

Children's Cancer Services: A review on behalf of NHS England 2019/20

Professor Sir Mike Richards, 20th January 2020

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1. Summary

This review was commissioned by the Chief Executive of NHS England to assist its Board in the evaluation of responses to a consultation undertaken in summer 2019 relating to a new draft service specification for children's cancers. The central issue I was asked to consider was whether or not co-location of a Principal Treatment Centre (PTC) for children's cancer with a level 3 Paediatric Intensive Care Unit (PICU) on the same site should be a mandatory requirement for an NHS England commissioned PTC.

I have reviewed all the consultation responses and I have looked back at previous reports and guidance pertinent to this issue [Annex A]. I have also visited relevant trusts in London and Bristol (as an example of an integrated service). During the course of the review I have spoken to a wide range of parents, charities, service managers, academics and clinical experts.

Whilst no serious incidents related to two site working have been recorded in recent years, my conclusion in response to the central issue is that from now on all PTCs must be co-located with a PICU and other specialised children's services. This is of particular importance for children receiving treatments for which there is a significant risk of requiring PICU care (say greater than 5%) and will increasingly be an issue. For example, CAR T therapy (which carries a risk of needing PICU of around 50%), bone marrow transplantation and a range of other treatments carry risks of needing PICU greater than 5%. Some chemotherapy treatments and radiotherapy carry a risk significantly below 5% of requiring PICU. These can, in my view, be safely given on sites without PICU as long as clear arrangements are in place for transferring patients safely on the rare occasions when this is necessary. Indeed, this is the current arrangement in place for Paediatric Oncology Shared Care Units (POSCUs) and some radiotherapy services.

I recognise that my recommendations have implications for some services and, in particular, for services provided at the Royal Marsden and St George's. The services

provided at the Royal Marsden site in Sutton are highly regarded, but the joint PTC arrangements, and crucially the lack of a co-located level 3 PICU presents an inherent geographical risk to patient safety. This risk can only ever be partially mitigated. Separation of services impacts significantly adversely on patient experience and places an additional burden on staff as well as being inefficient and costly. Looking forwards, the safe delivery of complex new and intensive therapies will simply not be possible under current arrangements. Indeed, one of this country's PTCs could find itself having to rule itself out of delivering some of the most innovative treatments.

I therefore firmly believe that the time is now right to grasp the nettle on this. It is not within my remit to make a firm recommendation in favour of a specific location for a PTC, but I do believe a decision should be made without undue delay. I have, therefore, made some suggestions on how this should be taken forward. Whatever configuration is decided upon, it must be able to deliver a world class service for children with cancer.

2. Background to this review

This review has been undertaken at the request of NHS England and was announced by the Chief executive on 25th June 2019, with a commitment to present the findings to the Board of NHS England in January 2020.

The central issue under consideration is whether a Principal treatment Centre (PTC) for children with cancer 'must' or 'should' be co-located with a paediatric intensive care unit (PICU). Work on revising the specifications for children's cancer services has been led by the specialist commissioning team in NHS England (who commission children's cancer services), informed by a Clinical Reference Group (CRG), chaired by Professor Rachael Hough. This involved NHS England's standard three phase process of engagement with patients and their families, clinicians and service providers in autumn 2017, followed by stakeholder testing and public consultation. The formal consultation on the draft service specification concluded in August 2019. The responses to that consultation form a key element of this review.

The consultation related both to children's cancer services and to those for teenagers and young adults (TYA). However, the current review focuses exclusively on children's cancer services and in particular to Principal Treatment Centre (PTC) services. During the course of the review I heard views about networks and Paediatric Oncology shared Care Units (POSCUs), but I have not undertaken detailed assessments of these elements of the consultation.

I am extremely grateful to the large number of people who have contributed to this review and especially to Professor Hough and the CRG. However, the conclusions are my own.

3. Approach taken to this review

The approach taken for this review has comprised:

- A brief review of the epidemiology of children's cancers in the UK and to the provision of services across England.
- A review of previous reports relating to co-location of children's cancer services.
- A review of the responses to the 2019 consultation on the service specification.
- A meeting with members of the Children's and Young People's (CYP) Clinical Reference Group.
- Other meetings or teleconferences with parents, clinicians, charities, professional groups and national and regional specialist commissioners.
- Visits to six NHS trusts providing elements of specialised children's services in London including discussions with parents, senior managers and clinicians at each location and to the Bristol Royal Hospital for Children.

