Consultation report on future location of very specialist cancer treatment services

for children living in south London and much of south east England

On behalf of NHS England (London and South East regions)

Annex A

January 2024

Content page

Formal responses

This document includes copies of the formal responses submitted to the consultation (either via email or through the survey) in full. Formal responses are categorised as those who have directly indicated they are responding on behalf of an organisation or where permission has been sought to express them as such. The consultation also received a number of responses from individuals from organisations, but who were not specifically identified as representing those organisations in their reply – these have been included in the relevant feedback sections in the report.

Responses are organised by organisation type, which includes:

A. Government bodies and Members of Parliament
B. Health bodies and associated groups
C. Local authorities
D. Parent bodies and representatives
E. Research organisations
F. Charities and not-for-profit organisations

A. Government bodies and Members of Parliament

1. National Institute for Health and Care Research

An email was received expressing no preference for where the service should be located.

2. Member of Parliament for Richmond Park

HOUSE OF COMMONS
LONDON SW1A 0AA

18 December 2023

To whom it may concern,

Re: Paediatric Cancer Care relocation response

I am writing in response to the NHS consultation on changes to children's cancer care in South London, Kent, Medway, Surrey and Sussex.

While I understand NHS England's preference is to relocate all care to the Evelina, I do not believe this represents the best deal for the public. Both the Evelina and St George's are excellent hospitals, however, concentrating paediatric oncological care at St George's would be cheaper for the public, pose a reduced risk to patients and would be operationally simpler to achieve.

Risk and cost to patients and their families

The highest priority for the NHS should be ensuring easy access to life saving medical treatment regardless of economic circumstance, while mitigating as much the risk as possible to patients.

Unfortunately, I do not believe a move to the Evelina would achieve these aims as effectively as a move to St George's. Public transport is not an option for children taking immunosuppressants and as such, easy access to parking close to the hospital is an essential pre-requisite for any site.

The Evelina's parking provision is limited and space considerations within central London would make this issue very difficult to rectify. Conversely, St George's plan outlines dedicated parking spaces and drop off zones for the families of children with cancer directly outside their proposed Children's Cancer Centre.

In the same vein, the Evelina sits within the Congestion Charging zone, meaning that any family member who wishes to visit an inpatient will be charged between £15 and £17.50 each time they enter the zone. While I acknowledge TfL will reimburse the cost to patients with compromised immune systems when they are attending an appointment, for families visiting on a regular basis not covered by the exemption, this could become a significant expense.

Cost to the NHS

Although the NHS' assessment required that both proposals were affordable, I do not believe

the rating system, which did not take into account the financial differences between the options, is adequate. St George's proposal has lower capital costs, a better revenue impact, and would save the public £3.5 million. Furthermore, the Evelina's proposal is dependent on a £10 million charitable donation. While there is of course precedent for public services to be supported by the public's generosity, I would like to be reassured that this funding is secure and not subject to any unreasonable caveat.

In addition, removal of paediatric cancer care from St Georges will create an additional demand on the hospital's resources as staff who were part funded through this stream, but have vital responsibilities across departments, will need to be compensated out of the reduced budget. This represents an estimated £2.5 million in the first year and I fear could have a knock on impact on the hospital as a whole as limited funding is stretched even further.

Experience of delivering paediatric cancer care

St George's and the Royal Marsden have 25+ years of experience treating children with cancer. Over the past 2 decades, St George's has built a team of surgeons, pathologists, nurses, anaesthetists and other support staff who deliver an incredibly high standard of care. There are very few paediatric oncology specialists in the country and between the national shortage of paediatric pathologists and handful of experienced paediatric oncology surgeons operating nationally, building a new team at the Evelina would not be an easy task.

It cannot be assumed that these individuals will move if the children's cancer service moves and since most of them provide care to children with cancer but also to other children, most will not qualify for automatic transfer under TUPE regulations.

It is undeniable that the Evelina has the resources and experience to deliver a high standard of care, however, St Georges decades long specialisation in this field should be considered and given proper weighting. The fact that professional experience was not considered in the initial assessment is concerning, and I hope that in the wake of this consultation the NHS will revisit this element of the framework.

Relative importance of cancer services

While most paediatric cancer services are available at both the Evelina and St Georges, key differences exist between their provision of neurosurgery, inpatient nephrology, and inpatient cardiology.

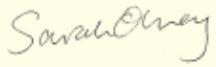
While St George's does not possess facilities for either inpatient nephrology or cardiology, it does possess a high degree of experience delivering paediatric neurosurgery. I am given to understand that this was measured as two points in the Evelina's favour and one in St George's, however, this decision appears somewhat arbitrary.

While on the surface, one hospital can provide two services to the other's one, in 2019/2020 86 children receiving treatment from at least one of the three bodies serving the region required cancer-related neurosurgery. In the same year, 6 received nephrological care and 25 were treated for cardiological issues. In terms of nephrology, only 3 were admitted overnight, while no patients treated for cardiological issues were admitted.

It is thus a dangerous oversimplification to treat provision of these services as equal. All are naturally important, but the actual need for these services should be considered alongside their availability.

I hope that NHS England will consider the points I have raised when making its final decision. Both hospitals have excellent staff and are capable of delivering exemplary treatment, however, St George's should be considered the better of the two for a single, unified, paediatric cancer care service.

Yours sincerely



Sarah Olney
Member of Parliament for Richmond Park

3. Member of Parliament for Twickenham

MUNIRA WILSON MP
Member of Parliament for Twickenham

HOUSE OF COMMONS
LONDON SW1A 0AA

Dr Chris Streather
Medical Director
NHS England
105 Victoria Street
SW1E 6QT

18th December 2023

Dear Dr Streather,

Consultation Response: Proposals for the future location of children's cancer principal treatment centre

I am writing in response to NHS England's consultation on the location for the principal treatment centre for paediatric cancer serving patients across south London and the southeast of England, with the firm belief that the new children's treatment centre should be located at St George's Hospital. I recognise that the Evelina is a brilliant hospital for a whole host of children's services which has, at times, treated my own children. However, I do not believe it is the right location nor has the right expertise to host children's cancer services for the region.

As the MP for a southwest London constituency, I am well aware of the excellent services that St George's provides for children and young people living in my constituency and beyond, rated Outstanding by the CQC.

The children's cancer service that St George's has provided in partnership with the Royal Marsden for the past twenty-five years has been invaluable to the communities of south London and the surrounding areas such as Kent, Surrey, Sussex and Medway. During this time, St George's has developed invaluable experience and expertise in treating children with cancer. A child living with cancer is an incredibly traumatic experience for the whole family, and at St George's, parents are reassured by the expertise and knowledge that have been developed over decades.

Furthermore, St George's has also developed invaluable collaboration and shared practice with other departments, particularly in surgery and pathology. This has resulted in important services being offered at St George's such as neurosurgery, which is a service required by a quarter of child cancer patients. This is a speciality that is not currently offered by the Evelina. Moving children's cancer care to the Evelina risks losing the knowledge, expertise and professional networks that have been built up over decades.

While it is possible to train new staff, this could take a number of years given the complexity of paediatric oncology and it would take even longer to develop the same level of institutional experience and expertise that St. George's currently has.

The Hamptons • St Margarets • Strawberry Hill • Teddington • Twickenham • Whitton

T: 020 7219 6474
E: munira.wilson.mp@parliament.uk
Newsletter: www.munira.org.uk/email sign up/

: @munirawilson
: www.facebook.com/munirawilson/
W: www.munira.org.uk

Furthermore, removing paediatric cancer services from St George's would likely result in loss of staff, presenting a considerable risk that broader paediatric surgery and pathology services could be disrupted and negatively affected at St George's. This could have serious consequences for patients across South London and the other regions St George's serves.

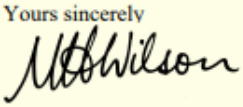
Another concern regarding the option to move the centre to the Evelina is how difficult it is to access via car. Child cancer patients are especially vulnerable, with many of them on immunosuppressants during their treatment. Travelling via public transport (which in many cases will be the only feasible option), adds potential risk to a patient and unnecessary stress and anxiety to those looking after them.

On the other hand, St George's is easily accessible via car, with good road links to other parts of the region, and car parking provision. Child cancer patients and their parents at St George's have said that this makes the process of hospital visits much easier.

Furthermore, NHS England's own analysis shows locating the PTC at St George's is a more cost-effective option. Building the new centre at St George's would therefore truly offer the best value option by retaining existing expertise, experience and collaboration; whilst also presenting a lower risk to wider services as well as patients; and at the same time being a lower cost option. It also ensures that wider NHS services are evenly distributed across the region and are not overly centralised.

I believe the case for locating the new principal treatment centre for children's cancer at St George's is overwhelming and urge you on behalf of my constituents and families across the southeast of England – in the strongest possible terms – to select that option.

Yours sincerely



MUNIRA WILSON MP
MP for Twickenham

4. Member of Parliament for Wimbledon

An email was received from the MP for Wimbledon stating 'It is my view and the view of my constituents that children's cancer services should be maintained at St George's. Whilst I understand the arguments which have been made for the centralisation of children's services at the Evelina, the existing capacity at St George's should not be lost. We cannot be certain that St George's capacity, expertise or institutional memory will be retained if services are moved to Waterloo.'

5. Merton Liberal Democrats councillors

Consultation on Future of very specialist Children's Cancer services in South London and part of SE England: Response from Merton Liberal Democrats

1. This is the response from Merton Liberal Democrats to the Consultation from NHS England on the future of very specialist children cancer services currently provided by the Royal Marsden Hospital and St George's Hospital.
2. The consultation has come about after a Report from NHS England by Professor Sir Mike Richards that specialist children cancer services should only be offered on sites which also have a paediatric intensive care unit. This means that services have to move away from the Royal Marsden and two groups have proposed to take over the services:

- Evelina London Children's Hospital in Lambeth, South East London, run by Guy's and St Thomas' NHS Foundation Trust
- St George's Hospital, in Tooting, South West London, run by St George's University Hospitals NHS Foundation Trust.

The NHS is recommending that the service be transferred to the Evelina but the decision is up for consultation. It is important that there is no scare mongering in such an important area: either option will give Merton's children a good, safe, local service.

3. Our approach has been to place a very high importance on the views of the independent experts who have made these recommendations while coming to our own conclusions. Cllr Gould and Cllr McGrath have visited both hospitals and we are grateful to their staff and those of NHS England who gave up their time to talk to us. We have also attended the consultation meetings and of course read the extensive documents which have been produced.

4. While we think that both hospitals have put forward excellent and persuasive cases, we believe that the case from St George's is stronger and that the marking scheme for NHS England does not give enough weight to the challenges of change. The comparison is

between what might happen at the Evelina with what does (to some extent) happen at St George's. An example of this is the evaluation factor for *"Transition: supporting children to make the move to teenage and young adult cancer services when they are ready."* The Evelina scores highly for this as their proposals exceeded the service specification while St George's met the specification. But St George's currently do actually carry out (in connection with the Royal Marsden) this activity. The Royal Marsden is set to continue to provide cancer care for those aged 16 and above whichever hospital is chosen. The evaluation does not weigh for the fact that this is a service already being conducted, compared to a theoretical provision.

5. Whichever hospital is chosen, the move from the Royal Marsden will involve very substantial change. It is not clear how many of the 170 staff involved in this area at the Royal Marsden will relocate: either option will mean that many staff who currently travel to work by car will need to use public transport and there is a risk that a significant number will not wish to do so. NHS England have rightly said that cost should not be a factor in making the decision but one advantage of the St George's bid is that it is cheaper - releasing more money to be spent elsewhere on patient care. We also note that one of the key points made by parents is that many children travel to their hospital appointments by car (as they are often immuno-suppressed) and it is easier from most of the catchment area to get to St George's. There are also a large number of research projects underway at the Royal Marsden which need to be able to continue which would appear to be easier at St George's.

6. We believe that any change of this magnitude will involve a substantial degree of risk, particularly in the initial stages. Given that the scoring differences between the two options are fairly low we believe that the option that reduces the amount of this risk should be chosen, and given the close relationship already between the Royal Marsden and St George's we believe that to be St George's. We were very struck when we visited St George's by the strength of their partnership with the Royal Marsden and their work with children with cancer. For example, the paediatric ICU at St George's has more cancer cases than any other hospital in England apart from Cambridge: we cannot see that the case for the Evelina is strong enough to overrule factors like this. We also have significant concerns as we understand that Evelina does not provide cancer neurosurgery and would rely on surgeons from St George's travelling to the Evelina hospital to conduct these services

7. Both proposals have strong points and we would urge that whichever hospital is selected they work with the other to ensure that the best ideas are shared and the final result is a service which builds on the strengths of both proposals.

For further information please contact Simon McGrath, Merton Liberal Democrats, simon.mcgrath@merton.org.uk

17 December 2023.

B. Health bodies and associated groups

6. British Association of Paediatric Surgeons (BAPS)

BRITISH ASSOCIATION OF PAEDIATRIC SURGEONS

Advancing paediatric surgery through education and research

at The Royal College of Surgeons, 38-43 Lincoln's Inn Fields, London WC2A 3PE • Tel: +44 (0)20 7430 2573

5th January 2024

British Association of Paediatric Surgeons (BAPS) response to proposals for the future location of very specialist cancer treatment services for children who live in South London and much of south-east England.

Background – BAPS has been approached to give comment on the above proposal and asked to review the public document released on the above. It should be noted that BAPS was asked to be involved 72 hours before closure of the public consultation process and has wanted to give due diligence to its response, hence the reason for emailing you directly.

Response – Professor Sir Mike Richards, in his paper of 20th January 2020 [1], in respect of the above, recommended three options for reconfiguration of Children's Cancer Services for South London. These included single site centres at Evelina or St George's with the third being at the Royal Marsden but only if it was viable for a new children's hospital to be built on the site. The proposal of the public consultation document [2] only includes the first two options.
BAPS is a registered charity and represents members from all units in the UK, including the two units that have registered proposals. It fully supports the need for a change to Cancer Services in South London as described by Professor Richards and are pleased that it is recognised that wherever the service is placed there will need to be experts in Oncology, Radiology and Pathology in relation to Cancer Care. It is wrong for BAPS to state at which centre the service should be located. It does, however, have the right to make sure those that make the decisions are aware of certain factors relating to highly specialised surgery.

1. Whilst both centres have excellent Paediatric Surgeons, only St George's have surgeons experienced in solid tumour resections. The surgeons at Evelina are clearly aware of this and have stated their willingness to support their colleagues with their experience, but a system must be developed where, in the end, no child comes to harm if the services are relocated.
2. It must be recognised that whilst the surgeon is important, and thus in theory, can be relocated, what is equally important is the extended surgical team, and, if the service is relocated, plans for this must be included.
3. Relocation of services has happened previously in Paediatric Surgery, but the support (both physical and psychological) has been lacking with some unintended consequences including staff leaving the relocated unit. This must not be allowed to happen again.

If these points are taken into account, BAPS will support any proposed plans.

President: **Ian Sugarman** • president@baps.org.uk
Honorary Secretary: **Alex MacDonald** • honsec@baps.org.uk
Honorary Treasurer: **Erica Makin** • hontreas@baps.org.uk
Registered Charity No: 1175257

adminsec@baps.org.uk • **www.baps.org.uk**

BRITISH ASSOCIATION OF PAEDIATRIC SURGEONS

Advancing paediatric surgery through education and research

at The Royal College of Surgeons, 38–43 Lincoln's Inn Fields, London WC2A 3PE • Tel: +44 (0)20 7430 2573

In the future, BAPS would like to be consulted if any proposal in London, or elsewhere in the UK, involves changes to the paediatric surgical footprint, as it does represent the majority of Paediatric Surgeons in the UK and was agreed with NHSE, in previous meetings.

With best wishes

Ian Sugarman	Sean Marven	Alex Macdonald	Erica Makin
Outgoing President	Incoming President	Honorary Secretary	Honorary Treasurer

1 - https://publications.parliament.uk/pa/cm5803/cmselect/cmhealth/345/report.html

2 – NHS_Principal_Treatment_Centre_Full_Consultation_V19_Desktop.pdf

President: **Ian Sugarman** • president@baps.org.uk
Honorary Secretary: **Alex MacDonald** • honsec@baps.org.uk
Honorary Treasurer: **Erica Makin** • hontreas@baps.org.uk
Registered Charity No: 1175257

adminsec@baps.org.uk • www.baps.org.uk

7. Children's Hospital Alliance

15 December 2023

To: NHS England (London and South East Regions)

By email: england.childrenscancercentre@nhs.net

Dear Sirs / Madams,

Children's Cancer Principal Treatment Centre for South London and much of South East England

I am writing as Managing Director of the Children's Hospital Alliance, on behalf of our member organisations, to express our support for the case for change that NHS England (London and South East regions) has set out in its proposals for the future location of very specialist cancer treatment services for children living in south London and much of south east England.

The Children's Hospital Alliance is a national network of 12 dedicated, specialist children's hospitals across England that works together to improve quality, access and experience of hospital care for children and families. (Please note that Great Ormond Street Hospital, which is one of our members, has already provided a response to the consultation as a current PTC provider in the geography in question. For this reason, the views expressed within this letter represent those of the other CHA member trusts; for further information on GOSH's position, we would refer you to their consultation response.)

Because of the rare and complex nature of conditions (including cancers) that affect children, and because of the specialist expertise that is therefore needed to provide the best quality of care and to advance research and discovery in childhood conditions, our network provides the invaluable opportunity for paediatric specialists from across the country to share experiences, learning and best practice. Our collective expertise and access to a national cohort of paediatric patients means that we have clear insight into what it takes to deliver outstanding children's services, and we are able to lead on service transformation and to develop and scale innovation in children's healthcare.

