December 2014

PTC activity data – PICU admissions and transfers (patients aged 0-16 years)

Hospital Name	**Admissions to PICU: In house admissions and transfers in from any London Cancer POSCU**				**Number of patient transfers from or to UCLH for PICU support**			
BY CALENDAR YEAR (Jan - Dec)	2011	2012	2013	2014	2011	2012	2013	2014
Great Ormond Street Hospital for Children NHS Foundation Trust	**#**	8	7	0	n/a	n/a	n/a	n/a

Hospital Name	**Admissions to PICU: In house admissions and transfers in from any London Cancer POSCU**				**Number of patient transfers from or to GOSH for PICU support**			
BY FINANCIAL YEAR (Apr - Mar)	11-12	12-13	13-14	14-15*****	11-12	12-13	13-14	14-15*****
University College London Hospitals NHS Foundation Trust	3	2	1	2	2	1	1	0

Hospital Name	**Admissions to PICU: Transfers out to any PICU**			
BY FINANCIAL YEAR (Apr - Mar)	11/12	12/13	13/14	14-15*****
The Royal Marsden NHS Foundation Trust	**#**	**#**	**#**	**#**

Key

data not provided

***** year to date to December 2014

POSCU activity data (patients aged 0-16 years)

Hospital Name	**Number of new patients referred to any PTC**				**Total patients in treatment (defined as any patient on active treatment for any part of the year)**				**Number of transfers out to PICU**			
BY FINANCIAL YEAR (Apr - Mar)	*11-12*	*12-13*	*13-14*	*14-15**	*11-12*	*12-13*	*13-14*	*14-15**	*11-12*	*12-13*	*13-14*	*14-15**
Whipps Cross University Hospital (Barts Health NHS Trust)	19	22	21	17	#	#	38	39	1	#	2	1
The Whittington Hospital NHS Trust	23	14	14	12	18	22	24	21	0	0	0	1
North Middlesex University Hospital NHS Trust	9	4	9	12	21	16	17	22	0	0	0	0
Barking, Havering and Redbridge University Hospitals NHS Trust	21	15	16	13	51	47	49	41	0	0	0	0
The Hillingdon Hospitals NHS Foundation Trust	14	16	19	21	33	38	50	41	0	0	0	1
St Mary's Hospital (Imperial College Healthcare NHS Trust)	20	24	21	#	22	37	40	#	2	1	1	#
Epsom Hospital (Epsom and St Helier University Hospitals NHS Trust)	7	6	8	#	27	29	38	#	2	1	2	#

Hospital Name	**Number of new patients referred to any PTC**				**Total patients in treatment (defined as any patient on active treatment for any part of the year)**				**Number of transfers out to PICU**			
BY CALENDAR YEAR (Jan - Dec)	*2011*	*2012*	*2013*	*2014*	*2011*	*2012*	*2013*	*2014*	*2011*	*2012*	*2013*	*2014*
St George's University Hospitals NHS Foundation Trust	12	14	16	24	17	26	27	41	3	3	2	4
Northwick Park Hospital (London North West Healthcare NHS Trust)	#	26	28	34	#	54	55	52	#	0	2	5
Kingston Hospital NHS Foundation Trust	25	34	31	#	72	53	57	#	0	1	1	#
King's College Hospital NHS Foundation Trust	13	11	10	10	58	59	55	72	5	3	1	3
Chelsea and Westminster Hospital NHS Foundation Trust	16	17	18	#	27	34	39	#	0	0	0	#
Newham University Hospital (Barts Health NHS Trust)	9	9	14	7	19	18	21	21	0	0	0	0
Queen Elizabeth Hospital (Lewisham and Greenwich NHS Trust)	28	40	32	35	58	65	59	57	4	5	13	8
Barnet Hospital (Royal Free London NHS Foundation Trust)	22	16	19	#	20	31	40	#	2	3	3	#
Croydon University Hospital (Croydon Health Services NHS Trust)	13	20	16	14	26	31	28	17	0	0	2	1

