

# Proposal for the Future of South Thames Children's Cancer Services



February 2022

## Contents

1	Foreward .....	3
2	Executive Summary .....	4
3	Background and Prof. Sir Mike Richards Review on Children’s Cancer Services .....	5
4	Key Considerations for Decision Making .....	6
5	Evaluation of Options .....	9
5.1	Option 1 - A single site PTC at Evelina .....	9
5.2	Option 2 - Royal Marsden Hospital Sutton.....	10
5.3	Option 3 - A single site PTC at St Georges’ .....	11
6	Conclusions and Proposal.....	13
6.1	Proposal.....	13
6.2	Our Final Thoughts .....	14
7	Biography of the Authors .....	15

## 1 Foreward

This document has been produced in response to Prof. Sir Mike Richards review into Children's Cancer Services and our objective has been to provide a clear proposal for the future of Children's Cancer Services for South London, Surrey, Sussex and Kent. We have produced this document to provide the *rationale* for our proposal. Our proposal has been created based on our own approach, knowledge, skills, experience and above all the experience of being parents to a child who was treated for Medulloblastoma at St. Georges' Hospital, The Royal Marsden Hospital and Frimley Park Hospital.

This document has been produced completely independently without the input or influence of any third party. Our objective is to provide the decision makers in NHS England with a balanced proposal for the future of South Thames Children's Cancer Services. Children's health has been the primary driver.

Our charity's vision is that "every child diagnosed with childhood cancer will not only survive but reach adulthood enjoying a good quality of life." This vision underpins our proposal.

Kevin and Karen Capel

Founders and Trustees of Christopher's Smile

## 2 Executive Summary

Professor Sir Mike Richards published his review into Children's Cancer Services and in particular, Children's Cancer Services in the South Thames Region. The review was commissioned by the Chief Executive of the NHS England in response to a draft service specification for Children's Cancer Services. The central issue being reviewed was whether Principle Treatment Centres (PTC) must be co-located with a level 3 Paediatric Intensive Care Unit (PICU) and other specialised children's services. Professor Richards came to the conclusion that from now on all PTCs must be co-located with a PICU and other specialised children's services.

While the vast majority of the 14 PTCs in England conformed to this standard there was an anomaly in the South Thames region. This is mainly due to the fact that South Thames Children's Cancer Services consists of 3 hospitals, The Royal Marsden in Sutton providing Paediatric Oncology treatment delivery and management; St. Georges' in Tooting providing neurosurgical, general surgical and PICU facilities; Kings College Hospital in Camberwell providing neurosurgical, general surgical and PICU facilities. With no PICU or general surgical facilities the review questions whether the Royal Marsden Hospital in Sutton should continue as a PTC.

Professor Richards' review suggests a shortlist of options:

1. Move the South Thames Children's Cancer Services PTC to the Evelina Children's Hospital in Lambeth.
2. Move the South Thames Children's Cancer Services PTC to St. Georges' in Tooting
3. Move the South Thames Children's Cancer Services PTC to a new children's hospital on the Sutton site adjacent to the Royal Marsden

Although options 1 & 2 may look appealing and could be chosen on a purely tactical viewpoint, they each have major flaws which must be examined carefully.

The Evelina option has both general surgical and PICU facilities. The issue with the Evelina is chiefly access for families living in Kent, Sussex and Surrey. The Evelina does not have radiotherapy facilities and current does not undertake paediatric neurosurgery. The Evelina is not co-sited with an academic research partner and there is a high risk that whereas currently the Royal Marsden is a world leader in paediatric oncology drug development and genomic diagnostic research, these activities will either cease to significantly diminish over time. For these key reasons we cannot recommend this option.

Whilst family and patient access to St. Georges' is slightly better than option 1, St. Georges' paediatric facilities are cramped and in need of updating. To move the PTC to St. Georges' would need building work at an already congested site. There would also be our serious concerns regarding future research activities. We could not recommend this option.