Our collective view is that it is a clear advantage for a children's cancer service to be co-located both with paediatric intensive care and with the other specialist services that a dedicated children's hospital can provide. As Professor Richards has pointed out, the overwhelming majority of clinical experts and parents of children with cancer who contributed to the development of the service specification and/or to the public consultation (on the 2021 service specification) agree that a Principal Treatment Centre for children with cancer ***must*** be co-located with a PICU. This was also the view expressed by the Royal College of Paediatrics and Child Health, on behalf of the profession.

Moreover, to be able to deliver new and emerging therapies, co-location not only with on-site ICU but also with other specialist children's services is essential. This case for change is about the future of care and ensuring consistent access, outcomes and opportunities to participate in research for children with cancer across the country. To achieve this, we believe that co-location with the wide range of dedicated paediatric specialties that these children may need is a crucial component of this proposed change.

This is the model that is widely employed across the rest of England, and it is notable that Principal Treatment Centres in all other regions of England are co-located both with paediatric intensive care and with other specialist children's services in specialist, dedicated children's hospitals. None of this is to

diminish the excellent care that the team at the Royal Marsden provide at present; rather, it is to underline the opportunity to further enhance the joined-up care, research and patient experience that will be provided once this important change is delivered.

We recognise the primary importance of ensuring that the wishes of patients and their families are respected, as well as ensuring that the clinical services offer the best range of care possible to be able to meet their needs.

We would be happy to share our expertise on the provision of children's cancer services and the co-location of services in Principal Treatment Centres further, if that would be of assistance.

Yours faithfully,

Alexandra Norrish

Managing Director, Children's Hospital Alliance

8. CYPCS Consultant Team, Paediatric and Adolescents Division, University College Hospital

NHS
University College London Hospitals
NHS Foundation Trust

18 December 2023

NHSE England London and South East regions consultation programme
By Email: england.childrenscancercentre@nhs.net

RE: Proposals for the future location of very specialist cancer treatment services for children living in south London and much of south east England – Consultation Response

UCLH Paediatric and Adolescent Division hosts the North Thames PTC for patients between the age of 13 and 19, working in conjunction with GOSH, who are the PTC for patients under the age of 13. We provide an Enhanced Level B POSCU service for patients under 13 which requires the capability to provide safe and effective care for our current cohort of paediatric radiotherapy patients, from GOSH, Southampton and Oxford PTCs.

We are fully supportive of this consultation process and both options under consideration have our equal support. We look forward to working with the future PTC to develop safe and effective care for photon radiotherapy patients from South London. This will need some investment in additional resource and capacity which we look forward to discussing further once this consultation process has been concluded.

It is clear that a huge amount of work has gone into developing proposals to date. Some reflections from our team about areas which may warrant further consideration as this process continues:

- As is known, the most valuable and important consideration is ensuring that there is developmentally appropriate healthcare (DAH) at all sites where children, teenagers and young people and families are attending.
- One of the age groups affected by this consultation is the 13-16 year old group, who we manage within our Teenage and Young Adult Cancer service as the PTC for North Thames. As per NCRAS data included at the end of this letter which you may be familiar with, there is peak incidence of paediatric cancer in younger children between the ages of 1-6 and relatively fewer of patients in the 13-16-year-old age group. These patients obviously have very different needs to the younger patients, and the future PTC must ensure that it recognises and can meet these, particularly as this proposal separates this group from the older teenagers, whose needs may be more similar.
- Within the 16-25 year age group, the 16-18 group also have specific paediatric needs including legal frameworks of care and safeguarding needs which must be supported to be maintained within the new service configuration.
- As the consultation identifies, transition must continue to be carefully and safely managed. Our team has worked hard with our colleagues at GOSH to develop safe, effective and supportive transition pathways between the PTC for <13s and >13s. While the transition age will be different in the South London configuration, if there are joint processes we can help support which could inform development of this new transition pathway, we would be happy to work with the clinical teams to develop a more Pan- London model of good transition. The NIHR funded Transition research programme at Northumbria Healthcare may also offer valuable resource, such as the DAH toolkit.

- We know that the long-term impacts of treatment for cancer in childhood can be significant. Clarity on and resource for Late Effects services for this group will also be key.
- We hugely value the support from services such as PATCH, who provide a telephone advice service to children, young people and their families, and for healthcare and allied health professionals for patients from across South Thames, and hope that the strength of this service is maintained in the future configuration.
- The consultation emphasises the importance of research. We currently refer patients under 16 for early phase clinical trials to the South London PTC and strongly support the focus on maintaining these pathways and research excellence in the future configuration.

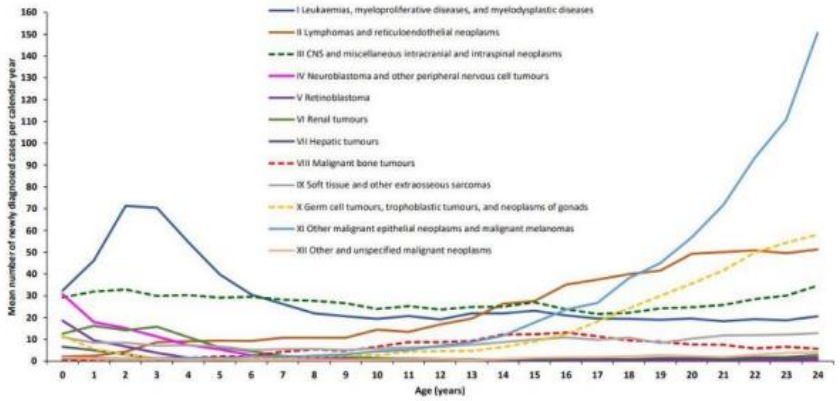
Thank you for giving us the opportunity to contribute to this very complex piece of work, to support the best possible care for children with cancer.

Yours sincerely

CYPCS Consultant Team, Paediatric and Adolescents Division, UCLH

NCRAS Data:

Figure 3: Mean number of newly diagnosed cancer cases per year registered among those under 25 years of age and resident in the UK, 1997-2016, grouped according to 'International Classification of Childhood Cancer, Third Edition' (ICCC-3) and age.



Source: National Cancer Registration and Analysis Service (NCRAS) for England (Public Health England), the Northern Ireland Cancer Registry, the Scottish Cancer Registry, and the Welsh Cancer Intelligence and Surveillance Unit

9. Epsom and St Helier University Hospitals NHS Trust

Epsom and St Helier University Hospitals NHS Trust
Wrythe Lane
Carshalton
Surrey
SM5 1AA

Direct line: 020 8296 3784
Email: James.blythe1@nhs.net

5 December 2023

Via email to
england.childrenscancercentre@nhs.net

Dear colleague

I am writing to give Epsom St Helier's response to NHS England's consultation on the future of the South Thames paediatric cancer principal treatment centre.

Epsom St Helier is a Paediatric Oncology Shared Care Unit, and so works closely with both the Royal Marsden and St George's in the delivery of children's cancer care. We are committed to continuing to do so whatever the future location of the PTC in our region, and to making that relationship work for our patients.

The consultation asks for views on strengths and issues related to the two options. Looking at the two options from the perspective of our local patients, we would highlight the following:

1. For Epsom & St Helier POSCU patients, accessing services at the Evelina will be more difficult than accessing services at St George's, which is closer to home and avoids the need to travel into central London. We are particularly concerned about the impact on less well-off families, given that parts of the catchment area we serve are relatively deprived.

2. We note that the consultation documentation outlines a potential negative impact on other paediatric services at St George's if the PTC moves to the Evelina (including paediatric surgery and paediatric pathology), and that consideration of mitigations has not concluded but is ongoing. Epsom & St Helier works closely with St George's paediatric services: paediatric surgeons from St George's operate on our patients at our hospital sites, and paediatric pathologists at St George's also provide us with support (for instance, in perinatal pathology). We are concerned that moving the PTC to the Evelina would have a negative knock-on impact for our other patients beyond children's cancer – and note that the risk would not arise if the PTC remained at St George's.

3. We note too that the consultation documentation describes the likelihood of stranded costs at St George's if the PTC is moved to the Evelina, with NHS England prepared in principle to provide support but only for a limited period and subject to further discussion. In the current NHS architecture, a financial problem at St George's becomes a financial problem for South West London, and therefore for Epsom & St Helier. Given the scale of the financial challenge we face in South West London this is a significant potential further pressure that could be avoided by retaining the PTC at St George's.

Our view for the reasons set out above is that retaining the PTC in South West London is likely to be better for Epsom & St Helier patients.

I hope you find this helpful as you continue your deliberations.

Yours sincerely

James Blythe
Managing Director ESTH

Cc Gillian Norton GESH Chairman
Jacqueline Totterdell GESH CEO

10. Great Ormond Street Hospital for Children

NHS
Great Ormond Street Hospital for Children
NHS Foundation Trust

By email to: chris.streather@nhs.net

Dr Chris Streather

Regional Medical Director & CCIO | Medical & Digital Transformation Directorate, NHS England (London Region)

CC: wendysingleton@nhs.net

CC Sanjiv Sharma, Acting Deputy CEO, Great Ormond Street Hospital for Children

14 December 2023

Dear Chris

I am writing to you as requested to provide a response to the public consultation on children's cancer services for South London, in our capacity as one of the current PTC providers.

Firstly, I would like to confirm our position remains that the outcome of this process must deliver against the new cancer service specifications - in particular, the co-location of paediatric intensive care services. The immediate adjacency of appropriately skilled staff and facilities to care for any child who may become critically unwell during their hospital treatment is essential for their safety, particularly for those who are under 13 years old.

We would also ask that in making this decision the programme board is confident that they have fully considered the various viewpoints of the expert staff groups who currently deliver these highly specialised services. Any potential impacts, including unintended impacts, on skilled specialist teams could have serious consequences for the sustainability of specialist cancer services in London and potentially adjacent regions.

Without the ability to attract, train and retain expert staff in sufficient numbers, and to allow them to realise their potential to contribute to the research, innovation and service developments that are shaping the future of cancer care, the NHS will not be able to deliver the service that children and families need and deserve.

Naturally, any impact on workforce will be a crucial issue for us to monitor and mitigate together as a region, to limit any destabilisation of these essential, life-saving services that may result from service change.

We acknowledge the earlier decision of the programme board that an appropriate location must be identified within the South Thames footprint. In terms of further considerations on geography, it is clearly essential to listen to the views of patients and families who have lived experience and can reflect what is most important to them in terms of accessing specialist care. It may be helpful to reflect that our own experience of running specialist cancer services in a busy urban location has not precluded our teams from delivering a high-quality service with excellent outcomes and patient and family experience.

Finally, I would like to re-iterate our commitment to working closely with any successful service provider in the best interest of patients, families, and staff. Our core purpose at GOSH is to advance care for children and young people with complex and rare health conditions. We remain committed to working with the successful provider to help ensure that patients and families can access new treatments, participate in clinical trials and that staff can contribute to the shared learning and data collaborations that drive global advancements in childhood cancer care.

Yours sincerely

Matthew Shaw

Chief Executive, Great Ormond Street Hospital for Children NHS Foundation Trust

11. Guy's and St Thomas' NHS Foundation Trust

Guy's and St Thomas'
NHS Foundation Trust

Professor Ian Abbs
Chief Executive Officer
St Thomas' Hospital
Westminster Bridge Road
London
SE1 7EH

To: NHS England (London and South East Regions)

Sent via email

Wednesday 13 December 2023

Dear Colleagues

RE: Children's Cancer Principal Treatment Centre for south London and south east England

Further to the public consultation on the future location of very specialist cancer treatment services for children living in south London and south east England, and as a member of the Programme Board, I fully support the case for change as set out by NHS England. The case for change has been supported by numerous experts and independent organisations, including Professor Sir Mike Richards in his 2019 report for the NHS England Board; namely, that the children's cancer service should comply with the national service specification so that it is located on a site that provides both level 3 paediatric critical care (intensive care) for children and other specialist children's services.

Guy's and St Thomas' NHS Foundation Trust is committed to providing the best possible care for children, young people, and their families and we believe Evelina London Children's Hospital is uniquely placed to serve as the home of the children's cancer Principal Treatment Centre. We are pleased that the independent expert panels convened by NHS England recognised the breadth and depth of our proposed offer to children with cancer – particularly our clinical service model and our internationally renowned research impact which will enable us to create the strongest future facing service – and that on the basis of this rigorous assessment, Evelina London is the preferred option for the future Principal Treatment Centre.

As the only dedicated children's hospital in south London and the South East, our proposal represents a once in a generation opportunity to bring the world-renowned team from the Royal Marsden together with the internationally recognised experts in children's healthcare at Evelina London, who already care for many children with complex medical conditions.

Placing the Principal Treatment Centre in a dedicated children's hospital is a proven service delivery model that will align our region with the rest of the country – and international best practice - making sure that children with cancer and their families in south London and south east England have access to the best possible clinical expertise.

Evelina London is undoubtedly the option that will deliver the most effective and innovative care for children with cancer in our region, and will do so in a way that:

- Builds on our existing cancer expertise, Care Quality Commission 'Outstanding' rated performance in children's healthcare, and existing partnerships with every local hospital in the region.

- Gives patients and families the comprehensive travel and accommodation support they need, including bookable parking spaces, a dedicated door-to-door car shuttle service, reimbursement of travel costs, and access to family accommodation at the largest Ronald McDonald House in the region.
- Ensures the new service will be up and running as quickly as possible by utilising our existing world-class facilities and capitalising on our ability to immediately begin new children's cancer clinical research studies and offer the latest immune therapies like CAR-T.
- Maximises the opportunities to develop leading edge technologies and translate rapidly into clinical practice as well as children's cancer clinical research, building on the Trust's extensive and internationally recognised track record.
- Benefits from the ability to share electronic patient records across the main trusts that will support the Principal Treatment Centre, thus improving patient safety, reducing administration and cost, and providing seamless continuity of care for children.

If Evelina London is selected as the future home of the Principal Treatment Centre, the current services at the Royal Marsden and the vast majority of staff would transfer to Evelina London, ensuring continuity of care for patients and families. We would also work in partnership with St George's, which would continue to provide supporting services for children with cancer, as well as continuing our existing close collaboration with King's College Hospital, which also provides cancer surgery in the current service.

Our approach would therefore be to work closely with the teams at the current Principal Treatment Centre – as well as with the families and children requiring cancer care – to co-design the new service and ensure continuity of care during the transition period.

The interests of children, families, and staff will always be at the heart of everything we do. Evelina London is backed by a Trust that has specifically prioritised children's care through more than £185 million of investment over the past 20 years, with plans to create a world-leading paediatric centre of excellence for the benefit of children and their families. This includes the support of one of the largest charities in the NHS, which has committed to supporting the future Principal Treatment Centre at Evelina London.

We are confident that the formal consultation response attached will strongly evidence why Evelina London is both NHS England's preferred option for this service and the option that will best support the Principal Treatment Centre's clinicians to continue to deliver excellence in the care of children with cancer.

Yours sincerely,

Professor Ian Abbs
Chief Executive Officer
Guy's and St Thomas' NHS Foundation Trust

Attached: Guy's and St Thomas' formal response to the children's cancer consultation

12. Healthwatch Richmond upon Thames and Healthwatch Merton

Healthwatch Richmond
82 Hampton Road
Twickenham
TW2 5QS
Tel 020 8099 5335
info@healthwatchrichmond.co.uk
www.healthwatchrichmond.co.uk

healthwatch Richmond upon Thames

Response to NHSE consultation on changes to Paediatric Oncology

We are writing on behalf of Healthwatch Richmond and Healthwatch Merton in response to the consolation on the move of cancer services from Royal Marsden to either St George's or Evalina Hospitals.

Our view is that the consultation is insufficient and does not discharge the duty to consult as it fails to meet the Gunning Principles for Consultations. As a result, we are unable to submit a response to the consultation survey questions and are limited to providing a narrative response relating to the consultation itself.

Provides insufficient information for people to give "intelligent consideration" to the consultation.

The benefits and negatives of the change itself were not articulated sufficiently clearly in the consultation material. As a result, we were unable to fully understand the benefits of the proposed changes in terms of the numbers of people impacted by the proposals and the extent of this impact on them vs the status quo.

Our understanding left us unconvinced that the reason for the proposed change to take place had been laid out in the consultation.

With respect to the impact of this for the Gunning Principles, providing an insufficiently persuasive and detailed rationale for a change undermines the reader's ability to give *"intelligent consideration"* to the consultation. Without clarity on this issue, responder is led to give *"intelligent consideration"* to the pros and cons of making **any change** from the status quo, rather than to engaging in consideration of the relative merits and challenges presented by the options themselves.

The evidence that the premise of the consultation was insufficient is clear from the following which oppose the change from the status quo:

- Extensive public statements made during the consultation
- Press coverage that did not engage with the need for the changes
- Petition responses

- Requests for clarification from the 6 Healthwatch in South West London, and the Joint Health Overview & Scrutiny Committee to NHS
- That we feel unable to provide a consultation response weighing the options

Whilst Professor Sir Mike Richards has contributed an introduction, and his report is available via a link from the consultation, the important rationale underpinning the need for change is not clear from the consultation materials.

Proposals are not at a formative stage

Gunning's Principles require engagement to have some prospect of meaningfully impacting the decisions being consulted on.

The consultation document sets out an extensive scoring process of bids by the 2 parties against a 42 page scoring framework of criteria all taking place prior to the consultation. It is a *fait accompli.*

Whilst the consultation documents contain empty assertions that *"the decision has not been taken"*, this is simply not credible. Were the consultation to have any prospect of influencing the decision previously arrived at via the scoring criteria, it would need to be able to influence either the scoring criteria that the bids were asked to address, or the scoring of the bids themselves, which are not provided in sufficient depth.