Note - data was not provided by The Royal London Hospital (Barts Health NHS Trust)

Key

data not provided

* year to date to December 2014

Analysis for PTCs

All new referrals				
Years (range: 2011/12 to 2013/14 or 2012 to 2014)				**Average/yr**
GOSH	n/a	178	150	164
UCLH	74	64	63	67
Total North	n/a	242	213	228
Total South (RMH)	163	190	190	181
TOTAL North and South		432	403	409

NRCT 2006-11	**Average /yr**	
1014	203	
201	40	
1215	243	PTC data < cancer registrations
719	144	PTC data > cancer registrations
1934	387	

NCRT data age < 15 years

Radiotherapy					
Years (range: 2011/12 to 2013/14 or 2012 to 2014)				**Average/yr**	
UCLH	112	108	106	109	
under GA	28	23	23	25	23% under GA
RMH	62	54	62	59	
under GA	18	12	12	14	24% under GA
TOTAL North and South	174	162	168	168	41% of all patients (average) had RT
under GA	46	35	35	39	23% under GA

Analysis for POSCUs

Years (range: 2011/12 to 2013/14 or 2012 to 2014)				**Average/yr**
QE Woolwich	28	40	32	33
Kingston	25	34	31	30
London North West Healthcare	n/a	26	28	27
St Mary's	20	24	21	22
Whipps Cross	19	22	21	21
Barnet	22	16	19	19
BHRT	21	15	16	17
Whittington	23	14	14	17
Chelsea and Westminster	16	17	18	17
Hillingdon	14	16	19	16
Croydon	13	20	16	16
St George's	12	14	16	14
Kings	13	11	10	11
Newham	9	9	14	11
North Middlesex	9	4	9	7
Epsom	7	6	8	7
Royal London	n/a	n/a	n/a	n/a
Total	251	288	292	277

Note - data was not provided by The Royal London Hospital (Barts Health NHS Trust)

APPENDIX 6

Summary of Review Panel's SWOT analysis for Option 2 (two PTCs)

STRENGTHS	**WEAKNESSES**
Better access for more families. Avoids perceived risk of investing all resources on one site and offers flexibility in response to capacity issues arising on one site. May be a more realistic option in terms of achieving commissioning support. Staff with skills will have more choice about place of work in relation to residence / commuting time. Fewer POSCUs to relate to if service is delivered to a smaller referral area.	Maintains two separate pathways of access to a service across the same commissioning area. Maintains the potential for differences in delivery of care with ongoing variation in patient experience across the same commissioning area. Duplication of resources and skills on two sites. Major service reconfiguration is still required to meet optimal service co-location. All potential sites for both PTCs are still geographically close. Some services may only be provided at one PTC (e.g. allogeneic SCT and neuro oncology) skewing case mix, distorting allocation of resources and further complicating relationships with POSCUs.
OPPORTUNITIES	**THREATS**
Existing services are already large by UK standards – maintaining PTCs on two sites may avoid the uncertainties associated with the size of a single PTC serving London and the South East. Demand for co-location with other specialities on two sites may spread the drive for improved configuration of paediatric speciality care across London. PTCs may have more capacity to provide POSCU care to their local populations.	Working to this model may result in compromise that erodes determination to meet requirements for optimal service co-location. Is there the political will, financial resource and logistic possibility to achieve the necessary service co-location on both sites? Competition may result, rather than co-operation. Opposition by groups/organisations with an interest in maintaining the status quo. Failure to deliver this option could result in a default to an unacceptable status quo. Loss of skilled workforce in PTC reconfiguration. Can be achieved only if there is successful delivery of an effective Level 3 POSCU network. Interim disruption to service delivery.

