Administrator – Judy Grimshaw
Tel: 020 3299 5172
Email: Judy.grimshaw@nhs.net

King's College Hospital
Denmark Hill
London
SE5 9RS

South London Paediatric Oncology

NCAT Review

Date of final report 31 May 2011

Dates of visits Wednesday 8 December 2010 (Main visit)
Friday 7 January 2011 follow up visit to sites (FS and KM only)

Venues: Royal Marsden Hospital, Sutton site (morning)
St George's Hospital, Tooting (afternoon)

NCAT Visitors:

Prof Ian Lewis	(IL)	Consultant in Paediatric and Adolescent Oncology, Leeds Teaching Hospital NHS Trust, Children's Clinical Strategy Lead, NHS Yorkshire and Humber
Fiona Smith	(FS)	Adviser in Children and Young People's Nursing, Royal College of Nursing
Dr Kevin Morris	(KM)	Consultant in Paediatric Intensive Care, Birmingham Children's Hospital NHST. President of Paediatric Intensive Care Society

Support to NCAT Panel:

Ursula Peaple	(UP)	Rare Cancers Lead, London & SEC SCGs
Linda De-Freitas	(LdF)	Rare Cancers Project Manager, London SCG –Admin support
Canan Ejder	(CE)	Rare Cancers Project Support, London SCG – admin support

Table of Contents

Introduction and Background 2
Scope of the Review 2
Terms of Reference 3
Documents Received: 3
1 Meeting Wednesday December 8th 2010 6
People met: 6
SECTION I: Views expressed 9
Issues of concern that we heard about during the review 13
SECTION II: NCAT response to Terms of Reference 19
SECTION III: Discussion, Options, Conclusions and Recommendations 27
Options 28
Conclusions 31
Recommendations 32

Introduction and Background:

NCAT was approached by NHS London (Dr Andy Mitchell, Medical Director) who requested a review of the existing model of care for the provision of services for children with cancer within the South Thames area following concerns about the model's safety and sustainability as a result of a reported clinical incident.

NCAT was provided with the following background information.

Since 2005 a collaborative model of providing children's cancer care has been evolving between The Royal Marsden Hospital (RMH) and St George's Hospital (SGH). RMH provides comprehensive oncology services and radiotherapy and SGH provides support for children with cancer requiring other paediatric support, those with acute illness, cancer surgery and PICU access. The service provided by RMH and SGH serves the South Thames Children's Cancer Network population of South West and South East London sectors and the three Cancer Networks in South East Coast Specialty Commissioning Group (SCG).

The current model for children's cancer is intended to benefit patients through access to the Royal Marsden's expertise in children's cancer care and the research developments in this specialist field, as well as continuity of care across the cancer pathway into adulthood. St George's Hospital offers a comprehensive range of tertiary paediatric sub-specialities, including neurosciences, infectious diseases, paediatric intensive care and cancer surgery. SGH therefore provides both elective and urgent surgical care and care of the acutely sick child to complement the care pathway at RMH.

Outcomes in children's cancer are measured nationally and internationally and against these standards the Royal Marsden Hospital has demonstrated outcomes as good as, or better than those found in other major centres.

Following some clinical issues during 2009/10 local investigation highlighted issues of medical out of hours cover and nurse training at the SGH site and as a result some interim changes to the model of care were put in place. NCAT was not asked to reinvestigate the detail of these issues, although it was recognised that the NCAT panel may wish to comment further in respect to their relevance to the long term model.

NCAT was given the following scope for the review and asked to respond to the subsequent terms of reference:

Scope of the Review

The scope of this review should include the model for children's cancers provided by the Principal Treatment Centre and the interface between the two sites as identified within the current model of care. This should include bone marrow transplantation for children, services for children who require cancer surgery, and either high dependency or intensive care.

The review panel should be cognisant of close interdependency with adult services in terms of the pathway for children and young people's cancer, which is part of the overall service provided.

Other tertiary and general paediatric services on the SGH site are out of scope, although the review panel may wish to comment on any relevant interdependencies where appropriate

Terms of Reference

London commissioners are considering the options for the configuration of tertiary children's services including children and young people with cancer. Commissioners are requesting advice on the clinical governance issues that could arise from

a) Commissioning on the basis of the current collaborative model
Or
b) Commissioning on the basis of an alternative model that takes account of the recommendations of the London Review of Tertiary Paediatrics, or other advice.

The advice from the panel will inform the options considered by commissioners. The advice given should assist commissioners in demonstrating a fit with national guidance to improve outcomes in children's cancer and the recommendations of the London Review of Tertiary paediatrics.

NHS London requests that the review panel advise on whether:

- *The current collaborative configuration of the Principal Treatment Centre for Children's Cancer for the South Thames Children's Cancer Network provides a safe and sustainable pattern of service that is consistent with relevant guidance, including:*
    - *The National Service Framework for Children and Young People*
    - *Commissioning Safe and Sustainable Tertiary Paediatric Services*
    - *Children's Surgery: A First Class Service*
    - *National Guidance for Children & Young People with Cancer*

NHS London would like the review panel to advise specifically on:

- *The strengths and weakness of the current collaborative model and if there any changes in the clinical or governance arrangements that should be made to strengthen this arrangement until the future model, whether the same or different can be confirmed and commissioned.*

- *A safe long term model of service provision including consideration of the fit with the proposed recommendations from the "London Review of Tertiary Paediatrics" in relation to children's cancer services.*

Documents Received:

A. Prior to main meeting December 8th

Section 1: Overview of Service
1. South Thames Children & Young People Cancer Network
2. London SCG Implementation Summary -Nice Improving Outcomes Guidance for Children and Young People with Cancer (Sept 2008 v2)

3. RMH, SGH and the Teenage Cancer Trust; Model of Care for Children and Young People with Malignancy For South London, Surrey, Sussex and Kent (April 2006 final draft)
4. Implementation of Model of Care of the Joint CYP PTC at RMH and SGH (undated /unattributed)

Section 2: Pathways of care

1. South Thames CYP Cancer Network Group Pathways for suspected cancer
    - suspected leukaemia; lymphoma; extra cranial embryonal tumour; carcinoma and melanoma; brain or spinal cord tumour; germ cell; (from PTC Operational Policy June 2010)
2. South Thames CYPNG pathway for long term follow clinic referral
3. Joint RMH and SGH PTC Pathways
    - for direct admission to St George's Hospital; for children under the age of 1 year; for surgical patients; for patients who have received a bone marrow transplant (BMT) (undated / unattributed)

Section 3: Audit / M and M

1. RMH Clinical Audit Results Forms (x3 audits 2009 /10)
2. Joint PTC Minutes of Mortality and Morbidity review meetings (x5 during 2010)

Section 4: System and evidence of communication methods between the 2 sites

1. Overview of communication between two sites (undated /unattributed)
2. South Thames Implementation Group London SCG Review of Paediatric Oncology and BMT Meetings Minutes (2008-10)
3. Joint Paediatric Oncology Primary Treatment Centre Chemotherapy Group Meetings Minutes (2009-10)
4. Joint PTC Senior Nursing Meeting Minutes (2009-10)
5. Joint PTC Late effect steering group Meetings Minutes (2010)
6. Joint Solid Tumour MDT Annual Meetings Minutes (2009 /10)

Section 5: Patient data

1. Data on patient numbers/year by diagnostic category and age (2008-10)

Section 6: Shared Care

1. South Thames CYP Cancer Network Group Shared Care Configuration and Agreement (Aug 2010)

Section 7: Operational Policy

1. RMH and St George's Joint Principal Treatment Centre Operational Policy (June 2010)

Section 8:

1. Flows from Paediatric Oncology Shared Care Units by Cancer Network (2008-10)

Section 9: Research

1. Research Interface at RMH NHS FT Children's and Young People's Unit (undated)

Section 10: Care of the Acutely Ill Child

1. Minutes of Joint Annual PICU Audit minutes and presentations (2009 /10)
2. RMH: Operational Statement for Urgent Transfer of Patients Requiring Urgent Neurosurgical Intervention (undated / unattributed)

3. RMH Paediatric Observation Chart and Paediatric Early Warning Score (Jan 2010)

Section 11: Bone Marrow Transplant
1. RMH - Application for JACIE accreditation: Summary Report and accreditation letter (2008/9)

Section 12: PTC Annual Report and Work Programme
1. RMH and SGH PTC Annual Report for Peer Review (2009-10) and Work Programme
Site Specific Information

Section 13: Serious Untoward Incidents
1. RMH - SUIs of relevance; associated action plans - updated as far as possible
2. SGH - SUIs of relevance; associated action plans - updated as far as possible
   2.1. SUI Final Report: Datix Incident No 666G and Actions (June 2010)

Section 14: Incidents
1. Incidents (IR1/IR2 / critical incident reports) relating to services at RMH over past 2 years with relevant actions.
2. Incidents (IR1/IR2 / critical incident reports) relating to services at SGH over past 2 years with relevant actions.

Section 15: Complaints
1. RMH Complaints relating to services over past 2 years with outcomes.
2. SGH Complaints relating to services over past 2 years with outcomes.