4. Epidemiology of children's cancers and current service provision

A useful summary of key facts about children's cancers was set out in the Consultation Guide, as follows:

- It is rare – around 1,600 children under the age of 15 are diagnosed with cancer each year in the UK.
- Most cancers affecting children are different to those affecting adults – they occur in different parts of the body; they are biologically different and they respond differently to treatments.
- Treatment can be complex and intensive.
- Approximately two thirds of children receive treatment as part of a clinical trial.
- Cure rates in children with cancer are much higher than for adults with cancer, with more than 80% of children surviving their cancer for 10 years or more (Cancer Research UK).
- Over the previous 15 years, although cancer survival rates are higher than they have ever been in children and are broadly in line with those of other developed countries, they still fall behind those with the highest survival such as Germany and Canada (Bonaventure et al 2017).
- Outcomes can still be improved, specifically in terms of preventing cancer, getting a quicker diagnosis and giving all those with cancer better treatment and care (NHS Five Year Forward View, NHS England, 2014).
- Despite clinical trial recruitment rates being high for children, it is estimated that only around 40% of tumour tissue is banked to support future research studies.

An analysis by Public Health England [Annex B] shows that between 2001 and 2015 an average of 1420 cases of cancer in children under 15 years were diagnosed in England each year. Acute leukaemia is the commonest cancer in children (31% of

cases pa) followed by brain/central nervous system tumours (25%) and lymphomas (10%).

Children with cancer currently receive care primarily from a Principal Treatment Centre (PTC), which provides specialist care and holds overall responsibility for cancer diagnosis, treatment and management. PTCs work in partnership with Paediatric Oncology Shared Care Units (POSCUs), which provide supportive care and shared care closer to a patient's home. Together, a PTC and its associated POSCUs are referred to as a Children's cancer Network. The new service specification seeks to replace the current network groups with more formal operational delivery networks.

There are currently 13 children's cancer PTCs and 80 POSCUs in England [Annex C]. Three of the PTCs are designated jointly - Royal Marsden and St George's; Great Ormond Street Hospital (GOSH) and University College London Hospitals (UCLH) and Leicester and Nottingham. Both Leicester and Nottingham have dedicated paediatric intensive care units (PICUs), whereas there are no on-site PICUs at The Royal Marsden or at UCLH.

5. Development of the new service specification (2017)

Development of the new service specification was led by NHS England's Children's and Young People's Cancer Clinical Reference Group, which includes representatives of relevant professional groups, charities and a parent representative. The stated aim of the service review was to improve access to excellent care for all children and young people with cancer across England, by improving outcomes and patient experience, while ensuring equitable access to high quality services.

Seven workstreams were established in January 2017, thereby bringing together a broad range of experts from across the country. These workstreams covered

- Incidence and outcomes
- Patient experience/holistic care
- Paediatric cancer services
- Teenage and Young Adult (TYA) services
- Tumour banking and clinical trials
- Follow up
- Assessment of quality

The key recommendations for changes to the service specifications were then taken to a series of stakeholder events including teleconferences, face to face meetings and two Facebook live events with patients and parents. This was followed by stakeholder testing in May 2018 and formal consultation beginning in June 2019.

6. Responses to the consultation on the service specifications (2019) and comments received during meetings and visits.

A total of 139 responses to the consultation were received by NHS England

6.1. General themes

- Children's operational Delivery Networks were overwhelmingly supported.
- Proposals to help improve participation in clinical trials were overwhelmingly supported, as were proposals to increase tumour banking.
- Shared care – there was broad support for simplifying and standardising shared care arrangements, but greater clarity was requested on this.
- Quality measures – several respondents wished to see more quality indicators included in the service specifications. Examples included indicators for emergency transfer from POSCU to PTC and measures of patient experience.

6.2. Co-location of services/PICU

The draft specification that went out for consultation in June 2019 stated that “the default position is that the following clinical services should be delivered on site at every PTC... The list included paediatric critical care (level 3).

However, the near unanimous view expressed by national organisations with an interest in children's cancers and from individuals or organisations based outside London was that PTCs must be co-located with a PICU. These respondents included

- The Children's Cancer and Leukaemia Group (CCLG)
- CLIC Sargent
- Teenage Cancer Trust
- Anthony Nolan Trust
- Children's and Young People's Cancer Coalition
- Royal College of Nursing.
- Children's Hospital Alliance
- Several trusts/ individuals.

The reasons given for this, which I also heard during my visits and additional meetings can be summarised as follows:

- Parent and patient experience: The diagnosis of a cancer in a child causes extreme anxiety both for the child and the parents. Treatment is often intensive and prolonged, requiring multiple hospital visits and admissions. I have been repeatedly told that having to get to know new members of staff at multiple different locations especially at a time of a crisis adds to anxiety and distress.