The consultation is perhaps useful in refining the proposals to some extent, and in socialising the change before it occurs. It cannot however be considered to be a genuine opportunity to influence a decision that was taken prior to the consultation closing.

Conscientious consideration cannot be given to consultation responses because information that would allow this is not being collected.

In addition to the fact that the decision has clearly been made prior to the consultation taking place, the consultation questions do not collect the information that would be needed to influence the decisions. To achieve this, the questions would need to:

- relate to the criteria in the scoring exercise, the way that these scores have been applied or the appropriateness/completeness of the criteria
- enable respondents to express a preference to the options by ranking them against the criteria; or
- enable respondents to describe the **relative** strengths and weaknesses of the 2 options.

As put, we are not convinced that the questions enable respondents to provide responses that could realistically lead to conscious consideration. There is also no reason to exclude all other sources of feedback such as petitions such as this.

Further

We are not assured that the risks arising from this change have been appropriately considered. There are apparent risks to both the incoming provider and to Royal Marsden Hospital.

Neither incoming provider has the experience or staff expertise required to undertake the services that would transfer to them. It is reasonable to expect that significant retention issues will arise from asking staff to both change from personal to public transport and increase their average daily commutes from c60min to c140 minutes.

Whilst the travel time will clearly create retention pressures for those staff that do transfer, existing staff may also be redeployed to vacancies within RMH, notably within teenage and young adult cancer services: *"Part of [the teenage and young adult cancer services] is currently provided by staff who support the children and young people's service"*, which will create competition for these.

The impact on the Royal Marsden is sufficiently significant the consultation documents state that ongoing support will be provided. No information is provided however as to what this impact is, or how it will be mitigated other than through short term funding however.

Travel time

Much consideration is given to travel time within the documents in terms of minutes spent travelling. Travel time however is important not just in terms of the amount of time that people have to sit on trains or in traffic, but in terms of the impact that it has on a person's ability to meet their essential commitments.

Parents and staff will have commitments outside of the hospital. These will have step change impacts. Parents will need to balance the time taken to visit a child in hospital with work and other family commitments. Travel times in excess of 1 hour lead to round trips in excess of 2 hours. The impact of this on parent and staff ability to manage their competing commitments is neither understood nor sought by the consultation. More so where such journeys cannot be undertaken by private transport – for example because parking is unavailable.

Conclusion

It is with regret that we feel that we have no option but to conclude that the consultation is insufficient as it fails the legal test for consultations and appears to have no prospect of altering the decision to award the new service to the Evalina.

As the consultation fails to identify the material unintended consequences of the move on staffing, patients and families and on the incumbent. We are concerned that these cannot be mitigated effectively as they have not been articulated or sought. The change would appear to present a considerable unknown and unmitigated risk as a result.

Furthermore, a substantial change of this nature requires a compelling reason to justify it. If such justification exists, it has not been articulated by the consultation. What rationale there is, appears to be quite limited in scope and focussed on hypothetical future benefits/problems or relying solely on national directives. We do not agree that sufficient justification for this change has been presented within the report.

Yours sincerely,

Mike Derry
Chief Officer
Healthwatch Richmond
0208 099 5335
mike@healthwatchrichmond.co.uk

Response submitted on behalf of:

healthwatch Merton

healthwatch Richmond upon Thames

13. Kent and Medway Cancer Alliance

Proposals for the future location of very specialist cancer treatment services for children living in south London and much of south east England

Please see Kent and Medway Cancer Alliance response.

Context

There are three paediatric oncology shared care units (POSCUs) in Kent and Medway that work in partnership with the Primary Treatment Centre, to offer the child supportive care closer to home. These are:

- Maidstone and Tunbridge Wells NHS Foundation (MTW)
- East Kent Hospital University NHS Foundation Trust (EKHUFT)
- Medway NHS Foundation Trust (MFT)

Process of engagement

As part of the Consultation process Kent and Medway Cancer Alliance has engaged with our community through the following process:

- Discussion led by Dr Christopher Tibbs, Medical Director Commissioning, NHS England (South East) at the Kent and Medway Cancer Alliance Delivery Board. This includes senior clinical and managerial representatives from across the cancer community.
- Direct engagement with colleagues in our POSCUs
- Discussions at the South Thames CTYA ODN.
- Kent and Medway Cancer Alliance Working Together patient partnership group.

Throughout this engagement process our POSCUs have told us that they have been very aware of the process and have attended a large number of the webinars / meetings with the PTC.

There have been additional meetings with the POSCUs and NHSE team to provide feedback, which has been recorded as part of the consultation feedback. EKHUFT colleagues attended the meeting on 11th December to give their feedback and a NHSE programme team joined clinics face to face and spoke to five parents - at significant length - and their children about their views.

Dartford and Gravesham NHS Trust NHS Trust do not provide POSCU services have shared their views with the South Thames Paediatric Network.

Key issues

Overall from our POCUs and patient groups the following requirements need to be addressed with the new PCT proposals.

Personalised care and purpose built environment for paediatric care
Clinicians and patient groups expressed the importance of a PTC offering child friendly services with holistic care. This includes access to :

- Education - critical to supporting development and providing continuity of education as well as supporting return to local schooling arrangements.
- Age appropriate play
- Facilities for the child / siblings / family
- Space for families to stay with/near their child.

It is also important that the PTC supports the transition to care closer to home to ensure continuity of personalised care and support.

Travel
New proposals need to understand the substantial travel required for a significant cohort of Kent and Medway patients and families in order to access specialist paediatric cancer services. We understand there has been dedicated work commissioned on behalf of the consultation to understand the impact of travel on the re-location of the PTC It is important that the new proposals seek not just to meet existing standards but to optimise ease of travel and mitigate against exacerbating health inequalities, not least our deprived coastal communities.

Our Working Together Group is keen to understand how families will be supported with travel logistics as well as costs at a time of extreme worry and concern with a sick child. The rising cost of living, increase in train costs and expansion of ULEZ have added to the stress and financial strain of travel. Some families may struggle to maintain work whilst caring for a sick child especially whilst at a PTC.

In terms of logistics there needs to be clarity around supporting families with ready access to the financial advice and support available to help with travel costs and benefits.

Additionally, appointment times need to be mindfully considered to enable patients to get to appointments at an appropriate time and cost. (with options to arrange travel overnight for early appointments if required/desired or to delay appointments until later in the day).

- Co-location of PICU with PCT to meet to meet 2021 clinical requirements for PTC.
- Co-location with as many paediatric subspecialities as possible for maximal expertise / opinion / timely review.
- To deliver a high class / state of the art / access to latest trials / safe service
- To build on existing relationships with clinicians known to local clinical teams and families.

- Alignment of IT systems to deliver shared care and support good communication with the POSCUs. PTCs should enable access to Kent and Medway patient records to support access to information as needed.
- Ensure bed mapping will meet demand to reduce wait times and transfer for new diagnoses or unwell children across for specialist review.

Both patients and clinical respondents are clear that the above requirements must be met in the new PTC.

From some of the POSCUs responses we have seen there is a preference for the Evelina London Children's Hospital. Providers have said it not only meets new PTC requirements with the co-location of services with the PICU, but also provides access to Cardiology and Nephrology, cited as two of the most frequent services needed.

There is support for all radiotherapy services to be delivered at University College London Hospitals NHS Foundation Trust.

As an Alliance we have not been party to all discussions and responses and wider family engagement and there recommend referring to the individual POSCU responses from Kent and Medway or more detailed views on the proposals.

For more information or to discuss this response please contact Ian Vousden at ian.vousden@nhs.net or Claire Mallett at Claire.mallett3@nhs.net

Claire Mallett
Lead Personalised Care and Support
18 December 2024

14.King's College Hospital NHS Foundation Trust

NHS
King's College Hospital
NHS Foundation Trust

Professor Clive Kay
Chief Executive
Denmark Hill
London
SE5 9RS

020 3299 3939
www.kch.nhs.net

By email: england.childrenscancercentre@nhs.net

16 November 2023

Ailsa Willens Programme Director Children's Cancer Principal Treatment Centre	**Dr Chris Streather** Medical Director	**Dr Christopher Tibbs** Medical Director, Commissioning
NHS England – London	NHS England – London	NHS England – South East

Dear Ailsa, Chris and Christopher

Response to the proposals for the future location of very specialist cancer treatment services for children who live in South London and much of South East England

King's College Hospital NHS Foundation Trust (King's) currently provide tertiary services to patients across South London and South East England, including some sub-specialties where we act as a quaternary and international centre. As a major provider of children's healthcare both locally and as a tertiary centre, King's College Hospital is a key stakeholder in the current consultation on the location of the Principal Treatment Centre for Children with cancer and has been an active member of the Programme Board. Of particular note for the services being considered as part of the consultation is the fact that we provide the majority of paediatric neurosurgery for South London and South East England.

King's is the only provider of paediatric liver services in London and one of only two sites (with St George's) that carries out paediatric neurosurgery. King's is one of the two busiest units in the UK for paediatric neuro-oncology surgery, with around 100 tumour operations – (including the most complex work) taking place each year at King's.

Continued collaboration with the future Principal Treatment Centre is of utmost importance to King's and our patient pathways. Wherever the future Principal Treatment Centre is located, it is vital that there is true collaborative work across other specialist centres; for King's this would be particularly with liver, neurosciences and haematology.

As an organisation we have discussed the consultation paper at a Board Development Day (19 October) and at King's Executive Committee (13 November). We have considered the the two options for the future location of the Principal Treatment Centre. As you know,

throughout this process we have maintained that King's is a 'fixed point' and that we would work in partnership with whichever site is chosen for the PTC. Having reviewed the proposals we believe that such partnership working would be possible with either side. We support the proposals relating to the move of conventional radiotherapy to UCLH.

We note that St George's already have expertise in cancer care and work closely with the Royal Marsden. However, we are concerned about the nature of the campaign that has been run by St George's and affiliated individuals. This has implied that all cancer care can (and will be) provided at St George's if that option is chosen. It is important to be clear in all correspondence that children will continue to be seen at King's, whichever option is chosen, and that most children on complex pathways are seen by multiple providers. This will not change as a result of these proposals. Specifically children with liver cancer and many of those requiring neurosurgery will need to be treated at King's.

We already work closely with GSTT and the Evelina as part of King's Health Partners. However, we recognise that the Evelina will need to develop expertise in the provision of chemotherapy to children if this option is chosen.

We are keen to engage with whichever provider is chosen to ensure that pathways involving King's are clear and offer children and families the best possible care and outcomes.

Yours sincerely

Prof Clive Kay
Chief Executive

15. NHS South East London Integrated Care Board

South East London Integrated Care System

NHS South East London

NHS South East London Integrated Care Board response to the NHS England consultation on the South Thames Principal Treatment Centre for Children's Cancer services

December 2023

The South East London Integrated Care Board (SEL ICB) expressed its support for work undertaken across London around Principal Treatment Centres for children's cancer as a significant opportunity to improve the experience and outcomes for children and young people with cancer, as well as the experiences for families' and carers'. In doing so the ICB endorsed the Guy's and St Thomas' Hospital NHS FT (GSTT) bid for the transfer of the Principal Treatment Centre (PTC) for children's cancer services in the South Thames region to Evelina London, which is now subject to public consultation as one of two consultation options.

From an ICB perspective, access to high quality specialist services when people need them remains a priority. The ICB remains confident that Evelina London, as a dedicated children's hospital, will be able to deliver high quality, coordinated cancer care for children if successful in becoming the designated South Thames children's cancer PTC. We are also confident that Evelina London's international impact as a children's health research leader, as well as the Trust's facilities and expertise in adult cancer research, will provide a strong basis for delivering a future-facing service, and that Evelina London's experience of caring for seriously unwell children will underpin its support for children with cancer and their families.

The ICB has a strong relationship with GSTT, from whom we already plan and secure £520m worth of care in total, including the full range of community and secondary care children's services.

If the outcome of the consultation is that GSTT is the preferred and recommended option, the SEL ICB is committed to working with GSTT, St George's University Hospital NHS Trust (SGH), and the Royal Marsden (RMH), other ICBs, NHS England, patients and families, and others to ensure the service move is a success. There are strong relationships across south east and south west London, and we will work closely to ensure the service transfer and integration of the service within SEL ICB but reaching into wider geographic catchments is seamless.

We expect that SEL ICB would become responsible for commissioning at least some of the children's cancer PTC in the future, in line with the national road map for integrating specialised services with ICBs published in May 2022. Recognising that SEL providers offer many specialised services across wide geographies we are already preparing for the delegation of those services suitable and ready. South London (including SEL ICB, South west London ICB, St George's University Hospital NHS Trust (SGH), GSTT, King's College Hospital NHS FT (KCH) and more recently the Royal Marsden (RMH)) has been working together since 2019 and we have developed a South London approach to specialised commissioning delegation in order to minimise risks and maximise opportunities, including significant planning and pre delegation work and the establishment of comprehensive governance and work streams.

Going forward we are committed to working with colleagues across the South London and wider London partnership to ensure that paediatric cancer services planning, and delivery is successfully embedded in to our agreed operating model and governance structures for specialised services.

16. Royal College of Paediatrics and Child Health

RCPCH
Royal College of Paediatrics and Child Health
Leading the way in Children's Health

5-11 Theobalds Road
London
WC1X 8SH

Phone: 020 7092 6000
www.rcpch.ac.uk

Children's Cancer Team, NHS England
Sent by email to: england.ptcchildrenscancer@nhs.net

Monday, 18 December 2023

Dear Colleagues

Re: Proposals for the future location of very specialist cancer treatment services for children who live in south London and much of south east England

The Royal College of Paediatrics and Child Health (RCPCH) has liaised with its affiliated specialty group - the Children's Cancer and Leukaemia Group (CCLG) – on preparing this letter intended to respond to the proposed future children's cancer Principal Treatment Centre consultation. The College endorses the detailed response prepared by the CCLG and its recommendations on the preferred provider, and agrees that there is much to welcome in these proposals.

We understand that NHS England have undertaken a rigorous process to prepare this consultation, focusing on important domains to assure a safe, effective and high-quality service is provided for children in London and the South East.

The College has been concerned for some time about families being able to access and afford to travel to hospital appointments throughout the UK, and we acknowledge the concerns raised by families as part of these new proposals. This is an area that should be looked at nationally, to ensure accessibility for all patients across the country, both in terms of strengthening the POSCU network and providing a travel costs fund for all families so that they are not left out of pocket by having to travel to hospital.

The College supports the aims of this consultation to ensure that the proposed future children's cancer Principal Treatment Centre will meet the requirements of the service specification. The priority for the RCPCH is that the new model provides high quality clinical care, an excellent patient experience, and the continuation of vitally important research.

Yours sincerely

Dr Camilla Kingdon
President, Royal College of Paediatrics and Child Health

17. St George's Hospital

St George's, Epsom and St Helier
University Hospitals and Health Group

St George's University Hospitals
NHS Foundation Trust
Blackshaw Road
London
SW17 0QT

Direct line: 0208 725 1635
Email: Jacqueline.Totterdell@stgeorges.nhs.uk

Sent via email:
england.childrenscancercentre@nhs.net

18 December 2023

Dear colleague,

Please accept this as St George's response to the public consultation on the future of the children's cancer Principal Treatment Centre (PTC) in the South Thames region.

St George's is home to a large children's hospital, with dedicated paediatric capacity and an extensive range of tertiary paediatric subspecialties. We are rated outstanding for paediatrics by the CQC, and have been delivering the PTC in partnership with the Royal Marsden for decades. Our proposal is to consolidate the PTC onto the St George's site in a new, state-of-the-art children's cancer wing – delivering outstanding facilities to match the outstanding care we already provide.

Our view is that the best option for children is for the PTC to be consolidated onto the St George's site. We believe this is the best option because:

- Unlike the Evelina, St George's **has 25 years' experience** of delivering paediatric cancer care. The expertise built up over these years, and the professional relationships built up between different clinical specialists as they collaborate to treat children with cancer, cannot be easily or quickly replicated overnight. See annex A for more detail.
- The **services that matter most for children with cancer are available on site at St George's**.
    - 15% of children with cancer will have a neuroblastoma, renal tumour, or germ cell tumour, and these children will often require major surgery performed by a paediatric oncology surgeon to remove or reduce their tumour. This expertise is rare: there are 20 such surgeons in the country, three of whom are at St George's. The Evelina does not have this expertise, and would need either to rely on surgeons from St George's going to work at the Evelina, or to build a new surgical team to cater for these children.
    - 25% of children with cancer have a brain or spinal tumour, many of whom will need neurosurgery. Some other children with cancer will also need neurosurgery as a result of their treatment. Sometimes this neurosurgical input

is needed in an emergency. Along with King's, St George's provides neuro-oncology surgery and acute neurosurgery, but the Evelina does not.

- 32% of children with cancer will have leukaemias or other blood cancers, and a further 10% will have a lymphoma. For these children, bone marrow transplants and increasingly CAR-T are key treatments for the PTC to be able to deliver. These are complex, high-risk, heavily regulated treatments. St George's has a bone marrow transplant programme for adults and is accredited to provide CAR-T for adults, and so is well placed to extend the offer to children. GSTT does not have a bone marrow transplant programme, and is not accredited to deliver CAR-T. These highly regulated and complex clinical and laboratory services are difficult to set up without past experience.
- The services available at the Evelina and not St George's (inpatient cardiology and nephrology) are important, but required for much smaller numbers of children with cancer (see Annex B for more detail). On the other hand, the commonly used aspects of these specialties are delivered at St Georges or could be through tele-medicine. Patient transfers would not be required.
- Taken together, this means that for some 80% of children with cancer, St George's can offer or is poised to offer key treatments that the Evelina will not, or will have to develop. To my mind this calls into question why the NHS has embarked on a competitive process, bringing in providers without experience of children's cancer, rather than working with the existing providers to meet the new service specification as has been done in North London.
- Looking further to the future, St George's, University of London is an international leader in research in vaccines, infection studies and clinical trials, a key strategic asset given the long-term potential for vaccine technology to be developed to support the treatment of cancer.