Section 16: RMH Staffing Profile
1. Nursing numbers and rotas
2. Oncology nurse training
3. Overview of Medical on call
4. Consultant rota
5. Junior medical rotas
6. Induction training for junior doctors
7. PiLS/APLS training for staff

Section 17: RMH Patient Experience
1. PICKER surveys
2. Late effects audit
3. Letters of praise

Section 18: SGH Staffing Profile
1. Nursing numbers and rotas
2. Oncology nurse training plan for both sites (Oct 2010)
3. Medical rotas
4. Induction training for doctors
5. APLS training for staff
6. SGH Patient Experience

On December 8th SGH tabled a document covering most of the areas addressed in Sections 1 – 18 above.

In early January 2011 the panel received the following documents in response to specific requests for additional information.

1. Outcomes for patients with leukaemia, solid tumours and central nervous system tumours provided by the Charles Stiller from the Oxford Childhood Cancer Registry and Children's Cancer & Leukaemia Group (2010).

2. Outcomes for autologous and allogeneic bone marrow transplant patients and details for bone marrow transplant patients (2005-10)

3. Details of patients transferred from RMH to SGH paediatric intensive care unit between 2008 and 2010
   3a Individual Patient Data
   3b Summary

4. (a, b, c, & d) RMH response to JACIE report

5. (a&b) Nursing structure

6. Nursing acuity for 2 dates (2010)

7. Patient pathways examples

8. Brain and CNS Activity and transfers

9. Current Governance Arrangements – series of papers

10. Proposed Governance Arrangements dated Jan 2011

11. Proposed Model of Care dated Jan 2011

1 Meeting Wednesday December 8th 2010

There were a series of meetings to explore the issues laid out in the Terms of Reference. The morning (am) meetings were held at RMH Sutton and an afternoon meeting at SGH.

During the morning there was a general meeting for introduction, fact finding and initial discussion, followed by specific meetings to address issues of current model of care, critical care, nursing, junior doctors and research. A small separate meeting was held with 3 patient/parent representatives. The afternoon meeting was a single large meeting with many participants.

People met:

RMH Executive, Board and Management Team

Cally Palmer	(CP)	CEO (a.m. meeting)
Shelly Dolan	(SD)	Chief Nurse (a.m. and p.m. meetings)
Martin Gore	(MG)	Medical Director (a.m. and p.m. meetings)
David Probert	(DP)	Chief Operating Officer (a.m. and p.m. meetings)
Lindsay McFarlane	(LMF)	Service Manager, RMH (am / pm)
Rev Dame Sarah Mullally		Non-Executive Director RMH (am – attended research session)

SGH Executive and Management Team

David Astley	(DA)	CEO (p.m. meeting)
Ros Given-Wilson	(RGW)	Medical Director (p.m. meeting)
Ruth Meadows	(RM)	Divisional Director of Nursing, SGH (am / pm)
Fiona Ashworth	(FA)	Divisional Director of Operations, SGH (am / pm)
June Allen	(JA)	Lead Nurse Cancer Services (pm)
Osian Powell	(OP)	General Manager for Children's services (pm)
Val Thomas	(VT)	Divisional Chair SGH (pm)

Network

Jo Champness	(JC)	SWLCN (Host Network - RMH / SGH) (am)

Clinicians

a) Paediatric Oncology

Dr Sucheta Vaidya	(SV)	Consultant, RMH&SGH (am / pm)
Julie Mycroft	(JM)	PTC Pharmacy Lead RMH & joint centre (am)
Amber Conley	(AC)	Matron and Lead Nurse, Children, RMH (am)
Louise Soanes	(LS)	TCT Nurse Consultant, RMH (am / pm)
Prof Andrew Pearson	(AP)	PTC Lead Clinician (am / pm)
Dr Darren Hargrave	(DH)	Consultant Paediatric Oncology (am)
Dr Donna Lancaster	(DL)	Consultant Paediatric Oncology (am)
Carly Snowball	(CS)	Nurse Educator (am)
John Daly	(JD)	Clinical Nurse specialist SGH (am /pm)
Libby Harmer	(LH)	Ward Manager (am)
Jane Masru	(JM)	Ward Manager (am)
Michele Dannatt	(MD)	Shared care Lead Nurse (am)
Lucy Coombes	(LC)	Outreach Nurse (am)

b) Paediatrics

Dr Frances Elmslie	(FE)	Clinical Director, Children's Services, SGH (am / pm)
Rachel Boland	(RB)	Paediatric Nurse Consultant, SGH (am)
Dr Andrew Winrow	(AW)	Lead Clinician Shared Care POSCU Kingston (am)
Dr AK Anderson	(AKA)	Consultant Palliative care SGH/RMH
Efe Bolton	(EB)	Paediatric Oncology Pharmacist SGH (pm)
Dr Joy MacInnes	(JM)	Consultant Children's Psychologist SGH (pm)
Dr Mike Sharland	(MS)	Consultant Paediatric Infectious Diseases SGH (pm)
Dr Rosie Allan	(RA)	Consultant Paediatrician SGH (pm)

c) Critical Care and Anaesthesia

Dr Ian Murdoch	(IM)	Consultant Paediatric Critical Care, South Thames Retrieval Service (am)
Dr Shelley Riphagen	(SR)	Consultant Paediatric Critical care, South Thames Retrieval Service (am)
Dr Robert Self	(RS)	Consultant anaesthetist, Lead for children's anaesthesia, RMH (am)
Dr Jonathan Round	(JR)	Consultant Paediatric Critical Care, PICU Lead, SGH (am/pm)
Dr Tim Wigmore	(TW)	Consultant, RMH Lead for Intensive Care (am)
Dr Linda Murdoch	(LM)	Consultant PICU Paediatric Anaesthetist SGH (pm)

d) Other specialists

Dr Mark Ethell	(ME)	BMT Lead, RMH (am)
Mr Bruce Okoye	(BO)	Consultant Paediatric Surgeon, SGH (pm)
Mr Keith Holmes	(KH)	Consultant Paediatric Surgeon, SGH (pm)
Mr Andrew Martin	(AM)	Consultant Neurosurgeon SGH (pm)
Mr Nicholas Hyde	(NH)	Clinical Director Cancer Services SGH (pm)

e) Middle grade / junior medical staff
Dr Cat Duncan RMH (am)
Dr Lynley Marshall RMH (am)
Dr Lizzie Cullis (am)
Dr Anoop Parameswaran (am)

f) Research

Prof Paul Workman	(PW)	Director of the CR UK Cancer Therapeutics Unit at ICR (am)

g) Patient / parent representatives
Teenage patient with ALL (am)
Mother of a patient with germ cell brain tumour (am)
Father of a patient with AML (am)

***SECTION I: Views expressed*:**

We heard that:

1. RMH is a comprehensive national and international specialist centre of excellence for the treatment and research of cancer. Historically it has been in the forefront of developing paediatric oncology services and research in the UK and internationally. Prior to 2006, RMH had been designated as one of three major children's cancer centres in London and was a longstanding contributor to the United Kingdom Children's Cancer Study Group.

2. SGH is a large teaching hospital that provides comprehensive secondary care for a geographical area largely within SW London and a range of tertiary services for a wider area. Historically, prior to 2006, SGH had participated in the paediatric oncology service as a shared-care centre, predominantly linked to RMH, for patients living locally. In addition, SGH paediatric surgeons provided the majority of oncology surgical support to RMH and some patients with brain and spinal tumours received neurosurgery at SGH.

3. The current model of care was developed in order to meet the recommendations of a review of paediatric oncology and associated blood and bone marrow transplantation, initiated by Specialist Commissioners for London in 2004. The model was subsequently reviewed in light of the NICE Guidance for Children and Young People with Cancer (2005). Following publication of the national Safe and Sustainable report in 2008, it was agreed that paediatric oncology services would be considered within the wider review of tertiary paediatrics across London.

4. In 2006 the London SCG designated 2 Principal Treatment Centres (PTCs), one for North Thames (Great Ormond Street (GOS)/University College Hospital); and one for South Thames (RMH/SGH). At the time it was deemed that it wasn't feasible for a single site in South Thames to provide a comprehensive paediatric oncology service alongside other tertiary services as is found in many other areas of the country. The model proposed was that of a joint PTC between RMH/SGH serving a population of approximately 1.7 million children and young people aged 1-19 from 5 cancer networks. Estimates were that this population would give rise to around 230 new cancer diagnoses in this age range. Approximately two-thirds (160) will be <15 years of age. Infants <1 year of age from South Thames would be referred to GOS as had been the case for a number of years.