APPENDIX 7

Summary of Review Panel's SWOT analysis for Option 3 (a single 'Pan London' PTC)

STRENGTHS	**WEAKNESSES**
Single pathway for access to the service. Consistency in setting standards for PTC care with a single governance and management structure. Consistent approach to support of POSCUs and in leadership of care across the POSCU network. Equity of patient experience. Economies of scale in terms of staffing and other resources. One entity: strong national / international 'brand' promoting positive profile and public confidence. Co-located specialities with considerable expertise in paediatric oncology. Enhanced power of negotiation with commissioners.	Perceived risk of placing all PTC resources for a large population in one place. Complexity of internal management arrangements that may be required. Relationship with a greater number of POSCUs than if service is delivered to a smaller referral area. Drive to sub specialisation may add complexity to POSCU relationships. Scale of staff recruitment and challenge of staff retention in an expensive part of the country. Dominance of paediatric oncology over other specialist children's services. Loss of competition with a parallel provider of PTC services may adversely impact drive to service development.
OPPORTUNITIES	**THREATS**
Opportunities for national and international leadership in care, research and training and for high level clinical sub specialisation and innovation with consequent direct benefit to patient outcomes. Demand for co-location with other specialities will drive improved configuration of paediatric speciality care across London. More consistent approach to patient care across a unified service. Development of clinical facilities fit for the future. 'Magnet' potential for attracting staff. Creation of a strong and sustainable programme of parent/patient engagement. Greater attraction for investment by voluntary sector and philanthropic individuals / organisations.	Political inertia and/or lack of courage to take the risk: is there the political will, financial resource and logistic possibility to achieve this? Unintended destabilisation of other services. Opposition by groups/organisations with interest in maintaining the status quo. Failure to deliver this option could result in a default to an unacceptable status quo. Referring hospitals on the edge of London may choose to redirect referrals to PTCs outside London. Loss of skilled workforce in PTC reconfiguration. Can be achieved only if there is successful delivery of an effective Level 3 POSCU network. Interim disruption to service delivery.

APPENDIX 8

Framework for defining co-location of services supporting a PTC

🟥	Essential co-location with PTC on the same site (as defined in section 7.2.2)
🟧	Desirable co-location with PTC on the same site
🟠	Desirable co-location with PTC on the same site but where it is recognised that this may not be feasible and that arrangements may need to be made to support access for children to this service elsewhere
🟨	On-site support from this clinical service may be needed but service co location on the same site is not required
🟩	No on-site service relationship is required
🟦	National / Supra regional service. Access is via agreed pathways (as for all PTCs in NHS England)

NO.	**CLINICAL SERVICE**	**CO-LOCATION REQUIREMENT FOR PAEDIATRIC ONCOLOGY**	**NOTES (INCLUDING WIDER REFERENCE TO OTHER SERVICES)**
🟥 1	Paediatric Critical Care (PCC)	Essential co-location on same site	All PTCs must have on site support from a Level 3 Paediatric Critical Care (PCC) Unit[67]
🟥 2	Clinical Haematology (non-malignant)	Essential co-location on same site	This includes on site access to clinical diagnostic advice and to paediatric laboratory diagnostics, coagulation and blood transfusion support
🟥 3	Specialised Paediatric Surgery (including urology)	Essential co-location on same site	The definition of 'specialised' includes all paediatric oncological surgery
🟥 4	Specialised Paediatric Anaesthesia	Essential co-location on same site	This is an essential component of PCC, specialised paediatric surgery and complex airway management
🟥 5	ENT with complex airway management	Essential co-location on same site	This is an essential component of PCC and may be required to manage acute problems in patients with brain and upper airway tumours

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[67] Royal College of Paediatrics and Child Health. (2014) *High Dependency Care for Children – Time to Move On*.