- St George's can deliver **what parents of children with cancer say they want**. Above all, expertise and experience. But parents have also said that when you have a child with cancer, potentially on immunosuppressants, you take them to hospital by car not on public transport. Parents have consequently said they would prefer the children's cancer centre to be outside of central London, with good parking provision. St George's will and does offer this, with dedicated parking spaces and a drop-off zone for the families of children with cancer, directly outside the entrance of our proposed new, state-of-the-art Children's Cancer Centre.
- Consolidating the children's cancer centre at St George's will be **easier and less costly** for the NHS to deliver. A large part of the service is already at St George's, and at St George's, an existing non-clinical space can, at relative speed, be transformed into a new state-of-the-art cancer centre. It will also be less disruptive for staff, and cost the NHS less, when compared with trying to move more services and more staff to central London. See annex C for detail.
- If children's cancer services are transferred from St George's to the Evelina London Children's Hospital, this will have an **impact on other children's services** at St George's. Children's cancer services are not neat, stand-alone services. For instance,

the surgeons at St George's who operate on children with cancer also operate on other children from across South West London and Surrey. In some cases, St George's will have to retain these staff but lose the income associated with children's cancer care. In other cases, the expert staff supporting children with cancer could leave St George's. This would weaken other services provided to children in South West London and Surrey, particularly surgery and pathology. See Annex D for more detail.

Since submitting our proposals, our position with regards to research and education has also grown stronger. We already support **more children into trials** of medicinal projects **than any other provider in South London**, and are uniquely placed to support the PTC's ongoing partnership with the ICR, given our proximity and the Government's support to build a new hospital in Sutton that would see the St George's, Epsom and St Helier Group co-located with the ICR. Now, with City University of London and St George's, University of London exploring a merger and developing ambitious plans to invest in the St George's campus, the opportunities are stronger still.
I know many of these arguments will be familiar to NHS England, as we have made them consistently over the past 3 years. Nevertheless, I believe that together they make a compelling case for keeping the PTC at St George's, and I hope you will feel able to consider them as you make your decision.

Yours sincerely,

Jacqueline Totterdell
Group Chief Executive

Cc:
Dr Chris Streather, Medical Director, NHS England, London
Dr Chris Tibbs, Medical Director – Commissioning, NHS England, South East

Annex A – St George's Paediatric Cancer Experience

The current PTC service at St George's and the Royal Marsden has been built up over 25+ years.
In many cases, it is reliant on the experience of individuals with extremely rare expertise. For instance:

- Paediatric oncology surgery requires surgeons with uncommon skill and expertise. There are only around 20 in the country, of whom 3 are at St George's. St George's is the only hospital in South London with such expertise.
- Paediatric oncology surgeons work with a small number of highly specialised paediatric anaesthetists for complex cancer cases – St George's is unique in South London in having such experts supporting children's cancer care.
- Pathologists – there is a national shortage of paediatric pathologists, and very few with paediatric oncology skills. In South London, outside St George's no other paediatric centre's pathologists routinely undertake oncology pathology

It cannot be assumed that these individuals will move if the children's cancer service moves – and since most of them provide care to children with cancer but also to other children, most will not qualify for automatic transfer under TUPE regulations.
If the individuals do not move, developing the expertise in new staff takes a long time. For instance:

- Advanced nurse practitioners in oncology take 4+ years of training and supervised practice before they can practise independently
- It takes between 5 and 8 years post completion of paediatric surgical training for a surgeon to develop competence in paediatric oncology surgery
- It takes 1 year to train nursing staff with oncology specific skills such as administration of chemotherapy and High Dependency Unit level competencies, and another 1-2 years for consolidation of skills

The importance of experience is also not just about individuals, but about multi-disciplinary teams building up years of experience and trust working together to provide patients with seamless care. For instance:

- Paediatric oncology surgery requires a whole team approach, involving surgeons, nurses, diagnosticians, anaesthetists, theatre staff, intensive care clinicians. This has developed over years at St George's
- The surgical service is highly integrated into a multi-disciplinary team, alongside pathology, diagnostic radiology, interventional radiology, paediatric intensive care and oncologists. At St George's this team benefits from years of mutual trust in each other's competence and knowledge.
- Some paediatric tumours are seen rarely in children – joint working with adult specialist surgeons is well established for these.
- The medical oncology service is similarly integrated with other medical and diagnostic services, particularly critical specialties like infectious diseases and microbiology.

Annex B – important services for children with cancer, including neurosurgery

Because children with cancer can need care from a wide range of paediatric specialists, the national service specification for PTCs sets out a number of service which, while they do not need to be on the same site, must be 'readily accessible'. Most of these services are available on site at both St George's and the Evelina, but the key differences between the two relate to neurosurgery, kidney care, and cardiology.

	Available at St George's?	**Available at Evelina?**	**Scale of need**
Neurosurgery (for cancer-related problems affecting patients' brains, nervous systems or spines)	Yes. Neurosurgery for children with cancer is delivered at St George's (the smaller service) and King's (the larger service)[1], primarily depending on which part of London/the South East the child is from.	No – patients would go to King's or St George's for surgery. In exceptional circumstances, emergency neurosurgery could be carried out on site at Evelina London by a neurosurgeon from King's.	Approximately 25% of children with cancer have a brain/spinal tumour. In 19/20, 86 children had cancer-related neurosurgery. Sometimes this is needed in an emergency.
Paediatric oncology surgery	Yes. Of the c. 20 paediatric oncology surgeons in the country, three are at St George's.	No – either surgeons from St George's would need to go to the Evelina to undertake the surgery, or the Evelina would need to develop the expertise.	Approximately 15% of children with cancer have a solid tumour of the type where a major paediatric oncology surgical operation may be needed.
Inpatient **nephrology** (for patients with kidney disorders)	No – outpatient clinics and dialysis available on site, but for other inpatient care children would go to the Evelina.	Yes	In 19/20, 6 children with cancer who were treated at The Royal Marsden also received inpatient care at Evelina London for kidney care. 3

[1] Depending on the data source and year in question, St George's provides c.20-30% of neurosurgery for children with cancer in the region, and King's 70-80%.

			of them had to stay overnight in hospital.
Inpatient **cardiology** (for patients with defects and diseases of the heart and blood vessels)	No – outpatient clinics and diagnostics available on site, but for inpatient care children would go to the Evelina.	Yes	In 2019/20, 25 children with cancer who were treated at The Royal Marsden also received inpatient care at Evelina London for heart care. All were seen as day cases (i.e. did not stay overnight in hospital), mostly for diagnostic tests which St George's can deliver on site.

Sources: NHSE Pre-Consultation Business Case, National Disease Registration Service (NDRS)

Annex C – finances

NHSE have assessed the St George's proposal as involving lower capital costs, representing better value for money, and having a better revenue impact (see table below).

	St George's	Evelina
Capital costs	£30.8m	£44.3m
- Funded by charitable donation	- £0m	- £10m
- Funded by NHS	- £30.8m	- £34.3m
Value for money ratio *The VfM ratio shows the relationship between a project's costs and benefits. If the ratio is greater than 1, the benefits outweigh the costs. If the ratio is less than 1, the costs outweigh the benefits.*	1.5	1.3
Adjusted financial performance of the service – retained surplus / (deficit) by 2030/31	-£0.018m	-£1.9m

Source: NHSE Pre-Consultation Business Case, finance section, available here.

Beyond the financial impact on each individual institution, there will be wider costs to the NHS as a whole. This includes stranded costs at St George's if the children's cancer service moves to the Evelina. St George's has estimated these costs at c. £2.5m in the first year if the service moved.

Annex D – impact on St George's other paediatric services if children's cancer moves

Paediatric cancer care at St George's is delivered by a wide range of specialties, as part of their broader caseload, including paediatric surgery, paediatric intensive care, paediatric acute medicine, gastroenterology, haematology, infectious disease, neurology, paediatric neurosurgery, and clinical support services such as paediatric pathology and radiology. There are few tertiary paediatric specialties at St George's whose work would not be affected by moving the children's cancer service to central London.
For most of these services, the Trust believes it would be able to mitigate the impact over time. But for some services (particularly paediatric surgery, paediatric intensive care, and paediatric pathology) the impact would be much more significant.

1. **Paediatric surgery**. Transferring the PTC would mean the service losing 20% of its elective caseload, and the element of its case load that makes it most attractive to current and future surgical staff – paediatric oncology cancer is complex, rewarding work for our surgeons. St George's view is that it is highly likely that in time it would result in some of the service's most experienced and capable surgeons leaving, and make the service a less attractive prospect for surgeons that the Trust would need to seek to replace them. This includes surgeons that the Trust currently relies on to deliver general and specialist paediatric surgery for children from across South West London and Surrey..

2. **Paediatric pathology.** Paediatric cancer constitutes a significant proportion of the total number of specimens examined by the Trust's paediatric pathology department, and an even more significant proportion of the department's workload (because cancer cases tend to be more complex and time consuming). It is also, as with surgery, the element of the caseload that makes the department attractive to current and future staff. The loss of cancer work would therefore significantly impact on the attractiveness of the department, at a time when paediatric pathologists are in short supply across the country. The Trust's view is that it would threaten the viability of the service. This would in turn impact on other services in South West London catered to by St George's paediatric pathology department, including perinatal post-mortems, and paediatric and maternity services.

3. **Financial impact - particularly for intensive care.** Paediatric oncology is an integral part of a range of paediatric services at St George's, rather than a stand-alone service. Clinical staff care for children with cancer but also children without cancer. Consequently, if the service were transferred to the Evelina, St George's would lose the associated income but not be able to cut all the costs associated with the staff and facilities. St George's currently estimates that the resultant financial gap would be c£2.5m in the first year after any move of the cancer service, reducing over time. The impact is particularly significant for paediatric intensive care, where just under £1m of these costs sit.

18. South Thames Paediatric Network

Dear Consultation Team

Please find the statement below issued on behalf of the South Thames Paediatric Board in response to the consultation request:

The South Thames Paediatric Network (STPN) works with 3 Tertiary providers (Evelina London, King's College and St George's), 17 acute providers and Royal Marsden Hospital as a specialist provider, and across 5 ICBs (South East London, South West London, Kent, Surrey Heartlands and Sussex). The STPN Board has clinical and commissioning representation from across all these areas, as well as from NHSE London and South East Specialised Commissioning. The STPN work programme spans across Critical Care, Epilepsy, Gastroenterology, Long Term Ventilation, Surgery, Rehabilitation for Children with Complex Needs and cross-cutting themes such as Transition. The network has a joint Memorandum of Understanding with the South Thames CTYA Cancer Operational Delivery Network, and supports their strategy and delivery of education to the PTC and POSCUs.

The STPN Board supports NHS England's position that the children's cancer Principal Treatment Centre (PTC) must move to a site that provides both intensive care for children and other specialist children's services, and that this change must happen without further delay. The move of services from the Royal Marsden site to either Evelina London or St George's Hospital provides new and exciting opportunities to develop consolidated safe and effective MDT care to improve the outcomes and experience for CYP and their families. As a network which works closely with both proposed new PTC sites, it is not appropriate to comment specifically on each option for which there are pros and cons of both models.

We would however, strongly recommend that any decision and future plans should focus on the four key elements of the STPN vision as outlined below:

•Children in the network having access to high quality specialist paediatric care in the place most suitable to their needs at the appropriate time
• The network is governed by quality standards and agreed pathways
•Shared learning across the partners on valuable aspects of service delivery or development from clinical best practice, service transformation, new models of care or new roles within workforce
•Economic benefits for both providers and commissioners achieved through improved efficiency of services, avoiding unnecessary duplication.

Based on our knowledge and experience it is vitally important that to achieve the above vision the PTC needs to work in a collaborative and networked way to provide, for example:
1. Clear documented referral and discharge pathways and processes shared with all stakeholders, that are audited, evaluated, and adhered to
2. Clear information for CYPYA and their families regarding their treatment, side effects, places of care with clear emergency contact details that encompass the PTC and all POSCUs
3. Good lines of communication between the PTC, POSCUs, acute providers, and both the STPN and the STCTYA Cancer ODN. This must also include the ULCH Radiotherapy Service

4. A named clinical care co-ordinator to collate and disseminate all investigations and results to relevant stakeholders
5. An MDT attended by all relevant clinicians including medical, nursing and AHP staff

The STPN Board and network team will commit to supporting and working with the chosen PTC to deliver high quality, well-coordinated care for Children and Young People undergoing cancer care within the STPN geographical region. We would wish to continue our close and collaborative working relationship with the South Thames CTYA Cancer Operational Delivery Network which is currently hosted by the Royal Marsden Hospital.

STPN Management Team

19. The Royal Marsden NHS Foundation Trust

The ROYAL MARSDEN
NHS Foundation Trust

Our Ref: DF/8629

The Royal Marsden
Fulham Road
London SW3 6JJ
Tel 020 7352 8171
www.royalmarsden.nhs.uk

The Royal Marsden's response to the public consultation on the future location of specialist cancer services for children living in south London and south east England

The Royal Marsden will always support any change in the provision of children's cancer services which is in the best interests of patients and families. As a specialist cancer centre, we are the current host of the Principal Treatment Centre (PTC) for children with cancer for south London, Surrey, Sussex and the south coast.

We understand what is important to our patients, parents, families, and our staff, because they tell us what they value. It is important that any future location can replicate all of the benefits patients currently receive at The Royal Marsden. Our concern as a Board is that other than achieving co-location with PICU, there will be fragmentation of the service, the number of transfers for patients will be higher, research will be affected and the experience and outcomes for patient and families will not be improved overall.

The key benefits of the current model are set out below.

Safe and high-quality children's cancer services delivered in a research active environment

Children, families, and staff value the high-quality specialist cancer care delivered in a research active environment, in bespoke paediatric facilities with a dedicated, highly trained team who are separate from, but closely integrated with, the specialist cancer care delivered in the wider hospital. This specialist team is responsible for diagnosing and treating a wide range of cancers in children. This includes solid cancers such as neurological cancers (malignant brain tumours), sarcomas (high grade cancers of muscles, bone, and other soft tissues) and of other organs, as well as blood and lymph node cancers such as leukaemia and lymphoma.

State of the art diagnostic techniques, specialist drug treatments and onsite radiotherapy

Our cancer model provides state of the art diagnostic techniques including imaging, pathology, and genomics, on site leading-edge drug therapy including chemotherapy, targeted drug treatments, bone marrow transplants and new immunotherapy treatments. The specialist cancer model at The Royal Marsden also includes onsite radiotherapy. This limits the number of journeys children, and their families must undertake to access the treatments they need most often.

The care children receive from the core paediatric team also relies on staff in other services such as anaesthetics, imaging, pathology, and surgery who have over many years developed expertise in

diagnosing and treating children with cancer.

In addition, The Royal Marsden is also able to draw upon its adult oncology expertise, when needed, for all cancers treated by the paediatric unit, both for standard of care therapies and for clinical trials. This further enhances expertise and capability available to children and their families.

This care is delivered in a well-established and successful partnership with other paediatric specialists at St. George's Hospital for children who need cancer surgery and for the very small number of children who need, or may need, paediatric intensive care. Royal Marsden consultants are on site at St. George's Hospital every day of the year to look after these children.

Modern purpose-built, children's cancer centre opened in 2011

The Oak Centre for Children and Young People is a modern, purpose-built, age-appropriate centre that opened in 2011. It is distinct from the main hospital and provides over 2,500 sq. m of accommodation for children (excluding TYA facilities), its own separate entrance, multiple outdoor and indoor play spaces available for children, dedicated parking spaces available for patients and families and onsite parking for staff.

The radiotherapy, MRI and PET/CT departments provide dedicated changing, waiting and preparation space for children requiring sedation prior to undergoing tests and treatment.

There is accommodation within half a mile of The Royal Marsden Sutton site for families who have longer journeys.

Ease of access for patients, families, and staff

Parking and access are a key issue for parents and families. The majority of patients live outside the M25 and rely on driving their vulnerable children to hospital in order to avoid the risk of infection from travelling on public transport. The majority do not use public transport to bring their children to hospital, especially when feeling unwell, undergoing treatment and particularly when they are neutropenic (immunosuppressed due to treatment).

Ease of access, parking and accommodation is therefore extremely important for parents of immuno-suppressed sick children, many of whom are on research trials as patients and must make additional visits to hospital.

More than 70% of our staff live either locally to Sutton or further out into Surrey. More than 80% of our paediatric staff drive to work and, of the remainder, many live close enough to walk, cycle or take a local bus. Many nurses and Allied Health Professionals who have children in local nurseries or the Royal Marsden onsite nursery, drive to work to support their own childcare arrangements.

The Royal Marsden and the ICR are ranked in the top 5 centres globally for the impact of their research

The research output from The Royal Marsden, in collaboration with the ICR, has had significant impact for children in South Thames, the UK, Europe and globally.

The Royal Marsden:

• Has opened the most clinical trials of new drugs for children with cancer and is the largest recruiter of paediatric oncology patients to early phase clinical trials in the UK currently

• Is the largest and most active of the UK's 12 Paediatric Experimental Cancer Medicine Centres (ECMC) for children and young people with cancer and the five UK designated Innovative Therapies for Children with Cancer (ITCC) European Consortium 'first-in-child' specialist centres.