5. The recommendation for South Thames was based on the recognition that RMH could not provide a comprehensive paediatric oncology service in isolation on the Sutton site without major supporting services such as PICU, and that SGH was already providing significant elements of the service, most notably surgery and neurosurgery.

i) There appeared to be a good fit between RMH and SGH in that the 2 sites had complementary strengths. It was recognised that RMH had specific strengths for oncology whilst SGH offered a broad range of specialist children's services.

ii) RMH had strengths in cancer diagnosis and overseeing cancer treatments for children, delivering non-surgical cancer treatments (both chemotherapy and radiotherapy) and having established nursing and psychosocial teams. There was a benefit of seamless cancer care from childhood through adolescence

to adulthood and major links for research with the Institute of Cancer Research (ICR).

iii) SGH was able to offer 24-hour paediatric critical care and anaesthesia, a full range of paediatric surgical services, paediatric neurosurgery, and expertise in paediatric infectious disease and non-malignant haematology. There was a range of other general and specialist paediatric medicine, and paediatric radiology and pathology although not cardiology or nephrology on site.

6. The model of Care was developed with the aims of:
   - Ensuring safe, effective and efficient care with a positive patient and family experience in a unified and integrated joint PTC
   - Reducing inter-hospital transfers and rationalising flows of children and young people with cancer in London
   - The two CEOs signed a joint model of care document in 2006.
   - In 2010 a joint PTC Operational Policy document (Section 7) was produced to reflect recommendations of the NICE measures.

7. We heard that after 2008 Commissioners agreed a change in flow within London. Children from SE London and East Kent being referred to the South Thames PTC rather than to North Thames as had happened previously.

8. Since 2007 the developing model has been supported in a number of ways.

i) Examples of enhanced staffing include:
   - The appointment of a Lead Medical Clinician for the joint PTC
   - The appointment of 4 new consultants to work at both RMH and SGH.
   - The appointment of 3 speciality doctors (non-consultant) to rotate between RMH and SGH.
   - Consultant rota (paediatric oncology) out of hours and weekends to cover both SGH and RMH
   - The appointment of nurse consultants, nurse practitioners within paediatrics and a clinical nurse specialist to specifically support paediatric oncology at SGH
   - Designation of specialist oncology staff at SGH, including dietetics; pharmacy; play specialist; and psychology.

ii) Examples of joint working include a series of joint meetings:
   - To achieve collaborative & partnership working on both sites
   - To ensure the same policies, procedures and practice on both sites
   - To ensure equitable care offered across both sites
   - To reflect safe and seamless care for patients
   - These include - joint PTC morbidity and mortality meetings; PICU and retrieval audit meetings; joint PTC consultant meetings; senior nurses meetings; improving outcomes guidance and peer review implementation meetings; and joint paediatric oncology chemotherapy meetings

9. Patient pathways were agreed for:
   - Suspected cancer for the each of the common children's cancer groups /diagnoses with the intention of supporting the aims of the model of care.
   - Long term follow up

10. Retrieval of sick children requiring or likely to require critical care was planned in conjunction with the South Thames Paediatric Retrieval Service (STRS) and intensivists at SGH, following stabilisation overseen by RMH anaesthetic staff.

The evidence provided to us suggested that this was working as planned, with no suggestion of adverse mortality.

i. A paediatric early warning score (PEWS) is in active use at both RMH and SGH. The documentation embeds clear guidance on when to trigger a more senior review. Any child at RMH becoming acutely unwell or triggering one of the referral criteria (PEWS score or requiring >20 mls/kg volume) is reviewed by a consultant anaesthetist and taken to a designated area within a day case theatre for stabilisation pending arrival of STRS.
ii. At RMH there are 8 consultant anaesthetists who regularly anaesthetise children. The department has signed up to the Association of Paediatric Anaesthetists peer-review process.
iii. STRS provide regular outreach teaching and training to RMH, with lectures and simulation scenarios of relevance to a paediatric oncology service (e.g. septic shock in a child with febrile neutropenia). This support is greatly appreciated by RMH staff.
iv. There are 20-25 emergency transfers from RMH to PICU each year, the vast majority of which are undertaken by STRS. Most children are transferred to SGH, other than some children with brain tumours who may be moved to Kings. In the event of no PICU bed being available at SGH some children are admitted to the Evelina Children's Hospital or an available bed elsewhere.
v. Occasionally acutely ill children who require a 'time-critical' transfer, for example a child with a brain tumour and a suspected blocked VP shunt, may need to be moved by a team from RMH rather than waiting for STRS to be available.
vi. Regular audit of cases requiring emergency transfer out of RMH to PICU is undertaken, with annual reporting in collaboration with SGH and STRS. Regular meetings take place between oncology and PICU staff

11. Alongside the service model both RMH and SGH had outlined plans in 2006 to improve their estate in line with broader Trust strategies. (Doc 1.3)
    i. RMH committed to a range of improvements including a new build capital development for inpatient care for children and young people; dedicated day care and out patient facilities; and a drug development unit, all of which should be fully opened during 2011.
    ii. SGH described providing a designated paediatric oncology unit as part of becoming a joint PTC and in line with their aspirations to increase their role as a tertiary paediatric service provider. It was noted the capital redevelopment required to achieve this is part of the overall strategy for paediatrics within South West London so cannot be substantively progressed until these wider plans can be endorsed by commissioners.
    iii. The new facilities at RMH are of an extremely high standard and provide excellent accommodation for children, young people and their families. They are in marked contrast to facilities at SGH, which clearly needs additional investment to achieve current expected standards. It was also said to us that SGH had indicated a desire to improve the overall standard of paediatric in patient care by re-designating a specific area of the hospital for children's services (Children's Hospital).

12. The PTC demonstrates high-level paediatric oncology outreach nursing and clinical nurse specialist support for children, young people and their families.

There is good support for shared care centres in terms of education and co-ordination.

13. We heard from both partners that there is strong support for nurse training and education. RMH is notable for its support of study leave, for personal development of nurses, and for encouragement to attend Masters courses. SGH has attempted to improve the specialist knowledge and practice of nurses in paediatric oncology by promoting and encouraging attendance for a range of relevant qualifications at foundation, degree and masters levels.

14. We heard that there are effective and valued paediatric psychology services and consultant led paediatric palliative care support that functions across both major PTC sites.

15. Survival for children with cancer <15 years diagnosed between 2003-7, registered as being treated at RMH, was largely within expected limits and comparable with other UK paediatric oncology centres. There was lower than the expected number of deaths from acute lymphoblastic leukaemia during this period. (Stiller –CCRG 2010)

16. RMH has a combined adult/ paediatric bone marrow transplant unit undertaking both autologous and allogeneic transplants. The service has an excellent reputation and was externally accredited by JACIE (the Joint Accreditation Committee of the International Society for Cellular Therapy and the European Group for Blood and Marrow Transplantation) in 2009. The service has carried out 91 allogeneic and 83 autologous transplants in children since 2005. We were given evidence of a low (1.7%) overall transplant related mortality. Outcomes at 1 year for BMT patients are comparable with those elsewhere in the UK (British Society of Blood and Marrow Transplantation (BSBMT) report) and internationally.

17. RMH has an excellent international profile in cancer research and is linked to the internationally renowned Institute for Cancer Research. Research outputs are highly impressive with excellent research assessment including a number of NHS consultants in paediatric oncology. We heard about the commitment to paediatric oncology research from the Head of the ICR Drug Development programme and that the speciality was being integrated into the cancer therapeutics programme with the aim of enabling children to have access to new agents at an appropriately early stage of development. We heard about the integral relationship between the clinical service and research and the importance of day to day interaction between clinicians and scientists. We also heard about the excellence of existing facilities at RMH and those being developed, including dedicated beds for drug development.

18. We heard about existing models in adult oncology whereby RMH links successfully with other organisations. The model is known as 'Royal Marsden at' or RMH@…
    The 2 examples include:
    a) The provision of an adult clinical service at Kingston Hospital whereby the service was provided and run by RMH consultant staff and RMH took overall governance responsibility for the clinical elements of the service.
    b) An oncology research programme at Mount Vernon Hospital where again RMH takes governance responsibility for this aspect of provision.

It was made clear that these developments had engendered robust and extensive discussion at the RMH Board before agreement to proceed.

Issues of concern that we heard about during the review

19. **Incidents and response -** This 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 St George's Hospital site. As requested we have not re-investigated this incident.

20. The investigation summary includes 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 cancer centre'

    The Root Causes were identified as:
    a) *The Medical staff failed to recognise a sick child*
    b) *The nurses did not recognise how sick A was. Nursing Observations were not well recorded and PEWS scores were inaccurate.*
    c) *The key clinical decision maker was not clearly identified*
    d) *The communication and prescribing guidance was inadequate*

    Staffing issues:
    e) *Lack of Safe and Sustainable out of hours specialist paediatric oncology middle grade medical and nursing staffing at St George's Hospital.*
    f) *Nursing staffing levels and Skill mix*

    The SUI made a series of recommendations and developed an Action Plan. All Actions were assessed as being implemented and in place when the Action Plan was reviewed in November 2010.

21. We were given information about a similar incident in June 2010 at SGH where there appeared to be a failure to identify a febrile neutropenia and act appropriately in a timely fashion, although this incident did not result in death or increased morbidity.

22. As a consequence of the concern about these incidents the Specialist Commissioners and SHA were informed. Decisions were made in August 2010:-
    i. To change the existing pathway for patients on an interim basis, reducing the role of the general paediatric ward at SGH, referring local patients to the shared care centre in Kingston, whilst retaining the role of SGH in providing critical care, surgical oncology and neurosurgery, until measures were put in place to address the issues identified.
    ii. To commission this NCAT review.