- Close working between paediatric oncologists and intensivists is a core element of an effective children's cancer service. Co-location facilitates timely discussions about complex treatment and care decisions.
- If a PTC and PICU are co-located children can often avoid admissions to PICU. Intensivists can visit the child 2 or 3 times a day to monitor progress. Equally, should a child require admission to a PICU, staff whom they know from the ward can visit them daily to provide much needed reassurance and continuity of support.
- Children with cancer frequently need advice and care from other paediatric specialties such as gastroenterology, respiratory, renal, cardiac and infectious diseases. These are almost invariably aligned with a PICU.

Several people pointed out to me that Level 3 POSCUs have to be co-located with a High Dependency Unit (HDU) for children. It was therefore illogical for a PTC giving more intensive treatments not to have to meet at least this requirement.

Many people also commented that the importance of co-location was likely to be even stronger in future as more intensive therapies such as CAR T cell therapy become more widespread.

Responses from within London were more varied especially those from South London. The response from the Royal Marsden was very positive about the care given on the Sutton site and emphasised that there had been no serious incidents relating to the transfer of paediatric patients between the Royal Marsden and St George's. Key to this is the commitment at the Royal Marsden to identifying deteriorating children at as early a stage as possible.

In contrast, the response from St George's stated that the joint arrangement with the Royal Marsden was by no means ideal with multiple hand offs. It also made clear that this takes a great deal of administration and leads to inefficiencies as well as poorer experience for children and their families. The paediatricians from St George's made it clear that they believe co-location is the right option for their patients even if it means that ultimately St George's is not able to retain these services.

I also heard from some clinicians who had worked at the Royal Marsden that concerns about the joint PTC arrangement was one of the factors that had led them to leave or not to apply for consultant posts there.

Other collective responses from South Thames (e.g. from the Children's Cancer Network) recognised that the current configuration was not 'ideal' but that co-location would require 'significant capital expenditure which has not to date been identified by commissioners'.

The joint response from Guy's, St Thomas' and King's emphasised that a range of services including critical care must be co-located on site with the PTC and that 'readily available' is not an adequate or auditable definition of clinical accessibility.

The response from GOSH/UCLH in North London was also nuanced. It stated “to offer children evidence based, high quality and safe treatment we believe that centres treating any of the childhood cancers known to have a high likelihood of requiring ITU must provide age-appropriate ITU care. For example, 50% of patients requiring CAR T cell therapy require ITU. This is likely to apply to other novel therapies. Similarly, PTCs must offer rapid access to the paediatric services needed to support their care. For example, we strongly believe that all PTCs treating children with brain tumours must have rapid access to emergency paediatric neurosurgery e.g. for management of ventricular- peritoneal shunts.”

7. Findings from visits undertaken for this review

As concerns regarding co-location of PTC and PICU services are confined to London, the visits undertaken for this review were almost exclusively undertaken in London. However, I also visited Bristol to see a service which I had been informed was very well integrated.

I therefore visited the following sites:

- Great Ormond Street Hospital (GOSH)
- University College London Hospitals (UCLH)
- Royal Marsden Hospital (Sutton)
- St George’s Hospital
- King’s College Hospital
- Evelina London Children’s Hospital (part of Guy’s and St Thomas’ NHS Foundation Trust)
- Bristol Children’s Hospital

At each site I met with senior management, clinicians/academics and parents/children. I also visited the children’s facilities. I was also provided with information on children’s services at each site.

7.1. GOSH/UCLH joint PTC

GOSH and UCLH are jointly designated as the PTC for North London/North Thames. They provide integrated services for patients aged 0-25 years, with a total of around 400 new patients per annum across the full age range. The two sites are 1.3 miles apart.

The PTC has joint leadership and a joint strategy and 6 joint multidisciplinary teams (neuro-oncology, general paediatric oncology, lymphoma, leukaemia, sarcoma and bone marrow transplantation) which meet regularly. Importantly, the two trusts have the same IT systems (EPIC and BEACON for chemotherapy) and clinicians on one site can see the records from the other site.

The allocation of patients between the two sites is based on risk stratification in terms of likelihood of requiring intensive care facilities. GOSH cares for the large majority of patients under the age of 13 years, including all children under one year (for North and South Thames), including CAR T therapy for this age group. Exceptions to this are a small number of patients under 13 years with Hodgkin’s

lymphoma, bone sarcomas and some germ cell tumours, for which there is extensive diagnostic and clinical expertise at UCLH. UCLH cares for all haemato-oncology patients 13 years and above and provides CAR T therapy for this age group. UCLH is a supra-regional provider of bone sarcoma services and is the largest provider of radiotherapy services for CYP in the UK. This includes radio-isotope treatments and will in future include proton beam therapy (along with the Christie Hospital in Manchester).