The 3<sup>rd</sup> option which would be a new children's hospital at the Sutton site adjacent to the Royal Marsden would in our view be the best strategic option. Although this option would mean the closure and transference of general children's services from the Epsom and St. Helier Hospital. Access for families and patients is the best of the 3 options and research activity would remain world leading. The main failing of this option may be cost and timescales. We would therefore recommend that in the shorter term, a level 3 paediatric facility be created at the Royal Marsden tailored for oncology children. We have seen during Covid how hospitals have created additional Intensive Care capacity when the need arose. There would need to be work undertaken, budgets reviewed and staff recruited.

Our view is that any new children's hospital on the Sutton site should be a centre of paediatric oncology research excellence and be a key component of the London Cancer Hub. We would also recommend that the new hospital be a centre for paediatric genomics incorporating a Children's Rare Disease Centre and fully embracing the UK's world leading research and application of genomic medicine.

The current situation which South Thames Children's Cancer Services currently finds itself in is the result of decades of individualistic decision making and no integrated strategic planning. This problem must not have a 'sticking plaster' solution applied. A sound strategic integrated solution is the only way forward.

### 3 Background and Prof. Sir Mike Richards Review on Children's Cancer Services

This document has been produced in January 2022, a full year after Prof. Sir Mike Richards review into Children's Cancer Services was completed and presented to the board of NHS England. The past year has been one of the most challenging in the NHS's history with the dual challenges of treating large numbers of patients with Covid 19 and simultaneously rolling out Covid 19 vaccines for the entire population. The NHS has performed magnificently since the pandemic spread in the UK during February and March 2020. The Covid 19 pandemic has forced the NHS to implement initiatives that would have been unheard of before the pandemic started.

In January 2020, in the middle of the pandemic, Prof. Sir Mike Richards published his review into Children's Cancer Services. The document can be found online at this location:

<https://www.england.nhs.uk/wp-content/uploads/2020/01/board-meeting-item-9-update-on-specialised-services-c-appendix-2.pdf>

In summary the review concluded that all children's cancer Principal Treatment Centres (PTC) must have a co-sited Level 3 Paediatric Intensive Care Unit and specialist children's services. At present there is an issue in South Thames whereby the services are fragmented and The Royal Marsden Hospital Children's Unit in Sutton does not have a Paediatric Intensive Care Unit (PICU). All other PTCs in England with the exception of UCLH have co-sited Paediatric Intensive Care Units and are therefore not an issue. UCLH, due to its geographic proximity to Great Ormond Street Hospital is not seen as an issue either.

In the South Thames area the three hospitals with PICUs are St. Georges' Hospital, Kings College Hospital and The Evelina Children's Hospital co-sited with St. Thomas's Hospital.

Prof. Richards review highlighted the fragmented services for South Thames Paediatric Cancer Services that currently exist. The review describes the transfer of paediatric oncology patients from hospitals in South London, Surrey, Sussex and Kent which do not possess a PICU to one of the 3 PICU units in the South Thames area in addition to transfers from Sussex to Southampton Hospital.

The review concentrated on the future of The Royal Marsden Hospital to continue as a PTC. It is made clear in the review that with no PICU and no plan for the creation of a PICU, The Royal Marsden could not continue as a PTC and that the service must move to another hospital with a co-sited PICU.

Five options were considered by Prof Richards to resolve the issue of the future of Children's Cancer Services in South Thames. Two options were discounted leaving three options. These three options will be discussed more fully in this document and whereas Prof. Richards does not propose any single favoured solution, we will make a firm proposal and give reasons for our decision.

In conclusion, we are of the opinion that the current situation in which Children's Cancer Services in South Thames finds itself, has been caused by decades of individualistic decision making. Clearly there has been no will to centralise every aspect of Children's Cancer Service delivery into a single facility resulting in the fragmented morass that has now been deemed as unacceptable.

## 4 Key Considerations for Decision Making

In his review, Prof. Richards listed 6 factors which should be taken into account for any decision on the future of Children's Cancer Services in South Thames. These are:

- 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

Below we give our views on these factors and provide views from our perspective.