NO.	CLINICAL SERVICE	CO-LOCATION REQUIREMENT FOR PAEDIATRIC ONCOLOGY	NOTES (INCLUDING WIDER REFERENCE TO OTHER SERVICES)
6	Neurosurgery	Essential co-location on same site	Paediatric neurosurgery must be provided on site for a PTC offering neuro oncology services.
7	Stem Cell Transplantation (allogeneic)	Essential co-location on same site	Allogeneic BMT for malignant disease may not be provided at every PTC but, where provided, it should only be provided within a paediatric oncology PTC.
8	Stem Cell Transplantation (autologous)	Essential co-location on same site	All PTCs should be able to deliver high dose chemotherapy with autologous stem cell support as part of standard therapy (regardless of their provision of allogeneic stem cell transplantation).
9	Paediatric pharmacy	Essential co-location on same site	Paediatric pharmacists are an essential component of the paediatric oncology MDT[68]. All PTCs must have comprehensive paediatric chemotherapy pharmacy resources, with electronic prescribing, and be able to deliver all forms of chemotherapy, including intrathecal therapies.
10	Endocrinology	Essential co-location on same site	This service is essential for managing both acute and long term complications of therapy.
11	Nephrology	Essential co-location on same site	Whilst the management of chronic renal failure with long term dialysis and renal transplantation may be provided at another site, specialist expertise in the management of acute renal failure, tumour lysis, difficult hypertension, severe renal tubulopathy etc. must be available on site.
12	Nutrition	Essential co-location on same site	All PTCs must have expert paediatric dietetic support and be able to provide complex enteral and parental feeding.
13	Gastroenterology	Essential co-location on same site	This also links with nutritional support. All PTCs should have access to on site endoscopy services, to specialist consultation and other diagnostic support.
14	Neurology	Essential co-location on same site	All PTCs should have on site access to specialist consultation and diagnostic support.
15	Cardiology	Essential co-location on same site	All PTCs should have on site access to specialist consultation and diagnostic support.
16	Respiratory Medicine	Essential co-location on same site	This links with PCC and airway support. All PTCs should have access to on site bronchoscopy services, to specialist consultation and other diagnostic support.

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[68] NHS England National Peer Review Programme. (2014) *Manual for Cancer Services: Children's Cancer Measures. Version 1.0.*

NO.	CLINICAL SERVICE	CO-LOCATION REQUIREMENT FOR PAEDIATRIC ONCOLOGY	NOTES (INCLUDING WIDER REFERENCE TO OTHER SERVICES)
17	Clinical Microbiology	Essential co-location on same site	This includes access to on site clinical diagnostic advice and to laboratory diagnostic facilities appropriate to the care of the immunocompromised child.
18	Paediatric histopathology	Essential co-location on same site	Paediatric histopathologists are an essential component of the paediatric oncology MDT. They should be available to participate in person at such meetings, be accessible for ad hoc consultation and be supported by access to laboratory diagnostic facilities appropriate for the diagnosis and on going investigation of children with malignant disease. This includes neuropathology where a PTC provides a neuro oncology service.
19	Paediatric radiology	Essential co-location on same site	Paediatric radiologists are an essential component of the paediatric oncology MDT and to the delivery of both diagnostic and therapeutic interventional procedures. They should be available to participate in person at MDT meetings, be accessible for ad hoc consultation and be supported by access to all forms of imaging appropriate for the diagnosis and on going investigation of children with malignant disease. This includes neuroradiology where a PTC provides a neuro oncology service.
20	Acute and chronic pain services	Essential co-location on same site	These services link with, but are not synonymous with, palliative care.
21	Palliative care	Essential co-location on same site	Access to on site advice and support is required even if the service is principally delivered in the community.
22	Psychological Health Services	Essential co-location on same site	Provision of health psychology support may also co-locate with CAMHS Tier 2/3 provision.
23	Rehabilitation	Essential co-location on same site	All PTCs should have on site access to paediatric physiotherapy, occupational therapy and speech and language therapy. PTCs offering neuro oncology services should provide on-site specialist paediatric neuro rehabilitation.
24	Play Specialist Service	Essential co-location on same site	Play specialists play a major role in the care of children with cancer. They are essential in preparing children for procedures and, in particular, for radiotherapy.
25	Education	Essential co-location on same site	All Trusts providing a PTC service must ensure full time access to appropriate educational support in line with national statutory guidance.
26	Social care services	Essential co-location on same site	All Trusts providing a PTC service must ensure full time access to appropriate social care support.