23. **Joint Governance** - We heard from executive members of both organisations (RMH and SGH) that they have governance responsibility for patients whilst they are receiving care within their institutions but that this responsibility ceases and sits with the receiving hospital if patients are then transferred to the partner, or a different, organisation. The RMH executive stated that in their view they had no

shared governance responsibility for events at SGH such as those that led to this review.

24. There are two standing committees with an over arching role in managing the service. The "South Thames Implementation Group" which is Trust driven with Cancer Network representation and is the forum which supports development of the joint clinical model and sharing of quality issues. Separately from this and in line with national cancer guidance there is a South Thames Children & Young People Cancer Network Group chaired by a Specialist Commissioner which includes sector commissioners, and cancer networks, as well as representation from the cancer centre and shared care hospitals. In addition following the introduction of the interim pathway a time limited commissioner and clinical group has been established to monitor implementation of staffing improvements to allow the service to reopen fully.

    What was less clear was whether senior management at either main partner organisation had recognised any responsibility to the whole paediatric oncology service and children's cancer pathways within the context of a joint Principal Treatment Centre, rather than just the element that their organisation provided. Neither the original 'Model of Care' Document (2006) or the Joint Principal Treatment Centre Operational Policy (2010) addressed or described the issue of overall corporate governance of this joint model. It appeared to us that the major body considering relevant issues was the South Thames Children's and Young People's Cancer Network Group under the auspices of the London SCG.

    Following the SUI above, there seems to us to have been very limited recognition of the concerns raised within SGH by the PTC Lead Clinician and how these may be addressed. Rather the point of contact for concern and eventual recognition and action seems to have been via SCG and the SHA.

25. Following our initial visit in December we were sent a new potential governance structure for the PTC which incorporated a Joint PTC Board with Trust Board level membership from both partners.

26. **Nursing leadership** – We heard that during the existence of the PTC, both organisations had experienced periods of problems with nurse recruitment and staffing in paediatric oncology but that nursing development and education had been carried out by each institution independently. There was a clear nursing structure and leadership for paediatric oncology nursing in place at the RMH site and we were advised the nursing structure at SGH split responsibility for nursing staff involved in paediatric oncology across 4 teams.

    Whilst there had been some interaction between the trusts at very senior levels, with joint meetings between senior nurses, and collaboration about education, there did not appear to be a systematic, whole PTC approach to nursing practice, resource and education. There had been no joint appointment of an overall Lead PTC Paediatric Oncology Nurse as recommended in the NICE Guidelines with a specified role across both sites. There had been no joint appointments of nurse educators, or of Clinical Nurse Specialists. There were no rotations at any level between the 2 main sites. If anything there was a suggestion of competition in nurse recruitment in oncology between the 2 sites. We heard that 4 nurses from SGH who had been seconded to undertake the 2-year degree level programme

at RMH in order to support the development of PTC status at SGH had then left to work at RMH.

27. **Four site Principle Treatment Centre (PTC) in South Thames** - Despite the recommendation of a shared 2 site PTC for South Thames, the current model determines that all children with cancer under the age of 1 year from the London SGC area be referred directly to GOS in North Thames. In addition there are 2 sites in South Thames, SGH and King's College Hospital, for the neurosurgical treatment of children with brain and spinal tumours. This reflects current agreed acute neurosurgical pathways. Paediatric Oncology care for children in South Thames is therefore currently delivered across 4 different sites and Hospital trusts. We heard that commissioning intention is that in the future all children from the South Thames area, including those <1-year old, should be treated at the PTC within the area and that the future sites for paediatric neurosurgery would be influenced both by the ongoing national review of paediatric neurosurgery and the London review of tertiary paediatrics.

28. **Patient pathways** – We heard that most episodes of in-patient care occur at RMH. A significant proportion of care is also carried out at a number of shared care centres throughout the South Thames region. However, the joint PTC model (prior to Sept 2010) resulted in patients perceived to be of high risk (highest acuity), or requiring surgery or critical care, receiving that care at SGH. We heard described a number of examples of complex pathways. This means that patients could be having different aspects of care in a number of different settings, sometimes within a short period.
    We enquired from the clinical team about how clear these pathways would be for individual patients and their families and to see relevant literature. We were given descriptions of the main diagnostic pathways and for long term follow up, but despite asking for them, we were not shown any examples of clear pathway descriptions or patient information for on treatment aspects of pathways, particularly aspects that could result in inter-hospital transfers.

    We heard from patients and families how disruptive and confusing the pathways could be. This was in contrast to the clinical team who did not seem to fully recognise the complexity of the pathways from the patient perspective. Apart from the critical care pathway and some aspects of neurosurgery, we were not shown any audits of these pathways.

29. **Critical care and anaesthesia -** At RMH Sutton there are 2 designated HDU beds in an adult area for adult patients requiring high dependency care. There is no dedicated paediatric intensive or paediatric high dependency unit or area co-located with the RMH children's oncology / BMT service. In view of this, clinicians at RMH recognise the need to have a 'conservative' trigger for referral for critical care. . Around 20-25 children are transferred for paediatric intensive care each year from RMH, mainly to SGH. Between 25% and 35% are ventilated at the time of PICU admission, usually prior to transfer. This is a much lower proportion of cases than would be expected at centres with a paediatric critical care facility on site. A number of children are transferred out of RMH for PICU care who would remain on the paediatric oncology ward were they cared for in a PTC with a co-located PICU.

30. A high proportion of transfers were for patients who had undergone either an allogeneic or autologous stem cell transplant procedure. Between 2008 and

2010, 21 of the 40 transfers from RMH (52.5%) were stem cell transplant patients. Most other critical care transfers were of patients receiving intensive chemotherapy for conditions such as acute myeloid leukaemia (AML), relapsed leukaemia or neuroblastoma. A 5-year review of bone marrow transplant recipients demonstrated that between 25 and 35% of such patients require emergency transfer for PICU care. It was emphasised to us that this had not resulted in excess mortality. The issue of lack of on-site critical care facilities was raised by the paediatric assessor for JACIE (2009). We have been unable to identify any direct reference to this in the RMH response.

31. There is no separate rota for paediatric anaesthesia at RMH. Out of hours an acutely ill child may need to be managed by an anaesthetist who does not regularly anaesthetise children. One figure that came to our attention (Figure 3 - The London specialised children's services review) suggests that there is occasional practice at RMH with respect to providing anaesthesia to children less than 2 year of age.

32. We did not see evidence of either a written policy for, or audit of, process and outcome for children who require ward to ward transfers between RMH, SGH or Kings.

33. **Parental and patient views** - The patient and parents were forthright in their appreciation of the high level of care received on both sites and they all wanted to express their gratitude. However they all raised issues concerning information provision; lack of clarity around care pathways; and problems about care being delivered on more than one site, with a particular issue about transfer between different sites.

34. Comments were made in particular about lack of consistency in information parents and patients received about care on different sites and this was also reflected in lack of consistency with procedures. All of those we interviewed found both emergency transfer and transfer back to RMH considerably unsettling and stressful even though they all acknowledged being told that this might be necessary as part of their or their child's care. Parents reported that it was very stressful having to pack up all their belongings urgently, and struggled with the uncertainty of when and to where they would return. In particular time delays were reported in transferring back to RMH from other sites (not just SGH). The families had experience of not only RMH and SGH, but also King's College Hospital and the Evelina Children's Hospital. We heard from one family whose child had, at different times, required transfer to the each of the 3 PICUs in South Thames because of PICU capacity problems. They found the lack of paediatric oncology expertise on site at Evelina and King's College Hospital (KCH) particularly stressful. The parents and patient we interviewed all commented on differences in the level of accommodation and facilities across sites. Preference was expressed for all services to be on a single site.

35. **Medical Staffing** - We heard that following designation of the PTC there has been robust week daytime oncology consultant input into both sites. Prior to the SUI out of hours, first line consultant cover to the ward oncology patients at SGH was from the consultant paediatrician who was also providing general paediatric care. This changed following the SUI to cover being provided by paediatric oncology consultants. This means that out of hours and at weekends, the current model relies on a single oncology consultant covering 2 sites 30 minutes apart.

36. The service at SGH relied upon a stretched, shared medical middle-grade rota covering all ward areas (other than PICU) and the Emergency Department. The majority of middle grade staff at SGH would not have specific oncology experience although there was a carefully planned induction programme intended to cover key areas. This process has been weakened by significant vacancies in the rota that have required the appointment of short-term locums. Following the SUI a system has been initiated whereby the out of hours on-call SGH middle grade calls the middle grade at RMH to conduct a 'virtual' ward round on all paediatric oncology patients.

37. SGH recognise the need to improve medical cover to the wards and ED out of hours. They have introduced extended evening cover by consultant paediatricians two days a week, with the plan that this will increase over the next year subject to funding being approved.

38. We heard from the trainees at RMH about the stress this situation engendered in the SGH middle grade staff and they were sure that the evening phone round had helped. They thought the current information systems, although not unified, were adequate to be able to provide safe advice and care from a distance. We did not have the opportunity to meet the SGH middle grade medical staff.