### **Feasibility of on-site provision of a PICU and other relevant paediatric specialised services.**

We understand the need for a PICU co-sited with a Children's Oncology Unit. We remember our time in the Royal Marsden where a white board indicated the availability of PICU beds at the Evelina, Kings College Hospital, St. Georges' and GOSH. We remember that there were times when there were no free PICU beds in London. In the intervening years we are not aware of major PICU expansion at any of the 4 centres mentioned above so we can only assume the situation hasn't changed in 14 years. As we are not able to see statistics for % bed utilisation in the London PICUs we cannot say whether there is equilibrium between demand and capacity. One aspect of PICU need as a result of oncology treatment is as a result of harsh cytotoxic regimens not being tolerated by some children. We know harsh regimens can result in acute febrile neutropenia which can be life threatening. A question we would ask is: Has there been advancement in chemotherapy regimens to greatly reduce 'over treating' children? If this is the case and with greater use of kinder, targeted treatments, will the demand for PICU beds decrease over time? We are aware that for treatments such as Bone Marrow Transplants, PICU availability will be needed as will post surgery care.

Paediatric radiotherapy services are also a key requirement. Whereas adults are given radiotherapy treatment awake, younger children need to be sedated so they do not move during treatment. Therefore there is a requirement for radiology staff to know how to treat children but there needs to be a facility where children are given sedatives and can recover post treatment with the appropriate staffing.

Surgery both general and neurological are both key requirements and any PTC should have the ability to perform at least general surgery with specialist surgery being performed by centres with particular expertise in those areas.

### **Access for patients and parents.**

Paediatric oncology patients fall into two distinct categories: inpatients and out patients. Each have their own access requirements which can be quite different. Let us take the case of inpatients first. Parents will stay with their children during chemotherapy treatment. This will necessitate taking clothing for both parent and child, toys, food and personal technology devices. Added to this a child may not be able to walk unaided and will need the use of either a buggy or wheelchair. If a hospital has poor vehicular access how would a parent and child physically get everything needed for a hospital stay to the hospital? We must remember that families from the farthest reaches of Kent and Sussex will need to be considered. Family visits must also be taken into account. Families do not want a long drive into Central London and then face the prospect of having to park at huge expense just to undertake an essential visit.

Outpatients have similar needs and whilst clothing and food are not needed, consideration must be given to children who cannot walk and need parental assistance. Children who are receiving radiotherapy must be seen as an important group as they will need to attend hospital on regular occasions. If they are starting their journey in farthest Kent or Sussex, then the frequency of long difficult journeys must be taken into account.

### **Workforce retention and recruitment.**

We cannot comment on NHS recruitment and staff retention but we would say that surely accommodation costs and quality would be an important factor especially for the specialist nursing community.

We would also state that doctors who wish to undertake a clinical fellow role, undertaking research whilst working as an oncologist would be looking for a strong academic partner institution.

### **Potential for clinical research.**

Currently the Royal Marsden Hospital and The Institute of Cancer Research are clinical/academic partners. This relationship is decades old and whilst there is always room for improvement there is an excellent record of paediatric clinical trials and treatment improvements which have resulted from this ongoing partnership. As funders of paediatric research we know only too well the issues that arise when researchers are in one facility and clinicians are in another. Even when we were dependent on staff at St. Georges' to provide samples, huge administrative and logistical hurdles had to be overcome.

The Royal Marsden Hospital Children's Unit runs more drug clinical trials than any other UK centre and the Royal Marsden Centre for Molecular Pathology has become a world leader in the development of paediatric tumour genomic diagnostics. We would not want to this work to diminish or stop altogether. Neither would we like to see paediatric research at the Institute of Cancer Research 'wither on the vine' and being stopped due to the lack of an effective clinical partner.

### **Timeliness of implementation**

The co-siting of a PICU and PTC has been accepted as a firm requirement. However creating a PTC at a new site will not be quick and consideration must be given to the whole spectrum of paediatric services needed, not just chemotherapy delivery. Obviously where a site has an existing PICU this is a huge advantage but we must remind ourselves that in the middle of the Covid pandemic hospitals were turning whole clinical/surgical wards into intensive care wards in extremely short spaces of time. If this can be achieved with Covid why can't the same thinking and impetus to make the necessary changes become a reality for paediatric oncology?