NO.	CLINICAL SERVICE	CO-LOCATION REQUIREMENT FOR PAEDIATRIC ONCOLOGY	NOTES (INCLUDING WIDER REFERENCE TO OTHER SERVICES)
27	Paediatric dentistry	Desirable co-location on same site	Specialist dental care is particularly required for assessment and acute care of children undergoing head and neck radiotherapy and those undergoing allogeneic stem cell transplantation. It also has an important role in the care of some long term survivors. On site co-location would facilitate access.
28	Paediatric orthopaedics	Desirable co-location on same site	Access to paediatric orthopaedic services is required but does not require essential co-location although this would facilitate access and, as paediatric orthopaedics is integral to other aspects of acute children's services, it may be available on site.
29	Paediatric cardiothoracic surgery	Desirable co-location on same site	Access to cardiothoracic surgical services may be required and as this service will co-locate with cardiology and PCC, it may be available on site.
30	Cancer services for teenagers, young adults and older people	Desirable co-location would be on the same 'campus' i.e. within the same hospital complex	The practicality and challenges raised at the interfaces between paediatric, TYA and adult services are further discussed in chapter 10.
31	PET CT	Desirable co-location would be on the same 'campus' i.e. within the same hospital complex.	All PTCs require routine access to PET CT (with paediatric sedation/GA support). Logistically, opportunities for co-location on the site of an acute children's hospital may be limited.
32	Radiation therapy	Desirable co-location would be on the same 'campus' i.e. within the same hospital complex	All PTCs require access to a range of radiation therapy techniques (simple and complex) under the direction of a paediatric radiation oncologist and with on site paediatric anaesthesia and play specialist support. Logistically, opportunities for co-location on the site of an acute children's hospital may be limited. This is discussed further in chapter 8.
33	CAMHS	Desirable co-location on same site	Tier 2/3 services are relevant to the care of some paediatric oncology patients. On site co-location would facilitate access.
34	Genetics	Consultation on site is required but formal co-location is not essential	
35	Maxillofacial surgery	Consultation on site is required but formal co-location is not essential	There are important links to specialist paediatric dentistry and relationships to other aspects of acute children's services may result in co-location.
36	Plastic surgery	Consultation on site is required but formal co-location is not essential	Relationships to other aspects of acute children's services may result in co-location.

NO.	CLINICAL SERVICE	CO-LOCATION REQUIREMENT FOR PAEDIATRIC ONCOLOGY	NOTES (INCLUDING WIDER REFERENCE TO OTHER SERVICES)
37	Neonatal intensive care	Neonatal and oncology services do not require co-location	Neonatology units may require oncological input in managing patients with congenital tumours but the care needs of a sick newborn take precedence over delivery of oncology care at a PTC.
38	Prosthetics, including access to the National Artificial Eye Service, and complex disability support	Services should be available on a regional basis but do not require co-location with PTC	
39	Specialised liver services including liver surgery and liver transplantation	National Service	Access required as per agreed national referral pathways.
40	Surgical services for bone and soft tissue tumours	National Service	Access is required as per agreed national referral pathways.
41	Services for children with retinoblastoma	National Service	Access is required as per agreed national referral pathways.