39. RMH has a fully staffed oncology middle grade rota and the middle grade staff at RMH were fulsome in their praise for their training, their educational support, and for the opportunities that they had received to pursue a career in paediatric oncology. They fully recognised the excellence of the service provided at RMH, and were proud to be part of a successful multi-disciplinary team.

40. We heard at RMH, that their current medical staff are not all up to date with resuscitation training but that this is in hand. Similarly we received training records which highlighted that not all medical staff have up to date Child Protection training.

41. **Co-location of specialist services** – We heard from the PTC Lead Clinician of his involvement in discussions about the future provision of specialist paediatric services in London in order to meet the guidance contained in the document *"Commissioning Safe and Sustainable Specialised Paediatric Services - A Framework of Critical Inter-Dependencies"*. The view was expressed that paediatric oncology in South Thames could continue with a similar model to present using the following definition of Co-location – *'Location in other neighbouring hospitals if specialist opinion and intervention were available within the same parameters as if services were on the same site'.* It was recognised that the most contentious area was provision of critical care but thought the paediatric oncology service could achieve a 'red relationship' for critical care by using the South Thames Retrieval Service as at present. The view was emphasised that outcomes were not adversely affected using this model.

42. We heard that there had been no final decision about the disposition of specialist services in South Thames in the future but that a variety of options were being considered that revolved around the proposed South Thames paediatric "Hub" with the relative contributions of the Evelina Children's Hospital (at Guy's and St Thomas's), St George's, and King's College Hospital. In January 2011, the NCAT team was presented with a document that made a case for the future

paediatric oncology service to function with a Joint PTC but with the partners being RMH and Evelina Children's Hospital. Any alternative model would need to demonstrate the improvements in pathways in both quality and from a patient perspective and this has not been explicitly stated in the information submitted to the panel

SECTION II: NCAT response to Terms of Reference

There were several sets of questions asked of us in carrying out this review.
A. The first area of response addresses the following issue:
1. NHS London requests that the review panel advise on whether:
The current collaborative configuration of the Principal Treatment Centre for Children's Cancer for the South Thames Children's Cancer Network provides a safe and sustainable pattern of service that is consistent with relevant guidance, including:

- *a) The National Service Framework for Children and Young People (2004)*
- *b) Children's Surgery: A First Class Service*
- *c) National Guidance for Children & Young People with Cancer*
- d) *Commissioning Safe and Sustainable Tertiary Paediatric Services*

2. *a) The National Service Framework for Children and Young People (2004)*
   - i. In the main we are satisfied both organisations are committed to delivering the relevant standards within the NSF and meet these standards.
   - ii. These standards stress the importance of partnership working; the need to tailor services to the requirements of children and young people; and the requirement to involve service users and their families and carers fully in treatment decisions. We recognise that the intention of commissioners, both main providers and the clinical teams is to put children and their families at the centre of care. There are excellent examples of this throughout the PTC and we were impressed by the dedication and commitment of the staff that we met.
   - iii. However we are concerned that the current configuration of the PTC creates complex patient pathways that many patients and families experience. We heard that this creates uncertainty and stress for a number of patients and families, despite them being made aware of the possibilities and we think these require attention. In particular we think that even without change, the existing pathways need to be much better described for patients and additional effort made to improve the patient and family experience in this regard. We think that there are opportunities to rethink these pathways around the needs of patients and families.

3. *b) Children's Surgery: A First Class Service (2000) and Surgery for Children – Delivering a first class service (2007)*
   - i. We think the surgical services within the PTC meet the guidance and standards laid down in these documents as far as we were able to ascertain. We did not have either a surgical or anaesthetic expert on our panel.

4. *c) NICE Improving Outcomes in Children and Young People with Cancer (IOG 2005). We have not carried out any formal assessment of subsequent Peer Review Measures.*
   - i. Again we are satisfied that in the main the providers have worked with SCG with the intention to meet and achieve this guidance. There are several areas we wish to comment on including 2 specific issues, which require consideration.
   - ii. The implication throughout this NICE guidance is that PTCs are housed within single organisations. This is not stated explicitly but is implicit in how it has been written.

iii. The Guidance states (p103) that PTCs should have *'defined clinical governance structures'*. The IOG did not specifically address a model whereby the PTC was shared between 2 organisations. 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. We recognise that both organisations –SGH and RMH – have their own governance structures but we are clear that there is a need to consider and demonstrate the overall governance of the paediatric oncology service within a joint PTC model and that this had not been adequately addressed.

iv. We understand that the intention of the London SCG and constituent cancer networks in recommending a shared PTC was that the PTC would have robust governance structures for which both organisations took responsibility, as evidenced in a range of documents. The South Thames Cancer Network Group was developed in line with national guidance but in the event did not specifically address how to ensure there was Executive overview and guidance between the two Trust Boards. The outline proposal we were sent in January 2011 would go someway towards providing a more robust structure.

v. The Guidance recommends appointment of an *'identified Lead Nurse'* for the PTC (Table 9 p 107). This is also a key Peer Review Measure. No such post has been developed.

vi. The Guidance states - '*There should be immediate access to: Paediatric intensive care; Paediatric neurosurgical services…(and a range of other services)'. There are a number of intensive treatment protocols that should only be delivered within a principal treatment centre; those that predictably produce profound and prolonged neutropenia and carry a significant risk of requiring intensive support. These patients should have access to other tertiary specialities and in particular direct access to intensive care facilities.*

vii. Clearly, the element of service on the RMH site does not satisfy these requirements and indeed was one of the major reasons behind the recommendation to develop the current joint PTC model. It is also clear that the teams have made a major effort to identify higher risk patients and situations so that they either receive their treatment at SGH or be transferred there by emergency transport. The service element at SGH does meet this requirement. Nevertheless a significant number of children have required emergency transfer from RMH to a critical care centre (mainly SGH). This includes a high percentage of patients receiving autologous or allogeneic transplant. The argument has been put to us that the current configuration and arrangements minimises risk for patients to the same level that would apply as if all services were on the same geographical site and therefore the joint PTC meets this element of the guidance. We do not accept this argument and address this further later in the report.

5. *Commissioning Safe and Sustainable Tertiary Paediatric Services - A Framework of Critical Inter-Dependencies (2008)*

i. We have examined the critical inter-dependencies for both oncology and bone marrow transplantation. We have focussed in particular on 'Red' and 'Amber

3*' and 'Amber 3' relationships. Our opinion is that the element of service at RMH does not meet this guidance for either oncology or BMT.

ii. The **Red** Relationships (*absolute dependency, requiring co-location*) are listed for
Oncology as:- Haematology (non-malignant); Critical Care; Specialist Paediatric Anaesthesia; Specialist surgery; and ENT – airway skills.
Bone marrow transplantation as:- Haematology; Immunology; and Critical Care. In addition Specialist Paediatric Anaesthesia, Specialist surgery, and ENT – airway skills are identified as cumulative red dependencies, i.e. are needed when critical care is required. The document defines co-location in this context as meaning either:

- *Location on the same hospital site, or*
- *Location in other neighbouring hospitals if specialist opinion and intervention were available within the same parameters as if services were on the same site. These would be reinforced through formal links such as: consultant job plans, and consultant on-call rotas.*

iii. The argument has been made to us that the service at RMH meets the second part of this definition because the availability of on site anaesthesia and the critical care transport service creates a situation 'as if services were on the same site'. We disagree. The intention within the document is clear to us. The qualification is allowed in order to allow consultant opinion to be available to the patient immediately. It is not intended to support this situation which is going to result in frequent patient transfer to another site at least 30 minutes away.

iv. The **Amber** Relationships are defined and listed as follows: *Amber relationships will best be achieved by co-location and this should generally be the expectation as there are important clinical linkages between services. However, unlike Red relationships, there is some flexibility in terms of service location.*

v. **Amber 3*** (*Co-location is essential to provide a full specialised service, but a decision not to co-locate may be made to ensure optimum access to service centres. If an Amber 3* relationship is not co-located the medical specialty would not be able to provide a full specialised service and a very close clinical network with the relevant surgical speciality would be essential.)*
For Oncology - Neurosurgery
For BMT - none defined
Clearly the element of the oncology service at SGH meets this dependency. That at RMH does not, but within a joint centre we recognise that the recommendation can be met if there are appropriate pathways for brain tumour patients. The element of the current service that does not appear to meet this guidance is for those patients who receive neurosurgery at King's College Hospital because there is no on site oncology service present.

vi. **Amber 3** *(An integrated clinical service; Visit by consultant; paediatric specialist, or transfer of care; Timescale - available within 4 hours)*
For Oncology – Neurology; Respiratory; Nephrology
For BMT – Oncology
These are largely met. There is no direct on site nephrology at SGH but we heard that PICU carries out necessary renal support and has available nephrology support from Evelina.

vii. Within the context of this guidance we think it important to highlight the following quote (p17) – *'While links to adult specialised services are important, the inter-dependencies between specialised children's services should take precedence'.*