### **Capital costs / value for money / affordability**

Capital expenditure must be seen as an investment for the future and not spend to plug a tactical gap. With this in mind the building of any new premises should be seen as a capital cost and therefore an investment for the future. The investment of public funds should never be taken lightly and should provide a firm foundation for future operational activities as well as providing the provision for future growth and/or new practices/technologies.

With regards affordability, the wider South Thames and Surrey areas should be looked at as a whole and not a group of competing trusts. From our perspective the current situation with South Thames Children's Cancer Services have been brought about by decades of individualistic thinking. The application of the 'if it ain't broke don't fix it' approach will only last so long. It is clear that there is a complete lack of integrated strategic planning and this has an impact not only on expenditure but

patient satisfaction. Therefore whichever option is chosen it must be part of a strategic plan to improve children's services and provide solid foundations for future services.

In our proposal below we will give an explanation as to how, from our perspective, each of the above factors are addressed by the three options listed by Prof Richards.

One conclusion we made after reading Prof. Richards' review was there was no mention whatsoever of any integrated strategic planning as part of the decision making process. Our opinion was that the review was written on the assumption that services would continue to be delivered in the current way and that no advances in treatment practices or application of new technologies was considered.

We therefore see a key factor in the decision making process to be how any new facility would be a firm foundation for the future and that allowance for innovation and advancement in treatment practice and technology would be integrated into the new facility's design.



## 5 Evaluation of Options

The three options for the siting of a PTC in South Thames proposed by Prof. Richards are:

- 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 Georges' (possibly Marsden@).

Note:- Marsden@ is an idea that the Royal Marsden name continues but the PTC siting is at another hospital.

To illustrate the current fragmented nature of Children's Cancer Services in South Thames see the table below:

	Royal Marsden Children's Unit	St. Georges' Hospital	Evelina Children's Hospital	Kings College Hospital
Paediatric oncology treatment delivery and management	✓	✗	✗	✗
PICU	✗	✓	✓	✓
Paediatric Radiotherapy	✓	✗	✗	✗
Paediatric neurosurgery	✗	✓	✗	✓
Paediatric general surgery	✗	✓	✓	✓

Let us now compare each of the short listed options against not only the factors listed by Prof. Richards but also factors associated with future growth, treatments and technologies.

### 5.1 Option 1 - A single site PTC at Evelina

- Feasibility of on-site provision of a PICU and other relevant paediatric specialised services.
  - The Evelina already has a PICU in place so this would need no development. However the Evelina does not have the services for the delivery and management oncology treatments.
  - The Evelina is not a current PTC
  - The Evelina does not have any onsite Radiotherapy facilities as these are housed at Guys Hospital
  - The Evelina does not have a Neurosurgical capability
  - The Evelina does have an excellent range of paediatric non oncology services
- Access for patients and parents.
  - With the Evelina part of St. Thomas' Hospital on the Southbank there are considerable issues with vehicular access and parking. We must bear in mind that families will come from a catchment area of Kent, Sussex and Surrey and although the Evelina is walking distance from Waterloo station, patients and their families may start their journeys many miles from a mainline station making car travel the only viable option.
  - If a family needs to drop off their child and parent they would be liable for a London Congestion Charge fee of £15 plus if their vehicle did not meet Ultra Low Emission Zone standards a further £12.50. This would mean that a parent/sibling/grandparent would need to pay £27.50 in fees just to visit their child/sibling/grandchild in hospital.