GOSH is the largest specialist children's hospital in England, with a wide range of specialised children's services including a PICU and neurosurgery. It does not, however, have an A&E department. Referrals are therefore almost exclusively from other hospital in the UK and internationally. Facilities for children's cancer are acknowledged to be in need of a major rebuild to make them fit for purpose. GOSH has plans to build a new children's cancer centre, largely funded through charitable sources (at a cost of over £250 m). This is planned to provide a total of 80 dedicated beds for children's cancer, including 16 PICU beds. Building is likely to take at least 5 years.

UCLH is a major teaching hospital with adult and children's A&E facilities and general paediatric services in addition to the specialist cancer services. If children require PICU they are stabilised and transferred to GOSH. Transfers of children with cancer to GOSH are rare (total 1-2 pa) and almost exclusively relate to children undergoing radiotherapy who require urgent neurosurgical interventions. UCLH is also a major provider of adolescent services (both for cancer and other conditions). Patients aged 13 years and over who need intensive care are cared for on the adult ICU at UCLH, but almost exclusively in single rooms.

It is important to note that the wording of the new service specification allows for some flexibility in the definition of the age boundaries for patients, as follows:

"It is acknowledged that, in some networks, age criteria may vary and there may be some flexibility in age boundaries of services to enable patients to access optimum disease and age appropriate services. Under network arrangements, and in conjunction with the teenage and young adult (TYA) cancer service, it may therefore be appropriate for a children's cancer PTC to treat people up to their 19th birthday. It may also be appropriate for a TYA cancer PTC to treat people aged 13 years and above, in line with the TYA cancer service specification."

There are therefore some minor anomalies in relation to patients under the age of 13 who are treated on the UCLH site without immediate access to PICU. However, because of the risk stratification undertaken across the joint PTC these patients are most unlikely to require PICU.

I am also aware that surgery for bone sarcomas in children is undertaken by the Royal National Orthopaedic Hospital (RNOH) at Stanmore, which does not have a PICU. This is a supra-regional service. I was unable to visit RNOH for this review, but my understanding is that these patients rarely if ever require PICU.

Similarly, I understand that some treatment for retinoblastoma is undertaken at the Royal London Hospital. This appears anomalous, but I was unable to visit that site.

7.2. Royal Marsden Hospital and St George's Hospital joint PTC

The Royal Marsden Hospital (RMH) and St George's were designated as a joint PTC for children's cancer in 2006. The joint PTC serves both South London and most of Kent, Surrey and Sussex. The two sites are around 8 miles apart. RMH has been rated Good for children's services by CQC, while St George's has recently been rated Outstanding for paediatrics.

RMH is exclusively a specialist cancer hospital and has two sites (Chelsea and Sutton). The RMH children's cancer services are provided on the Sutton site. This does not have an A&E, general paediatric services or a PICU or High Dependency Unit (HDU) for children. RMH does, however, have excellent facilities for the elective care of children with cancer including the 31 bedded Oak Centre, which was opened in 2011. Over 11,000 episodes of care for children are provided on this site each year (5,600 chemotherapy or day care; 4,700 outpatients, 1000 radiotherapy attendances and 600 inpatient stays). The Sutton hospital site is adjacent to the Drug Development Unit of the Institute for Cancer research (ICR). RMH is the second largest provider of children's radiotherapy services after UCLH.

St George's is a large teaching hospital, with A&E (adults and children), a major trauma centre, general paediatric services and a range of specialist children's services (including respiratory, gastroenterology, diabetes, infectious diseases, haematology, dermatology and neurology). St George's undertakes around one third of the paediatric neurosurgery for South Thames and provides paediatric surgery services including outreach services to RMH.