APPENDIX 9

Levels for POSCU care

These levels were quoted in: Pan Thames Paediatric Oncology Shared Care model for Patients aged 0 to 18 years. A Discussion Paper. July 2012 (Chair of Sub Group: Professor Sir Alan Craft) and have subsequently been included in the NHS England Commissioning Board standard contract for paediatric oncology (NHS England: E04/S/a. 2013/14 NHS Standard Contract For Paediatric Oncology: Particulars, Schedule 2 – The Services, A – Service Specification)

POSCU LEVEL 1 SERVICES

- inpatient supportive care including care of children with febrile neutropenia
- outpatient supportive care
- outpatient follow up
- outpatient oral chemotherapy
- outpatient IV bolus chemotherapy
- exclusions - day care infusional chemotherapy, inpatient chemotherapy and all exclusions listed in level 3.

<u>Allowable options from the above</u>:

1. Provision of all the above services

2. Opt out of outpatient IV bolus chemotherapy only

3. Opt out of outpatient IV bolus chemotherapy and inpatient supportive care including care of children with febrile neutropenia

4. Opt out of all chemotherapy and inpatient supportive care including care of children with febrile neutropenia

NB: The implication of this is that any service that is providing outpatient IV bolus chemotherapy should also provide care of children with febrile neutropenia.

POSCU LEVEL 2 SERVICES

- as for level 1 and, in addition, day care infusional chemotherapy
- exclusions - inpatient chemotherapy and all exclusions listed in level 3.

POSCU LEVEL 3 SERVICES

- as for level 2 and in addition inpatient 24-hour chemotherapy
- an intrathecal chemotherapy service in a POSCU is an option for level 3 (only) providing the following are fulfilled:

1. compliance with HSC 2003-010, as verified by a satisfactory peer review against the ITC measures (Manual for Cancer Services 2004, section 3C-3, or any measures which supersede it);
2. paediatric anaesthetic service on site;
3. agreement by CCNCG.

Level 3 Exclusions, for instance services which should only be offered in a PTC

1. final diagnosis and determination of treatment plan;
2. chemotherapy regimens or other procedures which would be rendered unacceptably hazardous or have their effectiveness reduced by reason of the limits of infrastructure or experience available at any of the POSCUs; these regimens and/or procedures should be specified at any one time for the CCN by the CCNCG;
3. stem cell transplantation;
4. recruitment to, and co-ordination of, phase I, II and III clinical trials;
5. radical radiotherapy.

NOTES ON APPLICATION OF THE LEVELS

The care "level" of a POSCU determines the highest level of services which it should offer. It may (and probably will) offer services at levels lower than its agreed level. If the POSCU is agreed as being allowed to offer services at a given level it is then required to have at least the minimum supporting infrastructure (staff and facilities) corresponding to that level. The POSCU is required to put its infrastructure forward against the corresponding infrastructure measures in topic 11-7C-1 for detailed peer review. Any given measure for a POSCU applies to all levels of POSCU unless otherwise specified.

The level 3 exclusions define a set of services which should only be offered by a PTC but a given PTC need not offer all of them. Also, some "PTC – only" services require that a PTC fulfils certain additional conditions specific to that service. These and the infrastructure requirements for PTCs in general are dealt with in the measures in topic 11-7B-1, against which the PTC should be reviewed. It is expected that a PTC should be offering POSCU levels 1 to 3 care (mostly to its own secondary catchment area) in addition to the PTC – only services.

APPENDIX 10

Information submitted by Dr Rachel Hough and Dr Louise Soanes – POSCU age limits

North Thames POSCUs

Network	POSCU	Age range
NLCN	The Whittington	0 – 18
NELCN	North Middlesex	0 – 16
	Barnet and Chase Farm	0 – 16
	PAH Harlow	0 – 16
	Barts and the London	0 - 18
	Newham	0 – 19
	Whipps Cross	0 - 16
	Queen's Hospital, Romford	0 – 19
NWLCN	St Mary's Hospital	0 – 16
	Chelsea and Westminster	0 – 16
	Northwest London Hospitals trust	0 – 18
	West Middlesex Hospital	0 – 16
ECN	Basildon	0 - 16
	Mid Essex Chelmsford	0 - 16
	Southend	0 – 16
MVCN	Watford	0 – 16
	Lister / QEWGC	0 – 18
	Luton	0 - 16