6. *High Dependency Care for Children – Report of an Expert Advisory Group for Department of Health 2001; Standards for the Care of Critically Ill Children, 4th Edition 2010. Paediatric Intensive Care Society.*

i. The current service at RMH does not meet the standards for children's High Dependency Care expected of any centre that admits children for in-patient care.

ii. These include a number of standards within the PICS document 'Standards for the Care of Critically Ill Children, most notably in section B1 statements 32-34, 38 and in section B3 statements 68, 70-73, 75-76.

iii. ***32 – 34*** *There should be a nominated consultant responsible for: Protocols covering the assessment and management of the critically ill child; Ensuring training of relevant medical staff; Ensuring training of clinical staff undertaking the roles covered by standards 34 and 35. This consultant should undertake regular clinical work within the area for which s/he is responsible.*

iv. *The nominated consultant (standard 32) should ensure that all relevant medical staff and clinical staff (standard 34) have appropriate, up to date paediatric resuscitation training. A clinician with up to date advanced paediatric resuscitation training should be on duty at all times.*

v. ***38.*** *There should always be at least one nurse on duty with up to date paediatric resuscitation training.*

vi. ***68.*** *There should be a nominated paediatric consultant with lead responsibility for policies and procedures relating to high dependency care.*

vii. ***70 – 73*** *There should be a nominated lead nurse with responsibility for policies and procedures relating to high dependency care. This should be a senior children's nurse with competencies and experience in providing high dependency care. There should be 24-hour on-site access to a senior nurse with intensive care skills and training. Children needing high dependency care should be cared for by a children's nurse with paediatric resuscitation training and competencies in providing high dependency care. Nurse staffing for children needing high dependency care should be 0.5:1 or 1:1 if nursed in a cubicle.*

viii. ***75-76.*** *An appropriately designed and equipped area for providing high dependency care for children of all ages should be available. Guidelines should be in use covering the type of children for whom high dependency care will normally be provided and the expected duration of high dependency care. These guidelines should specify the expected age and medical interventions (including duration of interventions).*

ix. Others may also need attention- we do not have sufficient information to judge all of them. The PICS Standards should be reviewed in conjunction with the DH HDU document, which contains additional information on training, equipment etc.

x. The panel did not include representation from paediatric anaesthesia so cannot address this area in full. The information contained within the document 'The London specialised children's services review' suggests that there is occasional practice at RMH with respect to providing anaesthesia to under 2 year olds.

7. *Additional guidance and standards*

- Safeguarding Children and Young People (RCPCH 2006) and Victoria Climbie Inquiry (Laming 2003)
- Improving services for Children in Hospital (Healthcare Commission 2007)
- Modelling the Future I (RCPCH 2007); Modelling the Future II (RCPCH 2008); Modelling the Future III (RCPCH 2009)
- Supporting Paediatric Reconfiguration: A framework for standards (RCPCH 2008)
- Defining Staffing Levels for Children's and Young People's Services' (RCN 2003)
- Guidance on the role of the consultant paediatrician in providing acute care hospital (RCPCH 2009)
- 'The London specialised children's services review' (CSL 2010)

i. We reviewed a range of additional guidance as shown above. In the main the current service meets the majority of the standards and guidance.

ii. The thrust of much of the service-related guidance is towards co-location of interdependent services and concentration of a stretched workforce. There are 2 areas to highlight, both concerned with medical workforce issues.

iii. *Standard* (RCPCH 2008)*: - There should be a named paediatric consultant on call available to attend within 30 minutes, serving only one site.*
This standard although specifically aimed at general paediatrics, is also relevant for other acute specialities such as oncology and is not met. Currently, the paediatric oncology consultants are rostered to cover both sites at RMH and SGH for out of hours, on-call availability. This is a relatively new development in response to a perceived weakness in the availability of oncology expertise and, we think, changed as a consequence of the SUI.

iv. Guidance (RCPCH 2008): - In Modelling the Future II, there is extensive comment about constraints on junior doctor rotas as a consequence of meeting the EWTD, and changing training requirements, particularly at middle grade. The conclusion is that middle grade rotas will increasingly have to be merged and alternatives developed. These include increase consultant input into acute management and enhanced roles for nurses.

v. 'The London specialised children's services review' (CSL 2010) – This summary document is currently out for consultation. The clinical expert panel publish their guidance on future commissioning of specialised children's services across North and South Thames. They highlight the

need for change based on fragmentation of services, interdependencies not being met, critical mass, and workforce and training issues – all of which are relevant to this review. Key recommendations include ending the provision of severely isolated services, ensuring that the hospitals identified to deliver specialised children's services meet all interdependencies, and ensuring that resources are used efficiently '(especially the limited highly skilled workforce)'.

B. NCAT was also asked to consider the following question

1. *NHS London would like the review panel to advise specifically on:*
   The strengths and weakness of the current collaborative model and if there any changes in the clinical or governance arrangements that should be made to strengthen this arrangement until the future model, whether the same or different can be confirmed and commissioned.

2. When initially examined, it would appear that the current collaborative model has much to commend it. The model was supported by the National Children and Young People's Improving Outcomes Guidance Advisory Group.

3. RMH is a comprehensive national and international centre of excellence focussed exclusively on the treatment and research of cancer across the entire age spectrum. It has major strengths and experience in cancer diagnosis, in overseeing cancer treatments for children and in delivering chemotherapy and radiotherapy to children. It has been a major children's cancer centre for several decades.

4. The single speciality nature of RMH combined with it's isolated geography meant that it could not provide immediate access to critical care or a range of other essential specialised services for children.

5. It was therefore recognised that RMH could not, by itself, fulfil the requirements of a comprehensive, paediatric oncology, principal treatment centre. In 2006, the current collaborative model between RMH and SGH was recommended by the London SCG in conjunction with the SE Coast SCG and associated cancer networks.

6. SGH provides a range of specialised children's services including some of those most relevant to the provision of a comprehensive paediatric oncology service such as critical care, oncology surgery and neurosurgery alongside a general paediatric service so the recommendation appeared sound.

Current Strengths

7. We (the NCAT Review Team) heard and have highlighted many of the strengths of the current model in the earlier part of this report. Essentially these include:
   - Clear aims for the joint service
   - Patients and families expressing gratitude for, and confidence in, the care they received on both sites.
   - A joint 'model of care' (2006) and joint PTC Operational Policy(2010) agreed by the Chief Executives of both organisations
   - Examples of enhanced staffing including appointment of new consultants, speciality doctors and senior nurses.

- Examples of joint working and meetings including mortality meetings; audit of PICU and retrieval; senior nurses meetings; chemotherapy meetings.
- Agreed referral pathways for suspected cancers
- Links to a robust and reliable retrieval system for sick children requiring transfer, with good outcomes
- Adoption of an early warning scoring system (PEWS) across both sites
- The general paediatric surgical services, the neurosurgical service and critical care at SGH all appear to be strengths
- Effective psychology and palliative care services across both sites.
- Support for nurse training and education
- Nationally comparable outcomes for children's cancer and bone marrow transplantation
- Integration into the excellent research environment at RMH and stated aim of being at the forefront of international paediatric oncology research
- Excellent training experience for medical trainees in paediatric oncology
- Development of new purpose built estate at RMH.

8. We were impressed by the dedication of all the clinical staff that we met, and by their commitment to providing an excellent service.

9. We also heard about the commitment of both organisations to wanting to deliver a successful comprehensive paediatric oncology service to South Thames.

Current weaknesses

10. The model far from being a two-centre model actually uses 4 centres. Children <1 year of age from South Thames continue to travel to GOS and the patients with brain tumours continue to be treated at King's College Hospital as well as SGH. There is limited direct oncology input into KCH.

11. The governance structure of the joint PTC is weak. The model of care and operational policy failed to identify the absolute need to involve both organisations' Boards within the governance structure and there appears to be a lack of recognition by the Boards of their shared responsibility for this service. As an example of this it was made clear to us by the RMH executive team that they thought they had no responsibility for the SUI at SGH that precipitated this review. We were made aware that the PTC Lead Clinician has had major concerns about the commitment of SGH to provide appropriate facilities and staffing but the structure did not seem to provide him with a clear route to the SGH executive team. An apparent consequence of this weak PTC governance structure appeared to be a reduced ability for commissioners to hold the organisations to account.

12. We think the clinical governance activity and reporting within the PTC requires significant strengthening. We have been shown a number of documents and minutes reflecting audit activity, incidents, risk management, complaints and other relevant activities. Some areas such as critical care transfers have been effectively audited and the data is robust but we were disappointed by the paucity of effective audit information provided for other important activities of the PTC. In particular we saw virtually nothing about specific patient pathways or patient experience in this regard. We were unable to determine what proportion of each pathway is delivered at either site and importantly how often care other than

critical care is transferred across sites. The joint PTC model is unusual and should have resulted in a careful examination of how it was working.