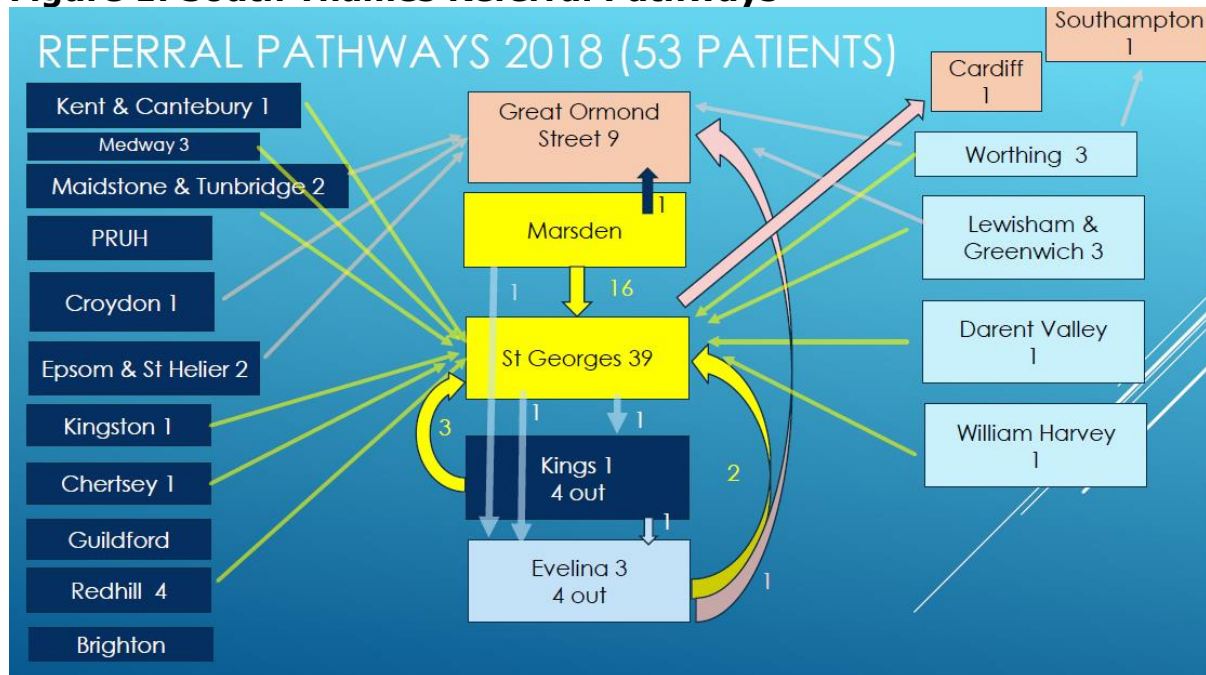
Excluding neonatal facilities, St George's has three paediatric wards (total 51 beds), a PICU (10 ICU beds 5 HDU beds) and a day case unit. One of the three wards is predominantly for surgical patients, one for general paediatrics and the third for oncology and infectious diseases. The facilities for children at St George's are cramped and need upgrading.

In relation to children's cancer, St George's provides PICU services for the joint PTC (typically 0-2 patients at any one time) and is a level 1 POSCU. They also have 4 designated "PTC" beds on the oncology ward. I was told that these were used for patients who were too sick to be at RMH but did not require ventilation/PICU.

Patients being treated electively at RMH whose condition deteriorates are transferred to St George's for PICU. The RMH has a low threshold for transfer to maintain safety, which means that some patients who might not need PICU in other PTCs are transferred. Between 2016 and 2018 this averaged around 12 patients pa.

A rather larger number of paediatric oncology patients were admitted to St George's PICU or to the 4 designated PTC beds from POSCUs in the region. The PICU admissions transferred by the South Thames Retrieval Service (STRS) are shown in **Figure 1**. This shows the complexity of movements between hospitals in South Thames.

Figure 1: South Thames Referral Pathways



Source: South Thames Retrieval Service

These figures do not provide a full picture of the ‘shuttling’ of patients between the two PTC sites. I heard from clinicians and parents that only a small number of patients are treated at RMH alone, with many receiving different aspects of care (including surgery for intravenous lines and other procedures) at St George’s because these are not available at all times they are needed at RMH. One parent who lives between the two sites told me that he takes his daughter to St George’s when she is acutely unwell and he is worried for her safety, but to RMH on other occasions as she prefers it there.

Staff at both sites work hard to maintain patient safety, but this requires additional time, effort and strain. It is also inefficient in use of resources. No serious incidents related to two site working have been recorded in recent years, though several clinicians I spoke to believe that the current arrangements present an increased risk.

Survival outcomes are reported by RMH to be comparable to those in other PTCs. The figures are not adjusted for the fact that RMH/St George’s do not take children under one year of age (for whom outcomes are generally poorer) or for the fact that some other patients have to be referred to other PTCs (e.g. GOSH) if they are acutely ill at presentation.

Patient experience at RMH is undoubtedly good, but no surveys of patient experience had been undertaken across the two sites. Increased anxiety and poor experience due to ‘shuttling’ and seeing different clinicians at the two sites was reported to me by some parents I met.

7.3. King's College Hospital

King's is a large teaching hospital in South London with a busy A&E (adult and children) and a major trauma centre. The Variety Children's Hospital on the Denmark Hill site has around 85 beds (excluding neonatal cots). There are 16 'PICU' beds (8 level 2 and 8 level 3). King's provides a range of specialist children's services including respiratory, gastroenterology, epilepsy, allergy and non-malignant haematology (including sickle cell disease).