South Thames POSCUs

Network	POSCU	Age range
SW London	St George's Hospital, St George's Healthcare NHS Trust (TYA DH) Joint PTC for children	0-15^{364}yrs (teenagers cared for on children's ward until 18yrs, no designated inpatient facilities for YA)
	Kingston Hospital NHS Foundation Trust	0-15^{364}yrs
	Epsom Hospital, Epsom and St Helier University Hospital NHS Trust	0-15^{364}yrs
	Croydon University Hospital, Croydon Health Services NHS Trust	0-15^{364}yrs
SE London	Queen Elizabeth Hospital (Woolwich), Lewisham and Greenwich NHS Trust	0-15^{364}yrs
	Kings College Hospital NHS Foundation Trust	
Sussex	Royal Alexandra Children's Hospital, Brighton and Sussex University Hospitals NHS Trust (TYA DH)	0-18^{364} yrs (teenagers cared for in RACH until 18yrs, no designated inpatient facilities for YA in BSUH)
	Conquest Hospital (Hastings), East Sussex Healthcare NHS Trust	0-15^{364}yrs

SWSH (Surrey, West Sussex and Hampshire)	Ashford and St Peters NHS Foundation Trust	0-18^{364} yrs
	Royal Surrey County Hospital NHS Foundation Trust (TYA DH)	0-24^{364} yrs (TYA cared for in a designated inpatient facilities)
	East Surrey Hospital, Surrey and Sussex Healthcare NHS Trust	TBC
	Frimley Park NHS Foundation Trust, Frimley Health NHS Foundation Trust	TBC
Kent and Medway	Medway NHS Foundation Trust	0-15^{364}yrs
	Maidstone Hospital, Maidstone and Tunbridge Wells NHS Trust (TYA DH)	0-15^{364}yrs
	Queen Elizabeth Queen Mother Hospital(Margate), East Kent Hospital University NHS Foundation Trust	0-15^{364}yrs
	William Harvey Hospital (Ashford). East Kent Hospital University NHS Foundation Trust	0-15^{364}yrs

APPENDIX 11

Responses from professionals to a question about how governance arrangements between PTCs and POSCUs might be strengthened

1. There are no formal shared clinical governance arrangements between the clinical teams, hence no forum for investigation of clinical incidents/complaints regarding patients on shared care arrangements.
2. There are no shared/virtual MDTs between PTC and POSCUs.
3. There are different prescribing systems used, both paper and electronic, thus increasing the margin of error and causing practical problems.
4. The patient information systems of the PTC and POSCUs do not communicate with each other.
5. Governance arrangements have been improved over the years. However there are still inadequacies particularly around the urgent care of sick children not yet requiring intensive care or children with unpredictable need (line blocks etc.).
6. Smaller number of POSCUs but with a larger Caseload.
7. Lead PTC and named consultant for each POSCU.
8. Common Data Sets leading to a single IT system/database.
9. Shared treatment protocols.
10. Joint education and training.
11. Central Audit programme, local audit programme with common methodologies.
12. Trials support.
13. Minimum staffing expectations for medical, nursing and administration.
14. Continuation of some form of peer review.
15. Sharing of incidents and a transparent shared risk register.
16. Hub and spoke model for service delivery and monitoring of KPIs.
17. Greater communication between the centres.
18. Greater standardisation of care and ensuring that community services are included and not seen as an ‘add on’.
19. Since 2012 the South Thames PTC has proposed reduction in POSCU numbers to facilitate safe / excellent care and to facilitate improved joint governance.
20. Governance should include: visits by PTC consultant(s)/nurses to POSCU.
21. POSCU video links to MDTs.
22. Teaching and training.
23. Staff rotations.
24. Regular governance meetings where incidents, complaints and risks shared.
25. Research governance.
26. In London we have wanted to develop Level 3 POSCUs but there has been funding shortfall to provide the necessary infrastructure. Any new model moving towards Level 3 POSCUs must address time lines, bed capacity and staffing.
27. The complexity/acuity of patients moving between PTCs/ home/POSCUs is a particular challenge.
28. Supportive Care Guidelines - useful resource.
29. Excellent communication is essential - dispense with faxes, use secure email.