13. We were given written pathways for diagnosis and long term follow up but not for patients whilst on treatment. The on-treatment patient pathways that have evolved lack clarity, are complex, and transfers add stress and anxiety for patients and their families. The stated aims of the joint PTC model included the need to ensure safe, effective and efficient care with a positive patient and family experience and the reduction of inter-hospital transfers. The current pathways do not meet these aims. We do not think that the pathways are clear or optimal. There are groups of patients that predictably have a high possibility of emergency transfer. These groups include BMT patients (>25% transfer) and those receiving high intensity chemotherapy.

14. The current distribution of patients does not meet the recommendations of either the national 'Safe and Sustainable' guidance or those contained in the consultation paper 'The London specialised children's services review'.

15. Medical cover outside of 'normal' hours at SGH has been weak, particularly at middle grade. Much of the clinical activity takes place at RMH but the plan for a joint PTC should place the patients with highest acuity at SGH. The middle grade and out of hours medical staffing at RMH is more robust than at SGH which is somewhat perverse given that clinical problems and the need for rapid assessment are at least as likely to be needed at SGH. We are also concerned that the current system of a single paediatric oncology consultant covering two hospitals more than 30 minutes apart is sub-optimal.

16. The nursing leadership for the service needs to be developed in line with the NICE recommendations. One of the key recommendations of the NICE Guidance is the appointment of a lead nurse for the PTC. This has not happened and indeed we were given the impression that this has been actively resisted. A consequence of this is that the senior nurses are encouraged to identify with their own organisation rather than the PTC and this has led to some conflict rather than a clear joint approach. There has been a lack of any joint appointments, most notably nurse educators or clinical nurse specialists and this has exacerbated the impression of two unequal parts of this supposedly joint collaborative model.

17. We think the lack of a whole PTC policy for nurse recruitment and retention requires attention. Both sites report difficulties in this regard and the situation is likely to worsen. Imminent changes in commissioning and delivery of undergraduate nurse education are likely to lead to a significant reduction in the number of RN Children programmes. It is expected that universities running these programmes will link with major providers of children's services for clinical placements and this will strongly influence which organisations can attract and retain children's nurses with additional specialist knowledge and skills, offer better career prospects and be better placed to provide CPD for their workforce.

18. We discerned a relative hierarchical imbalance between RMH and SGH. This did not appear to be a partnership of equals. RMH was the historical provider of paediatric oncology with a strong national and international reputation and has continued to present itself as the senior, driving element of this service. It appeared to us that the paediatric oncology consultants we met ally themselves

more closely to RMH than SGH. Certainly it would appear that the Lead Clinician and consultant staff have found it easier to interact with the senior team at RMH than SGH. Our perception is that this relationship receives tacit acceptance from SGH itself, the Specialist Commissioners and many other external organisations. Our opinion is that this imbalance has contributed to the governance issues highlighted above and has meant that SGH may not have given the paediatric oncology service the level of attention it has required.

19. There are some areas of the critical care outreach service and cover arrangements at RMH that require strengthening. Although there are a number of anaesthetists who regularly anaesthetise children, the on call system can result in an acutely ill child being managed by an anaesthetist who does not have a regular paediatric practice. There remains at least a theoretical risk that some patients who deteriorate rapidly may have to be transferred by such an anaesthetist. There is no designated high dependency area for children at RMH, and no medical or nursing lead for high dependency care for children.

20. Although we are not in a position to make a strong statement about the financial impact of a joint PTC approach it appears evident to us, supported by an extensive evidence base, that a multi-site model will be less cost-effective than a single site model. We recognise this contention may require a separate evaluation.

Summary

21. The current collaborative model has significant strengths but these are accompanied by significant weaknesses and the service fails to meet some of the standards and recommendations that we were asked to consider within the Terms of Reference.

22. There is an urgent requirement in the short term to:
    - restructure and strengthen the governance arrangements
    - reconfigure patient pathways to better meet the clinical needs and reduce emergency transfers
    - describe these pathways for patients and families, and
    - address some of the staffing issues including the appointment of a Lead Nurse for the PTC with a clear remit for the whole service.
    - ensure that all staff have up to date training in resuscitation and Child Protection
    - enhance the delivery of high dependency care to children at RMH

23. In the longer term we think that the current service disposition will require significant change to meet the recommendations of the ‘Safe and Sustainable’ programme and provide a more secure and improved future for this service.

SECTION III: Discussion, Options, Conclusions and Recommendations

1. RMH is a specialist cancer Trust with an excellent national and international reputation for both service and research. Despite having an established paediatric oncology service on it’s Sutton site since the emergence of the speciality over 30 years ago, it was recognised a number of years ago that the

isolated and specialist nature of the hospital precluded the provision of a comprehensive service for children on that site.

2. The decision to develop a collaborative model with SGH was entirely logical and provided a good fit of complementary services. There has been considerable effort by both provider organisations and commissioners in trying to make this work.

3. Outcome measures for children's cancer and bone marrow transplantation survival are at least as good as national comparators. Patients and family have confidence in the service although they reported some anxieties to us as we have described earlier.

4. The incidents that occurred in December 2009 and June 2010 highlighted that all was not well with the service and the investigation identified a number of workforce issues as root causes and the consequent need for additional training.. An action plan was developed and enacted as a result. Whilst we recognise the relevance of these issues, in our view there are additional factors which have weakened the collaborative model from its inception and that we identify in the previous section of this report.

5. As a consequence of these incidents, root cause analysis and action plan, one action was to downgrade the role of SGH in providing some elements of the PTC role and temporarily re-provide these either at RMH or at alternative shared care centres. This action is not sustainable for anything other than the very short term. The whole reason behind the development of the RMH/SGH collaborative model was the recognition that RMH alone could not provide a comprehensive service in the future. Neither would it meet the requirements of NICE Improving Outcomes Guidance for Children's Cancer, the DH 'Safe and Sustainable' recommendations or the London specialised children's services review.

6. In the short to medium term we see little alternative but to re-establish and strengthen the current joint collaborative model between RMH and SGH. This will require commitment from both organisations and commissioners to address the most obvious problems. Our recommendations are in the penultimate section.

7. Looking further ahead, beyond 2 years, then there is the potential to re-configure the paediatric oncology service in order to make it safer and more predictable for patients and create a more sustainable workforce for the future. This will also be necessary if the aim of repatriating infants <1 year to South Thames is to be achieved. We have considered a series of options for the South Thames paediatric oncology service.

Options

8. **Short to medium term** (1-2 years)
    1) A strengthened 2-site joint collaborative model between RMH and SGH. Realistically we don't think there is any viable alternative in this time scale. Our recommendations about achieving this are below.

9. **Medium to long term** (2+ years)

There are a series of theoretical options

1) A stand-alone service on the RMH Sutton site.

2) Status Quo. A 2-site model between RMH/SGH as currently (although recognising that a significant proportion of neurosurgery is at KCH and infants at GOS)

3) Enhanced 2-site model between RMH/SGH taking into account recommendations of this report and changes to intensive pathways/BMT.

4) Alternative enhanced 2-site model. As for Option 3) but with an alternative partner. Guys/ Evelina has been proposed

5) A stand-alone service on the site of a major provider of children's specialist services at the South Thames children's hub fully compliant with all guidance.

10. We have just included Option 1 for completeness and to dismiss it. It would require putting a comprehensive children's service, including PICU, onto the Sutton site. We are aware that this option has been considered in the past and found to be non-viable.

11. We also think that Option 2 would be a poor outcome of this process and we do not advise it. Although it is called a 2-site model in reality it is 4 site with GOS and KCH providing significant elements of the service. We do think that this model needs significant enhancement and change in the short to medium term and our recommendations for this are in the section below.

12. In addition we think it illogical to continue to provide neurosurgical services for children's brain and spinal tumours on more than 1 site in the area in the light of the impending national review of paediatric neurosurgery and because of the difficulty in meeting the recommendations for co-location of neurosurgery and oncology in the 'safe and sustainable' 2008 document. This element of the service would benefit from complete co-location with paediatric oncology.

13. Options 3 and 4 both envisage the continuation of a 2-site model, option 3 with SGH or option 4 with an alternative provider. We have received a paper suggesting that it may be more appropriate to link RMH with Evelina Children's Hospital at Guys Hospital rather than SGH but we have not been asked to assess this proposal and we don't feel able to comment on the specifics of this proposition.

14. We do think we can comment on the generality of an enhanced 2-site solution whichever the alternative provider. Any solution should be entirely in line with the 'Safe and Sustainable' programme and the London tertiary children's services review. In our view this means that at the very least there should be a major change to the elements of this service that can be provided from the RMH Sutton site.

15. Children receiving intensive treatments who predictably may require critical care intervention should **not** be managed at an isolated site but must be on the site a major hub. This includes patients with AML, high-grade non-Hodgkin's lymphoma and other dose intensive therapies. It also includes patients having allogeneic and autologous stem cell treatments. Despite the RMH BMT service receiving JACIE accreditation for children (as well as adults) we have not seen any

response from RMH to the query about critical care for children in the original JACIE inspection report. We are clear that the current service does not meet the recommendations of the DH best practice guidance '*Commissioning Safe and Sustainable Tertiary Paediatric Services - A Framework of Critical Inter-Dependencies' (2008)*

16. Both options 3 and 4 imply that much more of the inpatient activity of the paediatric oncology service would be provided where comprehensive children's services are sited, either SGH or an alternative. This should mean much less risk of emergency transfer, better experience for patients and families and in the longer term better outcomes. It would mean that any partner Trust would have to invest in additional staffing and facilities including establishing a BMT service and would undoubtedly be a major operational and cultural challenge.