- Workforce retention and recruitment.
  - With no specialist cancer academic partner there would be a little incentive for senior clinicians with a research interest to take a position in any Children's Oncology Unit located at the Evelina. Also the extremely high cost of accommodation in the area may be an influencing factor for specialist nursing staff.
- Potential for clinical research.
  - With the Evelina Hospital so far away from the Sutton home of the Institute of Cancer Research, the academic partner of the Royal Marsden Hospital, there can be no doubt that this relationship for paediatrics would be severely weakened or disappear entirely. It would not be the best use of clinical researcher's time to continually shuttle between Sutton and Lambeth. Therefore we would expect a serious deterioration in research activity.
- Timeliness of implementation
  - Moving Children's Cancer Services from the Royal Marsden to the Evelina Hospital must be seen as a tactical sticking plaster solution and does not in any way lay firm foundations for tomorrow's treatments, technologies or thinking. Although moving to the Evelina could potentially be the quickest solution to the current single shortcoming of the Royal Marsden in that it has an onsite PICU, other factors must be taken into account.
- Capital costs / value for money / affordability
  - The Evelina option may appear attractive in that Capital Costs would be lower than other options but we must take into account other costs such as providing a paediatric day ward for the site which undertakes paediatric radiotherapy.
  - Choosing the Evelina cannot be seen as the best strategic option in that there would be no plans to centralise all paediatric oncology activities into a single centre and be fully integrated with a world leading research institution.

## 5.2 Option 2 - Royal Marsden Hospital Sutton

- Feasibility of on-site provision of a PICU and other relevant paediatric specialised services.
  - The Royal Marsden does not currently have a PICU onsite. In order to meet the requirements of the Children's Cancer Services specification a PICU would be needed for the Royal Marsden to continue as a PTC. There would also be a requirement to provide paediatric surgical services in order to meet the need of fitting lines or ports for chemotherapy administration.
  - Professor Richards review stated that the Royal Marsden could only be considered if a children's hospital facility be built on the current Sutton Hospital site, part of the RMH/ICR campus. Whether this facility would eventually include paediatric neurosurgery is one that would be outside of the scope of this response but from a strategic viewpoint it would make sense.
  - The Royal Marsden has the RMH/NIHR Centre of Molecular Pathology onsite which has become a world leader in the development and application of genomic cancer diagnostics for children.
- 2) Access for patients and parents.
- 3) The Royal Marsden option is the only realistic option for children and their families originating Kent, Sussex or Surrey. The site has good vehicular access and although public transport links are not as good as the other two options, travel from the South of Sutton can only really be considered using a car.
- 4) Workforce retention and recruitment.
  - Maintaining and hopefully enhancing the strong relationship with the ICR would encourage clinical staff with a strong research interest to work at any new facility.
- 5) Potential for clinical research.
  - Currently the RMH runs more drug trials for paediatric oncology than any other UK centre. Children benefit from the strong drug development activities for adults between the ICR and RMH and this activity must flourish in order to address the current poor outcomes for some paediatric solid tumours.

- The Centre for Molecular Pathology is a joint RMH/NIHR facility which since it's opening has developed new genomic tumour diagnostics for children through close cooperation with the ICR. The centre is now a world leader in paediatric tumour genomic diagnostics. This has only occurred due to the centre's proximity to the RMH Children's Unit. We would not want to see this research activity in possibly the most important new area of medicine diminish.
  - If the spectre of closure of the Children's Unit was removed, clinicians with a strong research interest would be able to undertake research and their clinical duties on a single campus. This clinical partner/academic partner relationship stimulates translational research which ultimately benefits children.
- 6) Timeliness of implementation
- Full implementation of this option is undoubtedly the longest unless major building work needed to be undertaken at St. Georges'.
  - There was no mention in Prof. Richards review of the feasibility of a phased approach whereby a Level 3 care facility tailored to treating oncology children was implemented onsite at the Royal Marsden while a new children's hospital was built.
- 7) Capital costs / value for money / affordability
- There is also no doubt that this option would be the most expensive in the short term.
  - However this option may be the best value for money.
  - In order to determine affordability we need to be supplied with the tangible cost of a child's life. We can compare that cost against the NHS budget and then make a decision on affordability
  - If a new children's hospital was built at the Sutton site there would be cost savings from the closure of the Epsom and St. Helier site.