• With the ICR, The Royal Marsden forms the only NIHR Biomedical Research Centre (BRC) for cancer in the UK.

• Has the most comprehensive and integrated cancer Drug Development Unit encompassing paediatric and adult cancer trials and teams who work together to promote best access to clinical trials for all age groups.

This finely tuned research ecosystem was built up as a result of the long history of research collaboration between The Royal Marsden and the ICR and it is unlikely that this will continue in any future model.

Substantial investment of £100 million in children's cancer by The Royal Marsden over the last decade

Non-NHS income supports The Royal Marsden's highly specialised workforce on an annual recurrent basis and will need to be replicated in any future model to allow the existing infrastructure to continue.

In addition to the £100 million of investment in the paediatric service over the last 10 years, there is an income shortfall equating to more than £80 million over ten years that will be required to deliver the core service and preserve research activity. This includes support for 40 WTE staff including several consultants and middle grade doctors, as well as clinical and research nurse specialists, specialist pharmacists, play and other therapists, social workers, psychologists, and clinical trial managers all of whom are specialist staff in the paediatric unit.

Points to consider in the future provision of children's cancer services.

The relocation will not provide a single site solution and the proposed model will increase the number of transfers that children experience

At present, photon radiotherapy for children in the South Thames region is delivered on site at The Royal Marsden in Sutton and Proton Beam Radiotherapy (PBT) is delivered at UCLH. Both proposed options for the new PTC require moving all radiotherapy services away from the main PTC site to UCLH. Although reducing transfers is a headline aim of the NHS England decision to relocate the PTC, this proposed reconfiguration will introduce additional transfers due to the new necessity of delivering all radiotherapy offsite away from the PTC.

Over the last five years between 41 and 51 children have required radiotherapy with between:

- 14 - 21 children being admitted per year for their course of radiotherapy
- 480 - 830 attendances per year for children receiving radiotherapy as an outpatient

In the coming years it is expected that more children will have PBT. However, 40 to 50 % of children requiring radiotherapy will continue to require photon radiotherapy in the long term and those children will need to transfer due to the new model when they would not have otherwise.

A more fragmented oncology service for children

For the first time, the PTC relocation will disaggregate major oncology treatment modalities for children in the South Thames PTC, making radiotherapy services only available in North Thames.

Those children having radiotherapy as an inpatient will need to meet new staff on a new site. Importantly, this includes photon radiotherapy for Total Body Irradiation (TBI) for children undergoing bone marrow transplantation who are often in a vulnerable clinical situation. This means that very unwell children will be some of the most impacted, as without the relocation they could receive radiotherapy onsite in the PTC which will no longer be possible.

Those children requiring radiotherapy treatment as an outpatient will now have to attend an additional central London site, north of the Thames. For some families this will involve repeated long-distance journeys on a daily outpatient basis. In addition, some of these children require the delivery of chemotherapy during radiotherapy on the same day and it is unclear how that will be managed in any proposed future model.

A lack of future resilience with only a single site for radiotherapy in London and the South East for children with cancer

UCLH will be the only site for paediatric radiotherapy in the new model across a geographically large and highly populous region affecting all inpatient and outpatient radiotherapy services including for children who require Total Body Irradiation for bone marrow transplantation. The described 'larger service' introduces a new and significant risk, along with increased fragility, for the provision of radiotherapy for children across London, the South and South East of England, especially as this service also treats children from the Southampton and Oxford PTCs, neither of whom offer paediatric radiotherapy.

Impact on clinical research

The Royal Marsden is the most comprehensive, specialist research unit in the UK for children with cancer with onsite links to the ICR and to a comprehensive adult cancer research unit.

This finely tuned research ecosystem was built up as a result of the long history of research collaboration between The Royal Marsden and the ICR and it will not be possible to recreate the existing onsite integration with a comprehensive range of adult cancer speciality and drug development teams. As such, continuing the UK and Europe-leading position in research is at significant risk and trial recruitment will inevitably be adversely affected.

Maintaining research activity at the current level is unlikely to continue and access to world-leading clinical trials which is a national priority, will be at risk. The Trust, as result of its highly quality care and globally impactful research, has benefited from significant charitable funding from The Royal Marsden Cancer Charity. Charitable support is critical as paediatric research trials do not attract support from commercial funders. This charitable funding will therefore need to be replicated in any future model to ensure research activity is not adversely impacted.

Fully funded delivery plan

Parents and families will require assurance that there is a fully funded delivery plan which enables all of the benefits of the current service and the capacity to be made available in a new location. This includes very significant capital and revenue funding beyond the £20 million capital currently identified by NHS England London which is not sufficient.

Retention of a very specialist and expert workforce

It is imperative that the impact of any proposed relocation of the PTC can be managed and mitigated in order to retain highly specialist paediatric staff. Considerable efforts to recruit new staff have proved successful in the short term but the Board is concerned that a decision will be made in Spring 2024 and the service will not be able to relocate to the same capacity and quality of the current service for a number of years, and this will result in significant challenges with staff retention and potential impact on patient safety.

Impact on the Teenage and Young Adult (TYA) services

Relocating the PTC will have a significant impact on how TYA services are delivered in the South Thames region. At present, the TYA unit is located at The Royal Marsden's Sutton site, alongside the paediatric PTC in the Oak Centre for Children and Young People. There is close integration of facilities and staff with most of the care for Teenagers and Young Adults being led by consultants in the paediatric team. Following relocation of the PTC, there will need to be reorganisation of how this service is delivered with the additional necessary investment. Parents are concerned about the disaggregation of services for children and teenagers which will affect continuity of care brought about by this proposal.

In conclusion

As stated at the beginning of this response The Royal Marsden will always support any change which is in the best interests of children. We would strongly advise NHS England to ensure that a fully funded delivery plan is developed before any decision is made to transfer a safe and high-quality service. It would, in our view, be unwise to make a decision to relocate a service until there is absolute assurance that the NHS has the capital and revenue funding and service model in place which can genuinely provide better care for patients and families, and which can meet the high standards of service already provided by The Royal Marsden in partnership with St George's Hospital.

Yours sincerely,

Sir Douglas Flint CBE
Chairman of The Royal Marsden, on behalf of the Board

20. University College London Hospitals NHS Foundation Trust

NHS
University College London Hospitals
NHS Foundation Trust
David Probert
Chief Executive, UCLH &
Honorary Professor
UCL Global Business School for Health
Trust Headquarters
2nd Floor Central
250 Euston Road
London. NW1 2PG
Direct line: 020 3447 9890
Email: d.probert@nhs.net
Website: www.uclh.nhs.uk

14 December 2023

NHSE England London and South East regions consultation programme
By Email: england.childrenscancercentre@nhs.net

Re: Public consultation on *Proposals for the future location of very specialist cancer treatment services for children living in south London and much of south east England*

Intentions of the Consultation

UCLH are fully supportive of this consultation process and recognise the huge amount of work over a number of years involving a broad range of stakeholders to get to this point. The issues under consideration are complex, but this process offers the opportunity to build upon the high-quality care currently provided at the Royal Marsden Hospital & St George's for children with cancer.

We note that both options under consideration (both of which have our equal support) recognise the complexity of care for this very small, specialist cohort of patients. It is positive that the new PTC would enable the repatriation of South London and South East children who currently have to travel to the North Thames PTC for Car-T cell therapy under the care of a different PTC team. The research, recruitment and retention benefit to a PTC which is unrestricted by any lack of supporting clinical infrastructure is an important benefit of either option.

Radiotherapy

UCLH is, under both options, the destination of choice for paediatric radiotherapy. The introduction of proton beam therapy has had a significant impact on the requirement for conventional photon radiotherapy in children, and our team also note the increasingly complex needs of those children who do need photon radiotherapy as part of their care. We are strongly supportive of the proposal to consolidate paediatric radiotherapy into one specialist pan-London service.

Our team has a strong track record of providing radiotherapy as part of the PTC team in other organisations and would expect this to be no different in the new South London and South East PTC. The team is also familiar with supporting patients travelling long distances for their care, having provided radiotherapy for Southampton PTC since 2018. We would look forward to working directly with the PTC team to ensure that the pathways that we put in place fully support patients and their families during this period of their treatment and that care is seamlessly provided at UCLH but as part of their PTC care.

However, whilst we are supportive of the changes proposed, it is critical that we recognise the increased complexity and requirement for extensive age-appropriate support for these patients and families, which underpins a resource requirement in delivery of paediatric radiotherapy that far exceeds that for delivery of radiotherapy to older patients.

The PCBC makes reference to the need to ensure sufficient capacity and sustainable resourcing of the radiotherapy component of care for these patients, which we welcome, although note no cost allowance is currently in the financial case. It is our view that this will need to be rectified, as agreement on this will be essential to our final sign off of this service move. We will not be able to accept this service if in doing so it compromises patient care.

Given this, we ask for the following:

- Recognition of the significant additional resource burden of paediatric radiotherapy through development of a dedicated tariff or similar payment mechanism for this work.
- Recognition that depending on a number of other factors there may be a step change increase in capacity required for this service move with associated capital implications
- Recognition that transitional support costs may exist for a short period to support the service move to UCLH and ensure disruption for patients, families, staff and services is minimised. This is included for both options but without any specific reference to the radiotherapy move, and while this is a much smaller component of the overall proposed service change, adequate resource will be key.

We would ask that these financial considerations are reflected in your decision-making business case and risk register for the programme.

The final challenge of this programme is the uncertainty and instability that such a change proposal can bring. We would urge that a conclusion is reached as soon as possible to enable all organisations involved but most especially our colleagues at RMH to be clear on the future and begin working positively towards the changes that will be needed and realise the benefits this can bring.

Yours sincerely

David Probert
Chief Executive

21. University Hospital Southampton NHS Foundation Trust

NHS
University Hospital Southampton
NHS Foundation Trust

15th December 2023

Chief Executive's Office
Trust Headquarters
Mailpoint 14
Southampton General Hospital
Tremona Road
Southampton
SO16 6YD

Email: david.french@uhs.nhs.uk

Dr C J Tibbs FRCP
Medical Director Commissioning
NHS England South East

Sent by email: chris.tibbs@nhs.net

Dear Christopher

Re: Consultation on Paediatric Cancer Services in South London and South-East England

Thank you for the recent conversation regarding the above consultation. As you know, University Hospital Southampton NHS Foundation Trust (UHS) is supportive of the aims of the consultation to collocate paediatric cancer services for these patients on to a site with children's intensive care in place.

As the primary treatment centre (Southampton Children's Hospital) for patients in the South of England, our catchment area borders some of the patient groups affected by this consultation. It was therefore good to confirm that:

- There are no plans within the options outlined to move any referral pathways to Southampton Children's Hospital
- Following NHS England discussion with parent groups, there is not anticipated to be an increase in families exercising patient choice in order to transfer care to Southampton as a result of these changes
- NHS England are open to reviewing the impact of this move if activity at Southampton did increase as a result of these changes, to ensure that appropriate funding was allocated to support new demand

We wish you the best with the remainder of this process.

Yours sincerely

David French
Chief Executive

C. Local authorities

22. London Borough of Bexley

Leader of the Council

Councillor Baroness O'Neill OBE

LONDON BOROUGH OF BEXLEY

Civic Offices

2 Watling Street

Bexleyheath

Kent DA6 7AT

22 December 2023

By email to england.childrenscancercentre@nhs.net

Consultation on Principal Treatment Centre for Children's Cancer

To whom it may concern

We are writing regarding the consultation on children's cancer centres, known as Principal Treatment Centres. We welcome the opportunity to express our views about the proposal as to where the Principal Treatment Centre for children with cancer living in south London should be based.

We would like to express our support for the proposal for the future Principal Treatment Centre to be based at Evelina London Children's Hospital, run by Guys and St Thomas' NHS Foundation Trust (GSTT), with conventional radiotherapy services at University College Hospital. For families and children living in the London Borough of Bexley, who require this specialist care, Evelina Children's Hospital in Lambeth will be the most accessible option. However, we would like to emphasise the importance of ensuring there is support with transport for families of a seriously unwell child. It is essential that the Principal Treatment Centre Programme and the Trust deliver on the promises of travel solutions, including ambulance transport, sufficient free parking and

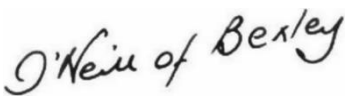
the cost of travel, such as reimbursement for the cost of ULEZ and congestion charges.

The Evelina London is a dedicated Children's Hospital with the experts and facilities children need on-site. The care at the Evelina London has also been rated by CQC as outstanding. This is a fantastic opportunity to bring together the Royal Marsden's leading children's cancer experts with GSTT's world-class specialist paediatric teams.

GSTT have extensive experience and expertise in cancer care and research. They deliver clinics in local hospitals and their clinical education team train staff at hospitals in the region. GSTT already provide a comprehensive range of lifelong, general and specialist care from their hospital and community sites. In the London Borough of Bexley, we have a Cancer Centre at Queen Mary's Hospital in Sidcup, which means local adult patients can be treated closer to home.

In expressing our support for the option to base the future Principal Treatment Centre at Evelina London Children's Hospital, we hope that it may also provide further opportunities to strengthen links and develop relationships with other services and support in local areas, helping to ensure people receive joined up and coordinated care.

Yours faithfully



Councillor Baroness O'Neill of Bexley OBE

Leader, London Borough of Bexley

23. Lewisham Council

Damien Egan
Mayor of Lewisham
Mayor and Cabinet Office
1st Floor, Laurence House
Catford
London SE6 4RU

damien.egan@lewisham.gov.uk

15.12.2023

Sent via email:
england.childrenscancercentre@nhs.net

Dear NHS England,

Re: South Thames Children's Cancer Principal Treatment Centre Programme Public Consultation Response

On behalf of Lewisham Council, we extend our wholehearted support for the proposal presented by Evelina London Children's Hospital to become the Principal Treatment Centre (PTC) for the South Thames Children's Cancer Program. Our endorsement is grounded in a thorough consideration of the comprehensive consultation documents, particularly its relevance to the residents of Lewisham and the broader South Thames region.

Lewisham Council recognises the pivotal role that Evelina London plays in delivering outstanding clinical care, as demonstrated by its 'Outstanding' rating from the Care Quality Commission. The commitment to continuity of care, support for families, and shared care aligns seamlessly with our mission to ensure the wellbeing of our residents, especially those facing the challenges of childhood cancer.

As we scrutinised the proposal, we noted that Evelina London scored highest overall in the rigorous evaluation process. The hospital's commitment to providing interdependent, specialist services, including paediatric intensive care and paediatric surgery, directly addresses the healthcare needs of the cohort it serves. The emphasis on seamless transitions for young patients and the provision of dedicated support services for families resonate deeply with our commitment to community-cantered healthcare and meeting the needs of the most disadvantaged within our society.

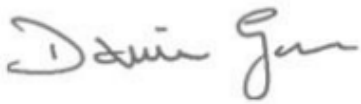
Furthermore, Evelina London's role as a leader in research, demonstrated by its collaboration with King's College London and its cutting-edge cancer therapies, positions it as the ideal institution to advance the future of children's cancer care in our region.

Lewisham

Considering the proposed move of the PTC is necessary to comply with service specifications, Lewisham Council believes that Evelina London's proposal represents a once-in-a-generation opportunity. It offers the chance to bring together leading experts and world-class specialists for the benefit of South Thames residents, including those from Lewisham, and underscores their commitment to streamlined and efficient healthcare for children with cancer and their families.

Lewisham Council wholeheartedly supports Evelina London Children's Hospital's proposal as the best option for the South Thames region to deliver the future vision to **'give the best quality care and achieve world-class outcomes for children with cancer for decades to come'.** We look forward to the positive impact this proposal will have on the wellbeing of our residents and the broader South Thames region.

Yours Sincerely,



Mayor Damien Egan

24. London Borough of Merton

COUNCILLOR PETER MCCABE

CABINET MEMBER FOR HEALTH AND SOCIAL CARE

(Labour, Ravensbury Ward)

London Borough of Merton

Merton Civic Centre

London Road

Morden SM4 5DX

Ms Caroline Clarke
By email only

england.childrenscancercentre@nhs.net

- Dear Ms Clarke
-
- **R.E: Proposed Changes to Paediatric Cancer Services**
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I am writing regarding the proposed changes to children's cancer services across South London, Kent and Medway, Surrey and Sussex. As a Cabinet Member for Health and Social Care in Merton and Chair of the Health and Wellbeing board, I know that this decision will have a significant impact on our residents.

The decision on the location of the new Principal Treatment Centre (PTC) will be of vital importance to local families and I understand that NHS England's preferred option is to move the current service which operates between St Georges and the Royal Marsden to the Evelina hospital in central London.

The Evelina hospital does not currently provide neurological care whereas St George's has been delivering excellent specialist cancer care for over 25 years. Given that around 25% of paediatric cancers are neurological and every other cancer centre (except for Leicester) is co-located with neurosurgery, it is essential to have access to skilled and experienced neurosurgeons who can deliver these services with easy access. Transferring the service to the Evelina would mean transporting very sick children to Kings College Hospital.

Parents of children with cancer have indicated that travelling to the Evelina Hospital will have a negative impact by making it harder to access treatment. Parents have made clear that it is easier, more comfortable, and safer to take them to hospital by car rather than public transport. Venues outside of central London with good parking provisions are essential, especially with the known difficulties of parking and driving in central London. St George's can offer

dedicated parking spaces for the families of children with cancer. I note that the evaluation of the bids placed St George's ahead of the Evelina on patient and carer experience. In my opinion this aspect should carry a greater weighting in the evaluation process.