17. These 2 options also imply the continuation of relatively low intensity inpatient activity on the Sutton site as well as day care and outpatient services. It would be reasonable to continue with treatments that could be given in a level 3 shared-care unit. The advantage of this approach would be the maintenance of direct links with RMH, with its research base, and continuing to use the impressive inpatient facilities designed for children. There would be direct links and vertical integration with the teenage and young adult service. The disadvantages include the need to continue to provide significant paediatric oncology expertise at 2 major sites some distance apart. It will still mean that some patients will require emergency transfer even though this is likely to be infrequent. There will be considerable ongoing workforce issues because of having to have equitable services on 2 sites. We think these options are likely to be less financially viable.

18. Option 5 is to centralise all paediatric oncology in-patient activity on a site co-located with other tertiary paediatric services including PICU, paediatric surgery, paediatric anaesthesia and paediatric neurosurgery. Less essential but highly desirable services would include respiratory, cardiology, nephrology, neurology, immunology and infectious diseases. Many other paediatric oncology services in the UK have moved towards, and achieved this co-location over the past decade.

19. The advantages of this approach are fairly obvious. The service would meet all guidance, would maximise the use of scarce workforce resources and is likely to be the most financially viable. The challenges are not inconsiderable and we do not underestimate the operational and estate challenges of re-providing a considerable resource onto a new site.

20. It is likely that even with this option RMH will continue to provide some elements of this service from the Sutton site for the foreseeable future. This includes radiotherapy for children, some outpatient and day care services and a more comprehensive service for teenagers and young adults. However even these are not immutable. The recent decision to site one of the 2 national proton therapy centres in North Thames means that there is likely to be a reduction in radiotherapy for children and young people at Sutton so this may offer a further opportunity to reconsider how children's radiotherapy can be provided.

21. Services elsewhere in the UK have found it difficult to maintain outpatients and day care activity on a site distant to the major inpatient activity so it would be appropriate to consider concentrating the whole of the PTC activity onto a single site.

22. In reaching our conclusions and recommendations we have been particularly exercised by the implication that the service may be divorced from RMH. We are only too aware of the commitment shown by the RMH Board and the Institute of Cancer Research to both service and research for children's cancer. The facilities are excellent and will be difficult to reproduce elsewhere. The environment for research is probably unparalleled in the UK. It is an institution that values, demonstrates and attracts excellence. Despite that our view is that provision of intensive inpatient specialised cancer services for children on this isolated site will not meet recommended standards and that commissioners and providers should develop viable alternative model(s).

23. We were very interested in the franchise models that RMH has adopted in conjunction with Kingston Hospital for service and Mount Vernon for research. We think this franchise model should be actively explored and promoted for the children's cancer service. We do not underestimate the challenges of this proposal but we were encouraged to hear from the SGH Chief Executive that he would consider any model that delivered excellence in a collaborative model. We hope this would also apply to any potential partner and we would encourage commissioners and all parties to explore this possibility. We think the RMH@ model offers the best prospect of a modern, safe and sustainable comprehensive service, with a very strong international research profile but clearly the success of this approach would be dependent on the strong commitment of both the RMH and partner organisation Boards.

Conclusions

24. Despite excellent clinical outcomes, a strong research ethos and excellent facilities, it is not feasible to consider providing a comprehensive single site paediatric oncology service at the RMH Sutton site.

25. The current collaborative model between RMH and SGH was developed to meet the clinical necessity of providing children with cancer appropriate access to critical care and a range of other essential specialised services, and to meet the recommendations of national guidance.

26. Following recent clinical incidents, it has become clear that notwithstanding some considerable strengths in this collaboration there are a number of areas that are weak and require considerable attention and development. These include the joint governance framework, patient pathway development, high-dependency care provision at RMH, joint nursing appointments, and strengthened out-of-hours medical cover.

27. We recommend a number of actions that need to be taken in the short to medium term to strengthen these areas whilst maintaining the current collaborative SGH / RMH model. These will require considerable clinical leadership and commitment and joint working between the 2 partner organisations and commissioners.

28. 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' recommendations. The site of this hub will be dependent on future decisions made by commissioners in the light of the London children's specialised services review. Commissioners would need to evaluate the level of investment required, not least to meet the same high standard of accommodation that currently exists on the RMH site.

29. We think that there would be considerable advantage in the paediatric oncology service continuing to be organisationally linked to RMH through a RMH@ model. This would have the advantage of maintaining the long-term relationship with the RMH Trust as a specialist cancer organisation with a sustained expertise in children's cancer, promote an integrated teenage and young adult service, and continue to promote links to the internationally outstanding research infrastructure of the Institute for Cancer Research.

30. If the total re-provision is deemed not feasible then an option of an enhanced 2-site solution could be considered but whilst this would improve the current situation, many existing problems would remain.

Recommendations

Short to medium term (immediate to 2 years)
It is clear to us that the issues we have identified below require urgent action. In particular there is need to:

31. Strengthen the governance arrangements for the Joint PTC so that there is Board engagement from both organisations in overseeing this service with clear lines of accountability for the Lead Clinician and Lead Nurse and defined access to Executive level.

32. Re-configure patient pathways to better meet the clinical needs and reduce emergency transfers. In the short term, particular attention should be paid to those pathways that include intensive treatments and prolonged hospitalisation such as AML.

33. In the medium to long term the whole provision of Bone Marrow Transplantation for children in South Thames requires rethinking. Bone marrow transplantation for children should be on a site that can offer immediate critical care support as set out in 'Safe and Sustainable'.

34. The clinical pathways need to be clearly described so that they are understandable to staff, patients, and families and can be subject to rigorous assessment and audit.

35. Improve the depth and quality of audit of the service. In particular audit of care pathways and service delivery across different sites; capturing numbers and reasons for all transfers, and patient experience.

36. Develop a written policy for children who require ward to ward transfer from RMH to SGH or Kings. This should, as a minimum, cover the personnel undertaking

these transfers (including when a medical escort be included), what training / competencies staff undertaking transfers should possess, what monitoring and documentation should occur during the transfer, and standardisation of the handover process.

37. Appoint a Lead Nurse for the whole PTC. We view the role of Lead Nurse for the PTC as essential in order to ensure quality and equity across the service. Alongside this appointment we strongly recommend the appointment to the whole PTC of clinical educators and clinical nurse specialists. We also recommend the development of fixed rotations of ward nursing staff between RMH and SGH.

38. Out-of-hours medical cover for the service at middle grade and consultant level needs to be strengthened. We heard that there were plans to continue to extend out of hours consultant presence at SGH as a way of providing more senior input. This is undoubtedly an important improvement measure but needs to be increased to 7 days per week. We also think that if the pathways are re-configured to further reduce the number of high acuity patients at RMH then there will be an opportunity to assess whether the current RMH middle grade staff and out of hours rota can be re-designed to support the service at SGH. This may also lend itself to alternative models such as a Hospital at Night system at RMH run by senior nurses and consultants.

39. Review the anaesthetic and critical care provision at RMH for children. This should include an Association of Paediatric Anaesthetists peer review of paediatric anaesthesia services at RMH with the specific remit to comment on apparent occasional practice for anaesthesia to <2 year olds and the out of hours provision of primary ‘time critical’ transfers by consultant anaesthetists. We would recommend establishing a separate ‘paediatric’ anaesthesia consultant out of hours rota – to ensure that acute stabilisation and primary transfer can be undertaken by someone who regularly anaesthetises children.

40. Ensure that RMH meets the High Dependency Care requirements set out in the DOH 2001 High Dependency Care document and the HDC sections in the PICS Standards for Care of the Critically Ill Child. Ensure that all medical staff (RMH and SGH, consultants and middle grades) have up to date BLS and APLS (or equivalent) training.

41. Initiate a training plan that will develop a group of RMH nurses who have training in high dependency care for children SGH/RMH rotations will aid this. In the medium term aim to have a nurse on every shift with high dependency competencies.

42. Establish a designated high dependency care area for children on the ward at RMH; identify a designated senior nurse for high dependency care and a designated RMH consultant to be responsible for high dependency care. In the medium term identify or develop a lead consultant who achieves the competencies set out in the RCPCH special study module ‘Consultant Paediatrician with special expertise in High Dependency Care’.

Medium to Long term (>2 years)

43. Develop a long term sustainable model by co-locating the Principal Treatment Centre for paediatric oncology in South Thames onto a single site which also provides all other essential specialised paediatric services, the most important of which are critical care, paediatric surgery and neurosurgery.

44. To explore whether this sustainable model can be organised under the direction of the Royal Marsden Hospital using an 'RMH@' model and maintaining links with the institute for Cancer Research. If the total re-provision is deemed not feasible then an option of an enhanced 2-site solution could be considered but whilst this would improve the current situation, many existing problems would remain.