30. No delayed discharge summaries from PTCs.
31. Joint input from PTC/POSCU to complex inpatients needs.
32. Consultant visits.
33. Single CCNCG for the whole of London.
34. Pan- Network Governance (e.g. mandatory shared incident reporting and governance meetings within the Network).
35. A single point of referral into Pan Thames Paediatric service.
36. Pan Thames shared care coordinating team.
37. First-class electronic communication e.g. shared information server.
38. A culture of working as a virtual single unit is vital to success e.g. joint PTC/POSCU MDT.
39. Possibility for rotational training of medical nursing and AHP staff between PTC and POSCUs.
40. Governance of clinical trials would be simplified and strengthened.
41. By integrating the PTC expertise with all referrals triaged through a single managed service, with appropriate shared information system and triage to the most appropriate PTC location according to patient age and clinical needs.
42. Joint appointments of staff between PTC and POSCU.
43. Integrated system for trial approval and data management.
44. Training schemes for medical, nursing and AHP staff.
45. Single clinical governance reporting and shared learning from incidents and near misses.
46. Single long term follow up service supporting stratified follow up and empowered patients, families and primary care.
47. POSCUs should function as local outposts of the PTC, truly shared between the PTC and POSCU. At present they function as part of the DGH delivering low-intensity oncology care.
48. Much of the risk in oncology care stems from poor day to day communication between PTC and POSCU.
49. Ensuring that named consultants in PTC are responsible for a number of POSCUs and therefore developing good communication pathways between POSCU and PTC consultants as we had previously.
50. A transparent shared governance system from diagnosis with an accountability structure and leads for each unit with good network arrangements.
51. Clinical governance meetings which can have an educational and training emphasis involving multidisciplinary groups in both PTC and POSCU units which also used occur previously but with more of an educational slant .
52. There are some excellent governance strategies in place for paediatric oncology, in the form of national peer review and annual appraisal of the service, however, there is inadequate shared learning across the PTC and the POSCU.
53. Most governance takes place ‘in-house’ within each individual ‘Trust’. We recommend strengthening these links across Trusts and the development of joint policies, which would include information governance.
54. The current structure needs improvement with a need for regular formalised meetings / incident reporting and regular logging of communication issues.
55. Named link consultant at PTC to feedback governance issues and ensure actions from incidents carried through at both sites.

56. Incident reporting systems for cross site incidents.
57. Shared prescription charts to reduce transcription of prescriptions e.g. so PTC can prescribe GCSF and CCN administers it.
58. Outreach nursing and pharmacy support.
59. Outreach consultant support or POSCU consultant regularly attending PTC (improving communication).
60. Regular joint governance/audit meetings for shared learning.
61. Current arrangements are currently person/team dependent and require greater transparency and formalization of the communication approach around bed accessibility for teenager care, solid tumours and brain tumours to ensure consistent and comprehensive communication between units in both directions.
62. Electronic prescribing would be of huge benefit.
63. Increase shared protocols.
64. Improve communication pathways.
65. Shared electronic records.
66. Joint clinical meetings .
67. More formalised regular meetings between PTC and POSCUs that are accountable. Better communication between the two teams.
68. More collaborative working such as more consultant presence at the MDT, and clinic.
69. More input from the clinical nurse specialists.
70. Increased training opportunities across sites (locally and without excessive charges).
71. More joint audits with feedback (such as febrile neutropenic audit, which hasn't yet been widely presented, and patient satisfaction surveys).