In relation to paediatric cancer, King's provides paediatric neurosurgery (around 50 cases pa or two thirds of the South Thames workload), paediatric liver surgery (a supra-regional service) and level 2 POSCU services. Over the past 6 years King's has seen an average of 31 new children with cancer each year. King's currently has 74 active paediatric cancer patients, accounting for around 1000 inpatient bed days, and administers around 170 outpatient chemotherapies pa. On rare occasions King's also administers inpatient chemotherapy to patients who require to be on PICU (with agreement from RMH and commissioners).

7.4. Evelina London Children's Hospital

The Evelina London Children's Hospital forms part of the Guy's and St Thomas' NHS Foundation Trust. It is the second largest children's hospital in London (after GOSH) and the largest south of the River Thames. It has 215 beds including 30 intensive care beds (PICU) and a kidney dialysis unit as well as six dedicated children's operating theatres and a 52-cot neonatal unit and two community health centres for children and young people in Lambeth and Southwark. It has a turnover of around £233m pa. Facilities are modern, with proposals for expansion to take on children currently managed by Royal Brompton Hospital.

Evelina carries out more than 107,000 outpatient appointments annually (32,000 new patients; 75,000 follow ups) and over 6,300 patients are admitted pa. In addition, around 20,000 children and young people attend for a planned investigation, treatment or operation each year.

Evelina provides both general paediatric services (including A&E and general surgery) and over 30 specialist children's services including respiratory, infectious diseases, haematology, neurology and deep brain stimulation neurosurgery, cardiology and cardiac surgery, nephrology, urology, gastroenterology, ENT and complex airways management, imaging, pain management, neurorehabilitation and palliative care. However, Evelina does not currently provide any oncology services.

Evelina hosts the South Thames Retrieval service (STRS), which takes 1700 calls for advice and undertakes 900 transfers annually.

7.5. Bristol Royal Children's hospital

I visited the Bristol PTC as an example of a service which has almost all services required by children with cancer on one site, though some patients with bone tumours and liver tumours have to be referred elsewhere as do those requiring proton beam therapy and

CAR T therapies. I met a wide range of doctors, nurses, therapists and managers who were all highly positive about the advantages of co-location with PICU and other paediatric services. I was told that the re-location of paediatric neurosurgery from North Bristol to the children's hospital site had made a 'massive' difference to the delivery of integrated care. Several staff told me specifically that they would not work on a site without a PICU. They were also very positive about the close proximity to the radiotherapy department and to adolescent and young adult services.

Clinicians at the Bristol PTC also work very closely with their colleagues in POSCUs across the South West Region, staff from Bristol regularly attending clinics at each POSCU. This was achievable through having only a limited number of POSCUs. It also meant that more children could be safely looked after closer to their homes. I joined a teleconference with the POSCU leads who were also very positive about the close partnership working.

8. Conclusions relating to co-location of services

An overwhelming majority of clinical experts and parents of children with cancer who contributed to the development of the new service specification and/or to the public consultation are in agreement that a Principal Treatment Centre (PTC) for children with cancer must be co-located with a Paediatric intensive Care Unit (PICU). This view is fully aligned with guidance from NICE (2005 onwards) and from the Department of Health (2008) and with reviews of children's cancer services in London undertaken in 2011 and 2015.

I concur with this view. I believe that without co-location there is an avoidable geographical risk to patient safety and poor patient experience and potentially poor outcomes. This is of particular importance in relation to treatments which carry a significant risk (say >5%) of requiring PICU care. This applies to CAR T therapy, bone marrow transplantation and several other patient groups. Treatments with a lower risk of needing PICU are, of course, currently administered in some POSCUs (though these would normally have a paediatric high dependency unit). While it would be ideal to provide radiotherapy and other low risk treatments on a site with a PICU, it has to be recognised that this isn't always feasible.

I have considered carefully the particular cases of GOSH/UCLH and RMH/St George's, which are the two joint PTCs which do not conform with the proposed specification.

In the case of GOSH/UCLH I am satisfied that safety and patient experience are not jeopardised by the current arrangements. This is because the two services work together very effectively, and the location of individual services has been carefully risk stratified in relation to the likely need for PICU. I understand that an internal review of sarcoma services is underway. This is to be welcomed. A similar review of retinoblastoma service provision might also be appropriate but is beyond the scope of this review.

The configuration of services between the Royal Marsden Hospital (RMH) and St George's is quite different. The main weight of clinical expertise and support is

located at RMH, while the sickest patients are largely at St George's. This means that oncologists who are in charge of a patient's care are not always readily available when difficult decisions and conversations are needed. A large number of patients and parents are required to 'shuttle' between the two sites, adversely impacting on their experience of care. I commend the staff who have worked tirelessly to mitigate safety risks, but the current arrangements should not continue longer than necessary.