I believe it would be far more practical and cost effective to keep the children's cancer centre at St George's. Following my discussion with Dr Chris Streather on 15th August 2023, I understand that the capital cost of redeveloping St George's is estimated at £31 million, whereas it would cost £44 million to transfer the service to the Evelina Hospital. I expressed surprise that despite the significant difference in cost, NHS England's preference was for the more expensive option. Those of us responsible for spending public money have a duty to secure value for money but this does not seem to have influenced the evaluation of the competing bids.

A significant part of the service is currently at St George's and there is an existing space which can be transformed quickly into a new state-of- the-art cancer centre, with fewer staff needing to be moved to central London saving both money and significant disruption. Such disruption must surely carry a greater risk to patients.

Furthermore, moving children's cancer care away from St George's could create a £2 million funding shortfall for St George's. Such services are not stand-alone as the specialists at St George's who work with children with cancer also work across a variety of major trauma cases for Southwest London and Surrey. In some cases, St George's will have to retain these staff but lose the funding associated with children's cancer care, meaning cuts would be made to other vital services. In other cases, the expert staff supporting children with cancer could leave St George's. This would weaken other services provided to children in Southwest London and Surrey.

This important issue was discussed at the recent meeting of JOSH Sub-Committee set up to scrutinise the proposals for Children's Cancer Care. Both hospitals were asked what the consequences would be if their bid to provide the Cancer Centre was unsuccessful. The Evelina team felt it would be a lost opportunity. However, the St George's team indicated that it would have an immediate and direct impact on its finances, staffing and other services.

My view, which is shared by colleagues in other boroughs in Southwest London is that consolidating children's cancer services at St George's is vital and this is the best option financially, for staffing and patients and families of children with cancer.

I look forward to your response.

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Yours sincerely,

Councillor Peter McCabe
Cabinet Member for Health and Social Care

25. London Borough of Sutton

Councillor Ruth Dombey OBE

London Borough of Sutton

Leader of the Council

Liberal Democrat Councillor for Sutton North Ward

Address: Leadership Office, Civic Offices, St Nicholas Way, Sutton SM1 1EA

Telephone: 020 8770 5406

Email: leadership.office@sutton.gov.uk

Consultation response sent to: england.childrenscancercentre@nhs.net

15 December 2023

To whom it may concern

RE: Response to Consultation on Changes to Children's Cancer Services

Having a child that is being treated for cancer is one of the most difficult things a family can experience. Whilst we all want to ensure that children affected by cancer and their families get the best possible clinical care, we must also acknowledge that the proposed move of children's cancer services in South West London will be disruptive for many children and families.

The Council's strong preference, if there is no option for services to remain at the Royal Marsden, is for the services to be located at St George's Hospital. We believe that this would be in the best interests of the residents of Sutton for the following reasons:

1. St George's is already part of The Epsom and St Helier Hospitals Trust offering consistency of care for patients and their families.

2. St George's has been part of the current Principal Treatment Centre, alongside The Royal Marsden NHS Foundation Trust, for more than 25 years

and their children's services are rated Outstanding by the CQC. The benefits of this established relationship means that staff already work closely alongside one another and so the impact of the relocation of services on children and their families would be significantly reduced.

3. St Georges's is the only site in South London already delivering paediatric oncology care.

4. St George's is far more accessible for Sutton residents (patients, their families and staff) to travel to.

We have taken an active role in the Joint Health Overview and Scrutiny Sub Committee that has been set up to scrutinise these proposed changes and the Council's position was also made clear at Sutton's Scrutiny Committee on the 13th December 2023.

Should the final decision of NHS England not accord with this, the Council will undertake the steps set out in Regulation 23 of the Local Authority (Public Health, Health and Wellbeing Boards and Health Scrutiny) Regulations 2013 (the 2013 Regulations) including if necessary referral of the matter to the relevant Secretary of State.

We ask that you accept this letter and detailed answers attached in Annex A as the London Borough of Sutton's formal response to the consultation.

Yours faithfully

Councillor Ruth Dombey OBE
Leader of the Council

Councillor Edward Joyce
Chair of Scrutiny Committee

St George's Annex A:

Sutton Council response to specific questions in the Consultation Questionnaire

● In a future Principal Treatment Centre, what would you value most?

Continuity of care and high quality clinical care and support for children and families.

● Having read about the option for the future children's cancer centre to be at Evelina London:-

- Please share your views on the good points of this option (including anything we may have missed)

No comments

● Please share your views on potential challenges of this option (including those we may have missed)

Travel and transport. It will take longer for children, families and staff to travel to Evelina London and be more expensive.

Inconsistency of care leading to greater disruption and more distress for families.

Staff could choose not to relocate which would affect children's continuity of care. St George's has been part of the current Principal Treatment Centre, alongside The Royal Marsden NHS Foundation Trust, for more than 25 years and their children's services are rated Outstanding by the CQC. The benefits of this established relationship means that staff already work closely alongside one another and so the impact of the relocation of services on children and their families would be significantly reduced.

Impact on other health services. The movement of children's services away from St George's to the Evelina will also impact on other services (e.g. children's surgery at St George's, teenage and young adult cancer services at the Royal Marsden) to the detriment of other services. NHSE have not assessed impact on health inequalities of the latter.

- What suggestions do you have to improve the things you've identified as potential challenges?

St George's to be the preferred option

- **Having read about the option for the future children's cancer centre to be at St George's Hospital:-**

  - Please share your views on the good points of this option (including anything we may have missed)

This is the least worst option with regards to travel and transport and provides better continuity of care for children and families due to the established links between staff at the Royal Marsden and St George's.

  - Please share your views on potential challenges of this option (including those we may have missed)

Transport and travel is still a challenge, but would be less of an issue with regard to time, access and costs than Evelina London

  - What suggestions do you have to improve the things you've identified as potential challenges?

Offer free or subsidised travel to the new site, particularly for lower income families. Offer accommodation for families on site and sufficient free or subsidised parking (e.g. for two cars per family).

- **Under both options, conventional radiotherapy would move from The Royal Marsden to University College Hospital where it would be delivered as part of a larger service alongside proton beam and other radiotherapy services.**

Please tell us what you think about this part of our proposal, including the effect it might have

This will result in disruption for children and families who currently receive radiotherapy at the Royal Marsden including longer and potentially more costly travel.

● **Do you have any other thoughts or ideas you want to share?**

No comments

I write this letter in my capacity as the Chair of Sutton Council's Scrutiny Committee in response to the consultation on the future of children's cancer services in South West London and beyond and together with the Leader of Sutton Council.

26. Medway Council

Good morning Sabahat,

Hope you are well.

Just wanted to let you know that I have spoken to Councillor Howcroft – Scott and she does not feel that a formal response letter is needed regarding the consultation. She believes she has fed in all the information needed for the consultation and encouraged members of the committee to do the same.

I have forwarded all the information to members and officers alive to promote the consultation.

Speak to you soon.

Kind Regards

Stephanie

27. Southwark Council

Southwark Council
southwark.gov.uk

Althea Loderick
Chief Executive
Chief Executive's Office
Althea.loderick@southwark.gov.uk

Sent via email:
england.childrenscancercentre@nhs.net

Date:18/12/2023
Ref:048/SL/AL

Dear Sir / Madam,

Response to public consultation - South Thames Children's Cancer Principal Treatment Centre Programme

1. Many thanks for the opportunity to respond to the public consultation for the South Thames Children's Cancer Principal Treatment Centre Programme.

2. We welcome the extensive information provided about the potential service providers. We understand that two Trusts responded to the call for proposals - Evelina London Children's Hospital (Guy's and St Thomas' NHS FT) and St George's University Hospitals NHS FT with both submitting proposals to become the PTC in future, providing all the required services on one site.

3. Over 30 experts, including clinical advisers, parents, charities, nurses and research staff, were involved in evaluating the proposals as part of an options-appraisal process designed by NHS England London and shaped by a range of stakeholders. Four panels looked at different aspects of the proposals. We understand that Evelina London scored highest overall and in three of the four domains. In terms of scoring, Evelina London is the preferred option based on the rigorous options appraisal.

4. With such a rigorous process, Southwark Council is assured that clinical services appointed will meet requirements providing high quality, safe, effective and compassionate cancer care to Southwark children and their families.

5. Below, we set out Southwark Council's additional considerations for cancer care provision.

Southwark's additional considerations for holistic integrated cancer care

6. Southwark's Council Delivery Plan sets out that one of our key priorities is 'Supporting Families'. We understand that families caring for a child with cancer are under great stress – including emotional, social and financial stress.

7. Therefore, our other key concerns relate to the mitigations, either already in place or that will be put in place, by the PTC provider, to provide a holistic pathway of cancer care. This needs to adequately take into consideration the challenges faced by many Southwark families and work to reduce preventable health inequalities in outcomes - whether care, experience, quality of life or clinical outcomes.

8. Drawing on the services and assets provided by Southwark Council, we would wish to remain a key partner in cancer care pathways and build on the strong relationships we have already within Partnership Southwark. This is a partnership of the voluntary and community sector, the NHS and Southwark Council, focused on improving health and wellbeing and reducing inequalities for people in Southwark. Our Partnership Southwark ambitions for improved health and care outcomes for our residents are set out in our Health & Care Plan 2023 – 2028.

About Southwark

9. Southwark is a densely populated and diverse inner London borough. It is a patchwork of communities: from leafy Dulwich, to bustling Peckham and Camberwell, and the rapidly changing Rotherhithe peninsula. Towards the north, Borough and Bankside are thriving with high levels of private investment and development.

10. Yet there remain areas affected by high levels of disadvantage, where health outcomes fall short of what any resident should expect. Our population is young, diverse and growing, with large numbers of young adults and residents from a wide range of ethnic and social backgrounds:
    - The average age (32.4 years) is more than two years younger than London, and almost seven years younger than England
    - Around half (51 percent) of people living in Southwark have a White ethnic background compared to 81 percent nationally
    - The largest ethnic group other than White is 'Black, Black British, Caribbean or African', accounting for one-quarter (25 percent) of Southwark residents
    - Southwark has one of the largest Latin American Communities in the country, predominantly made up of Colombians and Ecuadorians living around Elephant and Castle
    - The last census found that over 80 languages are spoken in the borough, with 79 percent of the population speaking English as their main language
    - There were over 40 distinct religions identified among Southwark resident

Disproportional impact of cancer on many of our families

11. Prevalence of childhood cancers may be broadly distributed across the population, however their impacts are not. Disproportionate burden of impacts fall to those least well off – the 'double whammy' effect – due to the 'invisible' costs of cancer care relating to, for example, different housing needs, challenges in maintaining family and school life for other siblings and family dependants, strains on parental job security and household income.

12. We know that for many children and their families in Southwark, they may enter the cancer care pathway already disadvantaged. We know for example that:

- Around 16,000 households in Southwark are classed as overcrowded, with more overcrowding that is seen across London and England;
- While the median (average) household income in Southwark in 2022 was £43,769 is broadly comparable to the national average of £38,984, there is a wide range of income in Southwark with around 1 in 10 households in the borough having a total income of <£15,000 per year;
- Across a wide range of health, social and economic measures, from child poverty through to obesity, hospital admissions and life expectancy, outcomes are poorer in central and northern parts of Southwark particularly communities in Faraday and Peckham wards;
- Residents from a Black African and Black Caribbean background are more likely to live in communities with high levels of deprivation, develop a greater number of long-term conditions, have poorer mental health, and experience discrimination and racism when accessing services.

13. In particular for our Southwark children:

- 10% (2,000) children 0-4 years have experienced 4 or more adverse childhood experiences and around 25,700 children live in poverty in the borough;
- 2,771 Children in Need, which is higher than London levels, of which 47% relates to abuse or neglect;
- 25% of 0-16s are estimated to be food insecure (75,000) with a similar percentage for people >16 (16,000), with prevalence higher in central and northern parts of the borough and for those who are Black, in social rented housing or with dependent children;
- Approximately 21% of Southwark's population live in communities ranked within the most deprived nationally. This increases to 23% among those aged under 18.

What Southwark residents want

14. From talking with our Southwark residents and communities through a variety of initiatives and partners, we would highlight the following when providing children cancer services which will need to address:

- Mental health and wellbeing for children, young people and adults is a priority
- People can struggle to access services, due to demand, or because they feel excluded, unsure of where to go or unable to interact with services
- Services need to be culturally-appropriate and accessible for all
- Discrimination and structural racism are impacting access and experience of services
- Vulnerable people are falling through gaps in support
- Concern regarding rising cost of living, food poverty and affordable housing
- Local communities and community autonomy is highly valued
- People want to be meaningfully involved and for their voices, insight and experience to be valued
- People want to be able to access as much as possible in their neighbourhoods.

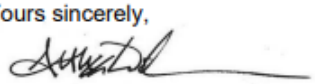
Southwark Council supports the Evelina London bid

15. In conclusion, taking into consideration these wider emotional, social and economic challenges facing our residents and in the knowledge of their impact on both the clinical outcomes of cancer care and the quality of life experienced by our children and their families, we support the more integrated and localised cancer service we believe we would receive from Evelina London. We feel more confident that Evelina London is able to work with partners to address our residents' needs and requests of us. As such we support the bid from Evelina London.

16. Evelina's familiar to our Southwark children and their families and we, as a borough, from cradle to grave, are familiar to them.

17. Please do not hesitate to get in contact with me or my Director of Public Health, Sangeeta Leahy, should you have any questions about our consultation response.

Yours sincerely,



Althea Loderick
Chief Executive

References:

1. Partnership Southwark Health & Care Plan 2023 – 2028. Available here.

28. South West London and Surrey Joint-Health Overview and Scrutiny Sub-Committee

In a future Principal Treatment Centre, what would you value most?

In short, the JHOSC Sub-Committee believes it is vital to have a service that is conveniently located in terms of private vehicular access, providing a patient and family centric service which employed world-class nurses, specialists and other staff – many of whom would ideally come directly from the Royal Marsden.

Specific areas of value are detailed via later questions.

Thinking about Evelina London … Please share your views on the good points of this option (including anything we may have missed)

The currently vacant area of the day-patient centre would be beneficial in allowing further out-patient care (chemotherapy etc.) to be built from a clean slate. Other benefits of the site include their close working relationship with Kings College London and Great Ormond Street, research capabilities, nephrology, kidney and cardiology services, and an on-site school (OFSTED rating of 'Outstanding'). For those families who wish to travel by public transport to visit their child, the site offers excellent public transport options although the nearest main transport hub at Waterloo is just over one kilometre from the hospital. Other than by taxi there is no obvious solution other than walking to cover that distance (note – parents may feel apprehensive about this option due to fear of transmitting viruses and other illnesses to immunosuppressed children). World class research facilities were available on-site.

Please share your views on potential challenges of this option (including those we may have missed)

The location of the site in Central London will be extremely off-putting to many families, adding unnecessary stress when transporting their child to hospital, or when visiting. Evelina's, by the very nature of its central London location, will be much more difficult to access for families living in Kent and Medway.

Travel times, travel distances and the need to use multiple modes of transport in order to make the journey would seriously impact on many families from within Surrey especially those located in rural areas or some distance from an easy route into London. It is therefore extremely likely that almost all parents would opt to travel by car rather than attempt to use public transport. Vehicle journey times

into a Central London location are extremely unpredictable but would be significantly longer than they are at present and somewhat longer than to St George's.

Whilst transport/parking costs would be re-imbursed for one parent, this site would disproportionately impact upon low and medium income families, as the second parent/guardian would be forced to pay for expenses and charges such as parking, ULEZ, Congestion chares and fuel costs. In addition, there is not currently a close working relationship between the Royal Marsden and Evelina's, meaning that a transfer of services could prove to be problematic. Accommodation, whilst offered at Ronald McDonald House, is ten-minute walk away from The Evelina and would be shared by lots of other families. The accommodation offered is the provision of bedrooms, with shared facilities and communal areas. Parents of very sick children will, naturally, feel very protective of their child, and will want to try and prevent passing on viruses or other illnesses from others wherever possible. Furthermore, the lack of on-site accommodation is likely to prove stressful to parents who will want to be physically in the same building as their very sick child. Construction and current service moves may also pose problematic for current patients and local residents.

The difficulties of recruiting and retaining staff in a Central London location are obvious and it was noted during the visit to The Evelina that the PICU was not fully staffed due to recruitment and retention issues. Those difficulties were confirmed to the sub-committee at the subsequent meeting. There is considerable concern that similar issues would be encountered with treatment centre staffing. As with any other similar service continuity of staffing and the built-up shared expertise gained over many years of working together are vital to success. Recruitment and retention issues must therefore be avoided.

While The Evelina would no doubt benefit from adding Paediatric Oncology to its list of services the lack of the proposed specialist service other than similar adult services in St Thomas's is a considerable concern. It takes many years to build the kind of full functioning team required and The Evelina would in many ways be starting from scratch.

What suggestions do you have to improve the things you've identified as potential challenges?

Many of these issues centre around the location of the hospital and their current relationship with the Royal Marsden (compared to the much closer relationship between the Marsden and St George's). As such, it is difficult to suggest possible improvements to these specific areas by the very nature of these issues. Any move from the Royal Marsden would necessitate a certain amount of construction disruption and associated works. This could potentially negatively impact on current service provision and cause an amount of disruption to local residents. Additionally, moving the service will cause uncertainty to current and future patients and families. Also, these children may still be required to be

transported to a different site in some cases, regardless of which site is chosen, dependent on the specialist care that individuals may require.