### 5.3 Option 3 - A single site PTC at St Georges'

- Feasibility of on-site provision of a PICU and other relevant paediatric specialised services.
  - St. Georges' already has a PICU and undertakes both paediatric neurosurgery and paediatric general surgery. In Prof. Richards review the paediatric facilities at St. Georges' were described as 'cramped and need upgrading'.
  - There would be a question as to where on the St. Georges' site any new paediatric oncology unit would be sited.
  - St. Georges' does not have it's own radiotherapy facilities and children would still need to use the Royal Marsden so a paediatric day ward would be needed at the RMH.
- Access for patients and parents.
  - St. Georges' benefits from good public transport services but like the Evelina, St. Georges' is not very accessible from the farthest reaches of Kent, Sussex and Surrey. Parking is not easy and there have always been limited space for parents to stay with their child during treatment.
- Workforce retention and recruitment.
  - We can only state that clinicians with a strong oncology research interest may not want to work at St. Georges' as it is not co-sited with a strong cancer research academic partnering institution.
- Potential for clinical research.
  - St. Georges' is a joint PTC with the Royal Marsden. Currently paediatric oncology research activity at St. Georges' is low compared to the research activity at the Royal Marsden. Although St. Georges' is a few miles from the Sutton home of the Institute of Cancer Research, the academic partner of the Royal Marsden Hospital, there can be no doubt that this relationship for paediatrics would be severely weakened or disappear entirely. It would not be the best use of clinical researcher's time to continually shuttle between Sutton and Tooting. Therefore we would expect a serious deterioration in research activity.

- Timeliness of implementation
  - To incorporate paediatric oncology at St. Georges' there would need to be a major expansion and upgrade to the St. Georges' paediatric facilities. We would expect this to be a lengthy implementation as it would mean the complete refurbishment of an existing operational facility with little or no impact on patient services.
- Capital costs / value for money / affordability
  - Capital costs would be dependent on the scale of building work on the St. Georges' site.
  - The cost of a paediatric day ward at the Royal Marsden would need to be included in any equation.
  - The St. Georges' option does tick many boxes but would there be space for any future expansion?
  - Complex building work would be costly and with no savings associated with the closing of Epsom and St. Helier hospital, would this be the most value for money/affordable option?

## 6 Conclusions and Proposal

We have attempted to provide the reader of this document with a pragmatic evaluation of the options for the future of South Thames Children's Cancer Services. We have drawn on our own experiences as parents of a child treated at both St. Georges' and the Royal Marsden and also as funders of paediatric oncology research. We stand by our comments on the current situation South Thames children's Cancer Services finds itself in. Change is urgently needed. Change not only in facilities but also in treatments. Childhood cancer is still the biggest killer by disease of children in the UK.

Research activity is key to improving the outcomes of children diagnosed with cancer. So any option that decreases or eradicates paediatric oncology research activity should not proceed unless there is endorsement and acceptance that the Institute of Cancer Research will significantly reduce its paediatric research in coming years.

We stated above that Prof. Richards' review did not take into account integrated strategic planning and that any new facility must be a firm foundation for future innovation and advancement of treatments. We see this as a critical factor and one that would enormously influence and decision on value for money and affordability for the longer term.

### 6.1 Proposal

Taking into account all of the comments we made above, we have come to the following conclusions:

- We cannot support moving the South Thames Children's Cancer Services to the Evelina Hospital for the following key reasons:-
  - Access for families from Kent, Sussex and Surrey would be almost impossible and the cost for vehicular access for some families would be unaffordable
  - No plan to centralise paediatric neurosurgery for oncology patients
  - An undoubted significant deterioration or elimination of paediatric oncology research activities.
  - The maintaining of a paediatric day ward at the Royal Marsden for paediatric radiotherapy patients
  - No allowance to improve clinical outcomes over and above their current levels
- We cannot support moving the South Thames Children's Cancer Services to St. Georges' Hospital for the following key reasons:-
  - Access for families from Kent, Sussex and Surrey would be significantly more difficult than the Royal Marsden
  - An undoubted significant deterioration or elimination of paediatric oncology research activities.
  - The maintaining of a paediatric day ward at the Royal Marsden for paediatric radiotherapy patients
  - No allowance to improve clinical outcomes over and above their current levels
  - In Prof. Richards' review he made mention of a family whose daughter preferred the Royal Marsden from a patient experience perspective. From our experiences we would endorse that opinion.
- Our proposal is that a new children's hospital be built on the Sutton site adjacent to the Royal Marsden.
  - Access for families from Kent, Sussex and Surrey would be significantly better than the previous two options.
  - A two phase approach would be needed whereby a shorter term PICU be constructed at the Royal Marsden site to cater for the needs of Level 3 care for children undergoing oncology treatment. At no time should this option be seen as a permanent solution.