If the recommendations of this review are accepted the service specifications should be published with appropriate modifications as soon as possible. Other improvements to service delivery which were widely agreed to be beneficial for patient care can then start to be implemented.

9. Options for South London and next steps

It is beyond the scope of this review to make firm recommendations regarding the future provision of a PTC for South London/Thames, but I hope it will be helpful to give some pointers regarding possible options and processes for decision making.

Through my visits to trusts in London I learned of a high degree of willingness to host children's cancer services, should that possibility arise. These trusts included Evelina, King's, St George's and GOSH. Several of these would also be very willing to explore a "Royal Marsden@" model should RMH wish for this.

I am also aware that there are proposals to relocate DGH services from Epsom and St Helier to a site adjacent to RMH in Sutton. This would undoubtedly strengthen the adult cancer services at RMH by providing an adult intensive care unit and other general surgical and medical specialties. However, a DGH would not normally have the need for a PICU or for the other specialised paediatric services needed to support children's cancer services. To make this viable, specialised services would need to be relocated from other sites which seems unlikely to be sensible looking at these services in the round across south London. However, this is a matter for commissioners.

In relation to the other sites I visited I would offer the following comments:

GOSH – All children's PTC services for North and South Thames could theoretically be concentrated on the GOSH site. Indeed, the concept of a single PTC provider was recommended in the Stevens report. However, NHSE rejected that option in favour of having two PTCs and I would support this decision. Having only a single site would create risks to resilience. In addition, it would take several years to establish, given current proposals for the developments on the GOSH site.

King's – King's undoubtedly has strengths in relation to paediatric neurosurgery and liver surgery and already has a level 2 POSCU and a PICU. However, it only has limited other paediatric specialties. I doubt whether the development of a full range of these specialties would be viable given the proximity of King's to the Evelina at St Thomas'.

St George's – St George's has longstanding experience of working as part of the joint PTC with RMH and also has paediatric surgery, paediatric neurosurgery (though less than King's) and a level 1 POSCU. Facilities at St George's are, however, in need of a major upgrade. This option should be explored further.

Evelina – Evelina is already a major children's hospital with a wide range of specialised paediatric services, though not paediatric neurosurgery (apart from deep brain stimulation neurosurgery). It does not currently have expertise in paediatric oncology. The Evelina has good quality facilities with the potential to expand.

I would therefore recommend that three options should be formally appraised:

- A single site PTC at Evelina (possibly Marsden@).
- Royal Marsden Hospital Sutton, only if a new children's hospital on the adjacent site seems viable / is being considered.
- A single site PTC at St George's (possibly Marsden@).

Detailed criteria for evaluating these options will need to be established but should include:

- Feasibility of on-site provision of a PICU and other relevant paediatric specialised services.
- Access for patients and parents.
- Workforce retention and recruitment.
- Potential for clinical research.
- Timeliness of implementation
- Capital costs / value for money / affordability.

I would recommend that such an option appraisal should be undertaken and completed within around six months.

Annex A

Summary of Key findings from previous guidance documents and reports

Over the past 15 years several national guidance documents and reports and two reviews of services within London have been published with relevance to the configuration of services for children with cancer. This section summarises key recommendations from these documents.

Improving Outcomes in Children and Young People with Cancer (NICE 2005)

This was the first national report to set out recommendations on the configuration of services for children with cancer. It followed a series of similar documents relating to cancers in adults. The guidance set out the roles of principal treatment centres and hospitals with shared care arrangements and the core components of a PTC including minimum levels of staffing. The guidance recommended that there should be “immediate access” to paediatric intensive care and other tertiary paediatric services (page 108).

Commissioning Safe and Sustainable Specialised Paediatric Services (Department of Health 2008).

This provided a framework of critical inter-dependencies for 23 specialised children’s services including oncology (including haemato-oncology) and blood and marrow transplant. The framework specified the nature of the relationships between services using a colour-coded system, as follows:

- Red: Absolute dependency requiring co-location.
- Amber: Relationship under some circumstances, requiring varying levels of access and contact between specialists, but not necessarily co-location. Amber designation was subdivided into the timeliness of visits or transfers with ‘amber 3’ requiring access within 4 hours.
- Green: Indirect or no relationship.

Oncology services were rated as red (absolute dependency) for clinical haematology, specialised paediatric surgery, paediatric intensive care and specialised paediatric anaesthesia. A further 14 of the other 22 specialised children’s services were rated as amber (four at amber 3 – respiratory medicine; neurology; neurosurgery and nephrology).

Blood and marrow transplant services were rated as red for clinical haematology, immunological disorder and paediatric critical care. A further 9 of the other 22 specialised services were rated as amber (two at amber 3 – oncology and nephrology).