From a Surrey point of view, we do not believe there are any significant mitigations that could be applied to reduce travel times, or the difficulties involved in using public transport to get to The Evelina. Provision of significant dedicated car parking would help as would the provision of dedicated accommodation on site.

The staff retention and recruitment issues might be ameliorated by paying substantial Central London supplementary payments but there are obvious difficulties in doing so.

Thinking about St George's Hospital… Please share your views on the good points of this option (including anything we may have missed)

The Hospital boasts 25 years of close-working relationships with the Royal Marsden, which will be critical in establishing the service. Tumour surgery is already carried out on the site, meaning this could be integrated into the new service provision seamlessly. It is also worth noting that the paediatric tumour surgery provided is recognised as leading and experience in the unit is a sought-after learning opportunity.

On-site accommodation in the form of family suites could be offered, providing a comfortable and private environment for families to stay alongside their child including a dedicated outside space. Due to the location of the hospital, travelling by private vehicle would be easier than in a truly central London location, especially for residents in Medway, Kent and areas of Surrey, whilst parking provision would be available on site. Car journey times are also much more predictable and generally shorter for Surrey families when compared to the Evelina. The site also benefits from being outside of the congestion zone, and has decent rail and bus links (note – parents may feel apprehensive about this option due to fear of transmitting viruses and other illnesses to immunosuppressed children).

Paediatric neurology and neurosurgery were conducted on-site, eliminating the need for transfer where patients required these services.

Whilst the Sub-Committee acknowledge NHSE's comments that the clinical risk of service change would be low at either location, the transfer of location to St George's would help with staff retention, and it is the cheaper option at a time when NHS budgets are tight.

World class cancer research facilities are available on-site. Members heard directly from surgeons that they did not work in isolation, and there was a complex system of care with significant institutional experience that had been developed over time and which could not be immediately replicated elsewhere.

Please share your views on potential challenges of this option (including those we may have missed)

Any move from the Royal Marsden would necessitate a certain amount of construction disruption and associated works. This could potentially negatively impact on current service provision, and cause an amount of disruption to local residents. Additionally, moving the service will cause uncertainty to current and future patients and families. Also, these children may still be required to be transported to a different site in some cases, regardless of which site is chosen, dependent on the specialist care that individuals may require. Staff retention during the move may be an issue with a risk that experience built up over decades will be lost.

What suggestions do you have to improve the things you've identified as potential challenges?

Provision of support for staff transferring from the Marsden site in the form of help with transport costs and accommodation would ameliorate the issues around retention of experienced staff.

Other changes. Please tell us what you think about this part of our proposal, including the effect it might have

As with previous comments, any move from the Royal Marsden would necessitate a certain amount of construction disruption and associated works. This could potentially negatively impact on current service provision, and cause an amount of disruption to local residents. Additionally, moving the service will cause uncertainty to current and future patients and families. Also, these children may still be required to be transported to a different site in some cases, regardless of which site is chosen, dependent on the specialist care that individuals may require.

Do you have any other thoughts or ideas you want to share?

All possible efforts need to be made to ensure that underrepresented and hard to reach groups have both had the opportunity to have their say on the proposals and have been actively contacted. In addition, current staff should be made to feel comfortable and confident to share their views openly and honestly.

A full and thorough assessment should be conducted to assess the impacts on St George's if their bid was unsuccessful.

Analytics of these open text responses will be time consuming and resource heavy. But, as this has been given as an option, it is imperative that every effort is given to reviewing and weighting these responses fairly.

29. Wandsworth Council

Wandsworth Council
Chief Executive's Group
Town Hall, Wandsworth High Street
London SW18 2PU

Please ask for/reply to:
Telephone: 020 8871 8347
Email:
callum.wernham@richmondandwandsworth.gov.uk
Web: www.wandsworth.gov.uk

Date 14th December 2023

Dear NHS England,

I am writing this covering letter to the SWL and Surrey Joint-Health Overview and Scrutiny Sub-Committee's consultation response on your proposals for the future location of very specialist cancer treatment services for children living in south London and much of south east England.

The Sub-Committee wish to stress the importance of the outreach and engagement of this consultation process, and hope that every effort has been made to engage and listen to the views of hard to reach and underrepresented (at the time of the mid-point review) groups and individuals. Members also hope that current staff have been encouraged and made to feel welcome to share their honest thoughts on the proposals set out before them.

Members understand that these proposals will cause a significant amount of stress and uncertainty to patients and their families, regardless of the selected venue. Whilst understanding the reasons for these proposals, and noting that neither site will be able to completely remove the need to transport these very sick children, the Sub-Committee urges you to fully consider the voices of patients, their families, clinicians and the wider community when deciding where and whether to move the service.

You will find the Sub-Committee's detailed responses to specific areas of your proposals within their attached consultation response. In summary, the Sub-Committee's consensus was that should the service be required to move, St George's was considerably the most preferable option, for the reasons as outlined within the Sub-Committee's consultation response.

Please do not hesitate to contact me should you have any queries.

Yours sincerely,

Callum Wernham
Democratic Services Officer
On Behalf of the SWL and Surrey Joint-Health Overview and Scrutiny Sub-Committee

30. West Sussex Health and Adult Social Care Scrutiny Committee

In a future Principal Treatment Centre, what would you value most?

Children and young people with cancer having access to the best possible care and treatments in order to achieve the best outcomes.

Having access to the latest treatments including research and trials.

Services that are supportive and understand the needs of children, young people and their families/carers.

Facilities that are designed for children and young people, separate from adult services and facilities.

Having good travel and access support, with dedicated parking for families who wish to travel by car.

Having accommodation or somewhere to stay nearby for families and carers of children and young people whilst they are having inpatient treatment.

If something else is an important aspect of your travel, please tell us more...

East Sussex has some areas of deprivation where families might not have access to a car or be able to afford public transport to get to the PTC. Therefore it will be important to offer travel and access support for such families, which could include financial help with the cost of travel and access to the patient transport service. Having information in advance about how to get to the PTC, parking facilities and what to expect when you get there are also important. We note both potential locations for the PTC have dedicated patient transport teams and it would be helpful to have a nominated Travel Liaison Officer, or similar role, to help families and patients with their travel and access needs, offering personalised support where needed.

Please tell us if other types of support or information might be needed, to make the change easier for staff and families.

Having good continuity of care arrangements in place for existing patients will be vitally important when the PTC service changes take place. As indicated above, this should involve details of the staff who will continue to be involved in the patients care as children, young people and the families often develop close relationships with those involved in their treatment and care.

Thinking about Evelina London … Please share your views on the good points of this option (including anything we may have missed)

The Evelina London has a lot of experience in treating children and working with them and their families.

There is evidence of good support for research and clinical trials of new and innovative treatments.

Staff are well supported and there are development opportunities for them.

The Evelina London currently operates the patient retrieval service for children who are unwell.

Please share your views on potential challenges of this option (including those we may have missed)

The Evelina London does not currently provide/have experience of providing PTC services for children and young people with cancer. The

consultation document highlights that they will need to develop surgical expertise for children's cancer surgery.

The travel time by car for both patients (80% currently travel by car) and staff is longer and the journey into central London for some may be more complex and challenging.

What suggestions do you have to improve the things you've identified as potential challenges?

Firmer assurances/arrangements should to be in place around the development of the necessary children's cancer surgical experience for this option.

Enhanced help and support with travel and access for patients, families and staff.

Thinking about St George's Hospital… Please share your views on the good points of this option (including anything we may have missed)

St. George's currently provides and has experience of providing the PTC services and supports the network of Paediatric Oncology Shared Care Units (POSCUs).

It has good track record of research work with access to new and innovative treatments.

It has an experienced staff team who are used to supporting children, young people and their families.

Travel and access by car is slightly easier with the commitment to provide dedicated on site parking.

Facilities are personalised with more individual rooms.

Please share your views on potential challenges of this option (including those we may have missed)

Journeys by public transport (e.g. by train) from East Sussex may be a little more complex.

St. George's has a higher staff turnover at present.

What suggestions do you have to improve the things you've identified as potential challenges?

Other changes. Please tell us what you think about this part of our proposal, including the effect it might have

Recruitment and retention is an issue across the NHS. Providing enhanced staff support and development opportunities might help with this.

Do you have any other thoughts or ideas you want to share?

If it provides access to more advanced treatment and therapies in the future then this change would be beneficial to patients.

The consultation document indicates that more children would need to travel to UCL under this proposal, but numbers are relatively low.

Travel from East Sussex is longer, and for those receiving treatment, travel and access support should be put in place to make travel to this site as easy as possible, especially for those who may have to attend regularly for a course of treatment.

D. Parent bodies and representatives

31. Greenwich Parent Carer Forum

Good morning,

I hope you're well. I'm writing on behalf of the Royal Borough of Greenwich, South East London ICB (Greenwich) and Greenwich Parent Carer Forum (GPCPF) to provide our view on the NHS England public consultation regarding the Principal Treatment Centre for children's cancer services. We would like to submit our preference that Evelina is selected for the Children's Cancer Principal Treatment Centre (PTC).

The clinical expertise that are within Evelina currently makes it the ideal place and will provide greater confidence to Greenwich families about the quality of delivery. The other key point is the location, Evelina is located centrally and would remove a significant amount of stress in being able to access services than if it would were it placed in St Georges. Unfortunately transportation links cutting across South London are not as well developed and therefore it presents significant challenges in needing to make this journey, particularly for families that rely on public transportation.

Please let me know if there's any further information or details you would like to know but we're happy to confirm our public support for the PTC being located at Evelina.

Kind regards,

Dave

32. Young Lives vs Cancer

In a future Principal Treatment Centre, what would you value most?

First and foremost, the future PTC should be the centre which would deliver the best possible clinical care to achieve the best possible clinical experience and outcomes for the children with cancer that are using the service, in line with the Service Specification for specialist Children's Cancer Services. This would take into account, for example:

- The clinical expertise in children's care within the centre and the staff team, including specialist cancer care (which could be further achieved by supporting current staff to move to the new PTC)

- The clinical facilities available within the centre and the PTC, including wards and beds, treatment facilities that enable delivery of the right treatments at the right time and enable innovation, diagnostics and pathology services, imaging, and ICU capacity

- Research and innovation quality and capacity, integrated with clinical care to enable access to clinical trials, innovative and cutting-edge treatments and therapies to drive improvements in clinical outcomes

It is also important that the PTC provides the wrap-around (non-treatment) services which children with cancer and their families need, and that these are integrated within the PTC and treatment pathway. This includes, for example, mental health services and support for the child and the family, dietician services, and other clinical specialties which are often required due to the impacts and side effects of cancer treatment, e.g. cardiology, nephrology, physiotherapy, and fertility.

Wrap-around services and support provided through the PTC should also include non-medical services such as educational support and facilities, dedicated play specialists and facilities, dedicated and well-resourced patient transport and travel support, and integrating external support providers within the PTC (such as Young Lives vs Cancer's social care service, as with the current service) so that as much of the support as possible that children and families need is readily available to them at the PTC site.

Where services cannot be delivered on the PTC site itself, the PTC should effectively enable children and families to access services on other sites by providing and supporting travel and transfers between sites. The administrative, cost and organisational burden of this should be removed from the family and be undertaken by the PTC as much as possible. Consideration is also needed of operational elements including planning and timing of appointments to allow for travel to multiple sites.

The PTC environment must be age-appropriate for children and families, across the full age-range of patients who will be accessing the services. This includes both the internal spaces e.g. wards and waiting areas, as well as external spaces and the overall hospital site environment, which will also e.g. help minimise the impact of their surroundings on children and families mental health.

The PTC should provide a sense of comfort for children and families, and have the right range of facilities for them readily available within the PTC or close by, including facilities:

- for families to stay with the child, both on site and close by, over prolonged periods where needed

- that provide privacy for children and families, both in the PTC, on the ward and in accommodation

- that allow families to remain on site as much as possible e.g. food, laundry, quiet spaces, and outdoor spaces

The PTC environment should also fully consider the safety of children and families. This includes ensuring that patients can enter the PTC and its facilities without coming into too much contact with patients using other services in and around the site (due to being immunocompromised), and ensuring the PTC is fully accessible for a range of needs including those travelling with medical equipment, those with physical, learning and mental health disabilities, sufficient space for families to move around the site safely, and parking and other facilities immediately available at the PTC site to minimise distances to reach the PTC.

Whilst factors such as travel distance and cost play a role in families experiences of the PTC, both currently and in the future, Young Lives vs Cancer know (though both our Running On Empty (2023) and Are We Nearly There Yet (2018) research) that these issues are not unique to any one PTC in the UK, or the specific move of the South London and South East England PTC.

These issues are experienced by patients across the UK due to the specialist nature of children's cancer care and the structure and locations of all PTCs. With only 20 PTCs in the UK, many patients will be travelling to a centre which is out of their immediate area (average distance patients live from their PTC is 40 miles across the UK). This naturally brings increased travel distances (average of 350 miles a month across the UK) and associated costs (average £250 per month across the UK). Travel distance and cost should therefore be considered for mitigation as far as possible for whichever PTC provider is chosen, but should not be a determining factor for the location of the PTC above other factors more directly linked to clinical outcomes.

We would welcome any and all efforts to reduce or remove the travel burden, including costs, that families face through e.g.

- Support with travel costs such as full re-imbursement of all travel costs associated with accessing the PTC and its services

- Support for London-specific costs, especially e.g. congestion and ULEZ charges

- Availability of parking directly at the PTC site, and free parking for anyone accessing the PTC that does not require reliance on obtaining a Blue Badge (due to impact of delays to benefits receipt)

- Support for public transport costs, and support to get to and from public transport hubs

- Transport provision provided by the PTC for transfer between hospital sites and to home location, especially for those with no recourse to alternative transport

Across all of these areas, the PTC must ensure that children and families, and organisations which support and represent them, are involved in the development, design and ongoing improvement of the PTC, once a provider is chosen. Young Lives vs Cancer are ready and willing to work constructively with the successful provider to ensure the PTC provides the best possible experience and outcomes for children and families, and as a service provider that it enables our organisation to effectively deliver the support services that we provide.

If something else is an important aspect of your travel, please tell us more...

We would re-iterate that whilst travel distance and cost play a role in families experiences of the PTC, both currently and in the future, these issues are not unique to any one PTC in the UK, or the specific move of the South London and South East England PTC. Travel distance and cost should therefore be considered for mitigation as far as possible for whichever PTC provider is chosen, but should not be a determining factor for the location of the PTC above other factors more directly linked to clinical outcomes.

Please tell us if other types of support or information might be needed, to make the change easier for staff and families.

Providing as much information for both families and staff up-front as possible, and being transparent about the transition and arrangements, will help make the change easier. A variety of formats of this information should be used including detailed information for staff, digital information including e.g. video tours of the new site, easy-ready information, information in different languages and other accessible formats, and information aimed at children across the entire age-range of those accessing the PTC. Staff not directly employed by the current PTC, but who provide key services as part of the PTC such as Young Lives vs Cancer social workers, should also be fully informed regularly throughout the process. They should be able to engage with any opportunities or information that other staff at

the current provider have. Young Lives vs Cancer is ready and willing to work with NHS England to scope the impact on our services and how to best support our staff, as well as the requirements for our services, including physical space, at the new PTC site.

Other changes. Please tell us what you think about this part of our proposal, including the effect it might have

The rationale for hosting all radiotherapy services at UCLH under either option is clear and looks to provide the best possible clinical care and outcomes for children needing these treatments and services.

With either option, children and families will need to attend an additional hospital site to receive radiotherapy care and access these services, therefore as previously noted, they should be fully enabled with minimal operational and cost burden to travel to, and transfer between, hospital sites. Consideration will be required as to appointment timings and flexibility to take into account transitioning between hospital sites.

More practically, it should be ensured that UCLH have access to all relevant information (e.g. care record) for patients accessing radiotherapy services and that there is no disconnect between the PTC and UCLH – arrangements should be seamless so it does not appear as though UCLH are a separate provider.

Staff at UCLH should also be integrated into the PTC and provide the same experience for children and families as they would receive at the PTC site. Staff should ensure that care is delivered in an age-appropriate way and, along with the development of the environment at the PTC site, we would recommend that the facilities and environment at UCLH are reviewed and further developed if needed to meet the needs of children across the full age range and families.

Do you have any other thoughts or ideas you want to share?

As leading experts in supporting children and young people with cancer and their families, and as a key service provider as part of the current PTC, Young Lives vs Cancer are ready and willing to work proactively and constructively with the chosen PTC provider throughout the development and transition of the service.

33. #HearTheMarsdenKids Campaign

PUBLIC OPPOSITION TO NHS LONDON & SOUTH EAST PROPOSITION TO MOVE SPECIALIST CHILDREN'S CANCER SERVICES

OPEN LETTER TO NHS ENGLAND, NHS LONDON & SOUTH EAST & THE SECRETARY OF STATE FOR HEALTH & SOCIAL CARE

December 2023

We write to you as a united group of parents who strongly oppose the current NHS London & NHS South East decision to move all paediatric specialist children's cancer services from The Royal Marsden hospital in Sutton and relocate them within either Evelina London in Lambeth or St George's hospital in Tooting. We have been vocally opposed to this as part of the internal stakeholder process for several years and have challenged the lack of public engagement throughout the entire pre-consultation phase, with both parents and children who have the lived experience to provide crucial feedback and will ultimately be the ones affected by this decision.

Since the public consultation phase launched late September, we have been able to share our concerns with the general public and garner huge support from thousands of people who are in agreement that this poorly justified proposal needs to be reconsidered.