- A new children’s hospital on the Sutton site would offer additional PICU capacity for the South East.
- A new hospital would offer general surgery and perhaps in the longer term, subject to a feasibility study, neurosurgery for children with CNS tumours.
- Paediatric radiotherapy would be on site.
- Paediatric research activities would continue and hopefully increase.
- It would be inconceivable for the London Cancer Hub planned for the Sutton site to proceed without a paediatric presence.
- The new children’s hospital could also house a Paediatric Genomics Centre and Paediatric Rare Disease Centre to leverage the world leading paediatric genomic diagnostics activity currently at the Royal Marsden.
- A paediatric genomics centre is needed to exploit the data from proposed Whole Genome Sequencing of new-borns.
- An integrated research and clinical campus consisting of the Institute of Cancer Research and the new children’s hospital would attract the brightest and best paediatric clinical researchers and children would be the benefactors.
- The new centre would provide additional surgical and medical capacity to the South East’s General Hospitals.
- Funding for any paediatric genomic facility should be sought from the MRC and NIHR.
- This option would provide a firm foundation for the research and development of future treatments for children.

This option would provide the following facilities:

	New Children’s Hospital at Sutton
Paediatric oncology treatment delivery and management	✓
PICU	✓
Paediatric Radiotherapy	✓
Paediatric neurosurgery	Subject to feasibility
Paediatric general surgery	✓

## 6.2 Our Final Thoughts

We fully understand and support the decision that every PTC must have a PICU on site. However we cannot support any option that proliferates the fragmented nature of South Thames Children’s Cancer Services. Cancer kills more children than any other disease. There is a huge unmet need for more effective treatments and these will only be developed through research. We therefore cannot support any option that reduces research activity. We firmly believe that the decision on the future of South Thames Children’s Cancer Services cannot be taken by NHS Specialised Commissioners alone and should involve all stakeholders. This problem needs a strategic solution and not a tactical quick fix. Our proposal is obviously the most expensive option but it would provide 21<sup>st</sup> century facilities for a small but the most emotive part of the whole cancer spectrum – paediatrics.

## 7 Biography of the Authors

Kevin and Karen Capel were parents to Christopher, their only child, who was diagnosed with Medulloblastoma in October 2006. After 21 months Christopher died in June 2008. Christopher was treated at St. Georges' Tooting, the Royal Marsden Children's Unit Sutton and their local hospital, Frimley Park. Following Christopher's death they started their charity Christopher's Smile to provide catalyst funding for drug development projects at the Institute of Cancer Research in Sutton. The Capel's were able to apply their career experience to their charity activities. Kevin Capel spent his working life in the airline industry, initially as an engineer and then various roles in information technology. Karen Capel started her career as a language teacher moving to airline customer service and training.

They are passionate advocates for new oncology treatments for children. They have spoken at European Health Committee meetings in Brussels and raised issues with childhood cancer with their constituency MP who is a current member of the Cabinet.

Kevin and Karen Capel changed their charity's focus from drug development to the development of genomic diagnostics. They funded the development of the first Next Generation Sequencing Panel for paediatrics which is now available as a standard treatment for children as part of the Genomic Medicine Service. Their current focus is to see the implementation of a circulating tumour DNA (Liquid Biopsy) diagnostic for children.

Karen Capel has been awarded two Honorary Doctorates, from Aston University Birmingham and London University for her charitable activities. Kevin Capel has been awarded an Honorary Doctorate from London University for his charitable activities.

Kevin Capel is a Public and Patient Voice representative on the NHS England Genomics Clinical Reference Group.