South London Paediatric Oncology: NCAT review (2011)

This was commissioned by NHS London and led by Professor Ian Lewis. It was 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. The Royal Marsden Hospital (RMH) at Sutton and St George's had been designated as a joint PTC in 2006, with most diagnosis and treatment being provided at RMH and PICU/HDU services at St George's.

The report noted several positive findings but also several concerns regarding serious untoward incidents with governance being the responsibility of the individual trusts rather than across a pathway. It noted that the PTC model involved 4 sites (GOSH for infants, RMH, St George's and King's for neurosurgery), with patients having care in multiple settings. Patients and families described the pathways as disruptive and confusing.

The report specifically noted the absence of a PICU at RMH and stated that RMH did not meet the standards for children's high dependency care expected of any centre that admits children for inpatient care. The preferred long-term option recommended was a standalone PTC which is fully compliant with the Safe and Sustainable report, with a "RMH@" model.

London Paediatric Oncology Review (2015)

This was also commissioned by NHS London. It was led by Prof Mike Stevens and a panel from outside London to avoid conflicts of interest.

It was a Pan London review, but recognised the implications for south East England outside London.

The review process involved an extensive review of documents, data requests on activity at PTCs and POSCUs, engagement with children and young people and families – but not site visits. Twenty-two PTCs and POSCUs responded to a survey. Of these, 16 thought that the current number of PTCs (2) was optimal. Only two wanted fewer. 17 of 22 recommended fewer POSCUs and 20 of 22 thought that PTCs should provide more outreach. Despite the large majority of respondents reporting that two PTCs for London was optimal, the key recommendation from this report was that a single PTC for London on a single site (and hence SE England) should be established. The status quo was dismissed. A two PTC model co-located with all necessary paediatric services was noted to be viable but was considered second best.

The report defined co-location as meaning the provision of two or more services on the same site. It further recognised that the definition of 'site' might also be open to interpretation. That report defined the term 'same site' as the "provision of a service within the same building or group of buildings in a configuration that does not require an ambulance or similar transport in order to allow a child within the PTC to access the service in question."

This review did not consider the costs of implementing the proposed model or the feasibility of the model proposed.

On the Right Course? (2018)

This report from the National Confidential Enquiry into Patient Outcome and Death (NCEPOD) highlighted the need for open discussions about the appropriateness of intensive care, of ceilings of treatment and of end of life care for individual children with cancer. These discussions often require the direct involvement of intensivists, paediatric oncologists and parents/children. The reviewers were of the opinion that good communication between specialists and with parents and children were better facilitated when the oncology unit and intensive care unit were co-located.

Annex B

Incidence of cancers in children aged under 15 years in England (from Public Health England report)

Cancer	Number p.a. (mean)
Leukaemia	434 (31%)
Brain/CNS	349 (25%)
Lymphoma	145 (10%)
Soft tissue tumours	91
Neuroblastoma	85
Renal	81
Malignant bone tumours	59
Germ cell tumours	47
Retinoblastoma	39
Hepatic	18
Other	75

Annex C

Principal Treatment Centres	New cases diagnosed (Jan to Dec 2017, under 15 yrs)	RT courses 2018/19	Notes
Great North Children's Hospital (Newcastle)	73	28	
Leeds General Infirmary	80	28	
Royal Manchester Children's Hospital	119	49	RT delivered at The Christie.
Alder Hey (Liverpool)	79	14	RT delivered at Clatterbridge.
Sheffield Children's Hospital	51	42	
Nottingham Children's Hospital*	69	31	
Leicester Children's Hospital*	33	0	
Birmingham Children's Hospital	232	34	
Cambridge University Hospital	69	15	
John Radcliffe Children's Hospital (Oxford)	80	16	
Bristol Royal Children's Hospital	45	38	
Great Ormond Street Hospital / UCLH	296	104	
Royal Marsden Hospital / St George's	130	55	
Southampton	67	0	
TOTAL	1423	454	

* Nottingham and Leicester are designated as a joint PTC, though each has a PICU.

NOTES

- Number of cancer cases diagnosed in children aged under 15 years during 2017 by PTC has been sourced from Cancer Stats.
- The Cancer Stats data reported that Birmingham Children's Hospital had 50 cases of eye and adnexa cancer, this is unusually high and may be a data coding issue.
- Importantly, a number of cancers were diagnosed outside the PTC organisations (420 cases in 2017). This activity has been excluded from the table, however, the cases would have been managed by a PTC MDT.
- The split of activity between Royal Marsden and St George's was reported as 63 and 67 respectively. For GOSH and UCLH it was 266 and 30 respectively.
- Radiotherapy data has been sourced from the national Radiotherapy Dataset (RTDS) and reflects palliative and radical treatments given to children aged under 15 years.