Public backlash to this proposition is mounting considerably with over 10,000 people now having signed our #HearTheMarsdenKids campaign petition and sharing their comments, (attached summary included with this letter for review). We have garnered the attention of national broadcast, print and online media with over 150 press articles and multiple interviews being published, (links to a snapshot of interviews also included below for review).

There are simply too many flaws in both hospitals proposals that showcase that neither option provides a better level of clinical care than what is currently provided at the world leading cancer specialist hospital, the Royal Marsden.

We appreciate that this decision has been based on the national service specification that states that all specialist cancer treatment services for children must now be provided on the same site as a Level 3 children's intensive care unit (PICU), but we believe this decision needs to be reviewed and reconsidered. Whilst we fully appreciate how traumatic it is for children and their families to receive PICU transfers and treatments; the impact of the decision to close and move all of the world-leading services from The Royal Marsden to an alternative London-based hospital, would cause far more

complications, inconsistencies in treatment and potentially hugely lengthy increases in travel times and logistics for families, at what is already a terrifying and incredibly stressful time for them.

We implore you to review our points below which clearly outline why the argument being put forward and the supposed 'Case for Change' is fundamentally flawed and will ultimately provide a far worse and more fragmented service for the future of children with cancer in the South East of England:

- **There is absolutely no guarantee that the new service would exceed, or indeed even meet, the current world-leading treatment programmes in place at The Royal Marsden**, especially if housed at Evelina London which is not a cancer specialist hospital. No detail has been submitted on a fully funded delivery plan for either option and it would be absolutely vital to see evidence now that could showcase how either would prove a stronger option and not simply meet an arbitrary specification requirement. There is no evidence because there is no guarantee of this.
- We are being told that the closure is needed due to the predicted increased need for PICU for future children's treatments – we have spoken to leading medical experts who dispute this as **many future treatments in development will also minimise the need for PICU** so the current figures are unlikely to change. **In 2022 only 3 children required PICU transfers from the Royal Marsden to St George's, this is less than 1% of patients**.
- Around 1,400 children, aged one to 15, are under the care of the Principal Treatment Centre for South London and much of South East England at any given time. More than 60% of the centre's patients are from outside London. All these children would face the extended journey time and continued dual and multiple site locations for treatments. More than 1 in 10 patients have 20+ visits to hospital, with some reaching to over 50 visits per child per year.
- **This does not solve the issue of single-site care**. Patients who do not require PICU but do require radiotherapy, among other treatments currently available at The Royal Marsden, would also all be moved and have to travel elsewhere. If Evelina London won the bid, they would not be able to provide Neurosurgery, so patients would still have to travel to King's or St George's hospital. The number of patients who require radiotherapy is far greater than those requiring PICU yet these are not being considered in terms of the huge impact this decision will have on them.
- **Travel times for the vast majority of patients and their families will be negatively impacted** – around 63.6% of patients do not live in South East or South West London determining that for the majority of patients their journey times and travel logistics would be increased. This proposal favours the idea that patients would travel by public transport to reduce their journey time to hospital – parents of critically-ill children with weakened immune systems would simply not risk this. Both hospitals being proposed have limited parking available and

Evelina London is also within the Congestion Charge zone. NHS London would only provide reimbursements for one member of the family to travel with their child, the other parent would be expected to pay all fees in full.

- **The Institute of Cancer Research, one of the world's most influential cancer research organisations, is based on the same site as The Royal Marsden Hospitals in both Chelsea and Sutton**. Its teams undertake laboratory-based and translational "bench to bedside" drug development research. They work closely with The Royal Marsden, which is a leading centre for cancer research, and St George's Hospital. This helps turn discoveries made by scientists into new treatments for patients. The co-location of the research labs and the children's unit in Sutton enables children for whom there is no known cure to be offered drugs on a compassionate basis. These drugs, formulated for adult cancers are not available for children but target the same abnormalities found in children's tumours. Moving these children away from the specialists running these trials would render access to these trials very difficult if not impossible. Neither proposal provides a viable option to navigate this effectively and would ultimately impact this crucial aspect of leading cancer research.
- **This is estimated to cost around £40million** at a time when the NHS is already underfunded, over-stretched and desperately in need of additional budgets and resources – how can this be justified when there are no actual safety or quality issues with the current offering?
- **The Oak Children & Young People's Drug Development Unit (OCYPDDU) is the largest and most active drug development programme for children and young people in the UK**. It is also one of the most active first-inchild clinical trial centres in Europe (where new treatments, drugs, therapy combinations or procedures are tested in children for the first time). This proposal highlights the poor decision that NHS London are prioritising meeting standard National specifications over patient choice & specialist care, spending public money and future research developments.

What is the alternative?

There is a simple and effective solution that has previously been discounted without solid justification and we want to push for it to now be approved. We are in agreement with the suggestion of proposing a 'risk-adapted' model whereby any patients who, upon diagnosis, are deemed likely to require PICU services throughout the course of their treatment, would receive their specialist care at St George's hospital to ensure minimal need for transfers.

For the remaining 93% of patients, they would continue to receive the world leading specialist care of The Royal Marsden including both in and outpatient appointments, on-site access to research specialists and drug trials and radiotherapy treatment.

This would remove the huge transportation challenges, issues of potentially reduced expertise and cohesiveness of care, remove the huge financial burden on the NHS and maintain the quality of care we all believe is crucial to ensure the best outcomes for our children.

There is no other hospital like The Royal Marsden Cancer Hospital in this country – without this hospital and its staff's expertise; the future of children's cancer services for South London and most of the South of England are at huge risk of failing.

We are requesting that as senior officials with vast experience and the necessary power to relook at this decision, that you choose to do so. NHS asked the public for their feedback and thousands have provided it. They, as us, don't want this move, don't agree it is in the best interest of patients and do not believe it is a justifiable expenditure of publicly funded money.

Thank you in advance for your time and we very much hope you hear from you soon. Yours sincerely, Parents, patients and supporters of the #HearTheMarsdenKids campaign

PRESS COVERAGE LINKS:

• Metro: https://metro.co.uk/2023/11/22/hearthemarsdenkids-call-nhs-londonreconsider-cancer-services-move-19852806/

• ITV London News

• ITV Meridian News: https://www.itv.com/news/meridian/2023-11-08/childcancer-patients-face-three-hour-trip-for-treatment-under-nhs-plans

• BBC Radio Surrey: https://www.bbc.co.uk/sounds/play/p0gn6ls4

• London Live: https://www.londonlive.co.uk/news/london-live-exclusive-reportfamilies-oppose-move-of-london-specialist-child-cancer-treatment-to-new-location/

• The Independent: https://www.independent.co.uk/news/uk/royal-marsdensutton-surrey-sussex-kent-b2454276.html

• Evening Standard: https://www.standard.co.uk/news/health/royal-marsdensutton-surrey-sussex-kent-b1123160.html

• Yahoo News: https://uk.news.yahoo.com/families-terrified-over-proposals-move050000963.html#:~:text=Services%20are%20not%20expected%20to,worldleading%20cancer%20specialist%20hospital

• Planet Radio: https://planetradio.co.uk/greatest-hits/surrey-easthampshire/news/a-home-from-home-parents-from-surrey-speak-out-asuncertainty-around-future-of-children-cancer-services-at-the-royal-marsdencontinues/?fbclid=IwAR0Hv67X9uiaImxLOMcoB4emXjCPo0e7ecJaXV20WhV1BIDFyoV3zIRcUw

• Radio Jackie: https://radiojackie.com/a-campaign-to-stop-childrens-cancerservices-being-moved-from-south-west-london-is-gathering-pace/

• My London: https://www.mylondon.news/news/south-london-news/parentsutterly-terrified-plans-move28072310?int_source=amp_continue_reading&int_medium=amp&int_campaign=continue_reading_button#amp-readmore-target

• Your Local Guardian: https://www.yourlocalguardian.co.uk/news/23873113.plan-stop-royal-marsdenhospital-childrens-cancer-care/

PETITION QUOTES: Attached

E. Research organisations

34. City, University of London

Colleagues,

I wish to add my support, and that of my institution to the proposal to locate the PTC at St George's.

As you may be aware City, University of London is in the final stages of agreeing a merger with St George's, University of London. This will create an extraordinary research and health education capability. We will possess a multidisciplinary strength and breadth fully equivalent to the other major institutions of the University of London. In short our merger will change the game in London.

We will have a unique focus on professional engagement and will be the most comprehensive health educator in the UK with capacity that spans medicine, nursing and the allied health professions. City strengthens the case for St George's. We bring research in computer science, engineering, psychology, social sciences and more. We have leading communication and business schools covering areas that include health leadership.

We have ambitious plans to invest in the St George's campus, to develop further impact and entrepreneurship facilities, and to support multidisciplinary research contributing to health.

We look forward to collaboration with the Royal Marsden and the ICR, and bringing our own networks to this opportunity.

Yours,

Anthony Finkelstein

Prof. Sir Anthony Finkelstein CBE FREng
President

City, University of London
Northampton Square
London EC1V 0HB

www.city.ac.uk
finkelstein.uk

35. Institute of Cancer Research

In a future Principal Treatment Centre, what would you value most?

We acknowledge the proposals put forward and are pleased that the importance of research continuity has been highlighted as an important part of the decision making.

Research is an absolute central requirement to the delivery of an excellent state-of-the-art clinical service and future improvements in patient outcomes. The optimal solution is for clinical care and research to be co-located. We are concerned that the relocation of the PTC poses significant risk to the delivery of a highly successful paediatric research programme led by ICR and RM.

The ICR and RM have worked in partnership for over a century and together are ranked as one of the top comprehensive cancer centres worldwide for research and clinical care. RM together with the ICR is designated as the UK's only National Institute for Health and Care Research Biomedical Research Centre (BRC) dedicated solely to cancer. Also, together we host the London paediatric Experimental Cancer Medicine Centre (ECMC). We contributed 23% of all cancer drugs licensed by the EMA between 2000 and 2016. RM and ICR together are one of the largest clinical trial centres for children in Europe and we run an integrated and funded adult and paediatric drug development programme which is internationally renowned. ICR and RM have also established a Centre for Paediatric Oncology Experimental Medicine (POEM), which identifies and studies the molecular changes underlying the development and progression of childhood cancers in order to derive innovative new treatment strategies. The Centre develops novel treatments and diagnostic tests and aims to deliver changes to clinical practice for children with cancer. The Centre builds on our track record of delivering significant benefits for paediatric cancer patients through our close working relationship and joint research strategy.

The paediatric research groups at ICR have long-standing and strong relationships with clinicians in the PTC at RM, arrangements for on-site training in research and rapid collection and processing of fresh materials from patients for research. The continued co-location of clinical care and research is the ideal preference. Where this is not the case, there is a real and major risk that we will lose synergy between the clinicians and research leaders that ultimately comprises future improvements to patient care.

In any alternative solution a commitment to research is essential, this includes a commitment to people, training and funding to facilitate research related activities. This is required both in the lead up to any transfer as well as for ongoing activities after the transfer.

People: Maintaining the relationships built up over many years is key. Co-location allows daily interaction between clinicians and researchers. In the current arrangement this has led to training clinical fellows, joint supervision of PhD students and honorary academic appointments. ICR lab members are embedded with the clinical team as clinician scientists and ICR researchers partner with clinicians in the development of clinical trials. Together this fosters a shared understanding of the clinical issues, rapid and optimised processes for collection of fresh patient samples and capitalises on opportunities arising from ICR's research.

At the moment, uncertainties around relocation have affected retention of key staff and the ability to recruit. These issues will continue if we lose RM/ICR co-location and represents a risk in an already highly competitive global market centred around the value of the RM and ICR brands.

Early phase trials: There is potential to lose the excellent track-record and recognition as an Innovative Therapies for Children with Cancer (ITCC) Centre, ECMC Partner and developer of early phase clinical trials based on specific clinical expertise and molecular research / preclinical studies. In the proposed models there will also be a loss of co-location with teenage and Young Adult (TYA) and Adult Drug Development & Disease Specialist Teams. There is also an associated risk of losing industry attractiveness which would reduce the number of opportunities for new treatment options open to children and young people.

A commitment to supporting translation of research into development of early phase trials is required. Also, detailed discussions are needed to support the interface between Paediatric, TYA and Adult Drug Development & Disease Specialist Teams.

Samples: The established relationships and pipelines at RM are key to the availability and pipelines to access fresh or other samples and transfer them into the laboratory for collaborative research efforts. There will be an increase in cost both in terms of people's time and transport costs. A commitment to support ongoing sample collection, processing, biobanking and transport of fresh samples to labs is required.

Funding:

• Grant funding: The current uncertainty around the clinical service is a risk to grant applications. There is a requirement for a clear statement which can be provided as part of funding applications. Our current grant funding in this area is over £25m.

• Infrastructure funding: BRC and ECMC infrastructure funding supports the research programme, this would be lost in the future models.

• Charity Funding: Paediatric research and associated infrastructure at ICR and RM has benefitted from the RM Children's Charity Fund. RMCC investment has been very significant. A commitment to continued funding is essential for the paediatric research programme to continue, wherever the partners may be.

To maintain the excellent ICR/RM track record of research, establishing early phase trials and high enrolment of young people onto trials for new treatments, there needs to be a strong and public commitment to:

• Develop clear plans for the future that build on current excellence in laboratory and clinical research at ICR and RM.

• Support clinician time (release of clinical PAs) to facilitate research across organisations.

• Financial support for activities that facilitate laboratory research and foster continued collaborations.

Thinking about Evelina London … Please share your views on the good points of this option (including anything we may have missed)

Access to onsite infrastructure and services including sample storage and office space, noting however that the operational detail of this will need to be clarified with a commitment to support infrastructure and promote collaborative working across organisations. Although welcome this requires a strong commitment to maintain the current synergistic model of clinicians and academics being permanently co-located and is seen as a risk to the current paediatric research programme.

Please share your views on potential challenges of this option (including those we may have missed)

Although current research funding is detailed at this centre, it is not clear if any of this funding can / will be redirected to support the paediatric oncology research programme. A plan to replace the current RMCC funding will be essential for the continued success of the research programme.

Distance between PTC and the research labs, creates real challenges in maintaining synergy between researchers and clinicians, impact on laboratory research training for clinicians, sample availability, transfer and transport for research.

Impact on retention of research leaders and talent acquisition.

What suggestions do you have to improve the things you've identified as potential challenges?

A strong and public commitment to:

• Develop clear plans for the future that build on current excellence in laboratory and clinical research at ICR and RM.

• Support clinician time (release of clinical PAs) to facilitate research across organisations.

• Financially support activities that facilitate laboratory research and foster continued collaborations.

Thinking about St George's Hospital… Please share your views on the good points of this option (including anything we may have missed)

Dedicated space for ICR staff in the proposed children's cancer centre (lab and office). Noting however that the operational detail and financial support for this will need discussion to develop a clear plan. Although welcome this requires a strong commitment to maintain the current synergistic model of clinicians and academics being permanently co-located and is seen as a risk to the current paediatric research programme.

A potential interest in maintaining the ICR and/or RM brand at St George's, at least in the short-term.

Please share your views on potential challenges of this option (including those we may have missed)

Research funding, is there an ability to divert research funding to support the paediatric research programme?

Distance between PTC and the research labs, creates real challenges in maintaining synergy between researchers and clinicians, impact on laboratory research training for clinicians, sample availability, transfer and transport for research.

Impact on retention of research leaders and talent acquisition.

What suggestions do you have to improve the things you've identified as potential challenges?

A strong and public commitment to:

• Develop clear plans for the future that build on current excellence in laboratory and clinical research at ICR and RM.

• Support clinician time (release of clinical PAs) to facilitate research across organisations.

• Financially support activities that facilitate laboratory research and foster continued collaborations.

Other changes. Please tell us what you think about this part of our proposal, including the effect it might have

We understand that in both options radiotherapy services would be provided by University College London Hospitals NHS Foundation Trust, as such clinical services wouldn't all be on one site, still requiring children to travel. We think this is important to take into consideration given the significant concerns regarding risks to research and to the delivery of a highly successful paediatric research programme led by ICR and RM. Research is an absolute central requirement to the delivery of an excellent state-of-the-art clinical service and future improvements in patient outcomes.

Do you have any other thoughts or ideas you want to share?

Whilst acknowledging the options proposed will achieve colocation with level 3 specialist paediatric critical care we do not think you can underestimate the importance of the co-location of research with clinical care in providing state of the art clinical services for the benefit of children and young people. We also understand that in both options radiotherapy services would be provided by University College London Hospitals NHS Foundation Trust, as such clinical services wouldn't all be on one site, still requiring children to travel.

Our current grant funding for research in this area is over £25m.

The following studies exemplify the patient impact ICR and RM have delivered for children with cancer and therefore the significant risk to paediatric cancer research in the UK if this is not sufficiently protected.

Fadraciclib (a dual inhibitor of two cancer-driving proteins from the cyclin-dependent kinase (CDK) family, CDK2 and CDK9) was discovered by ICR scientists in collaboration with the company Cyclacel. Fadraciclib has already passed safety tests and shown promise in treating a range of adult cancer types. Together RM/ICR are leading the research into using this drug to treat high-risk children's cancer. An ICR and RM study provided evidence that fadraciclib might be effective in treating neuroblastoma. Neuroblastoma is often driven by high levels of the cancer-causing gene MYCN. Unfortunately, the structure of the N-Myc protein makes targeting it extremely challenging, and efforts until now have been unsuccessful. Inhibiting the cancer-driving proteins CDK2 and CDK9 can stop activity from the MYCN gene, causing cancer cells to die. Our study showed fadraciclib slowed down and stabilised neuroblastoma growth in mice, and the mice who received it also survived for longer after treatment than untreated mice. The combination of fadraciclib with chemotherapy, shrank the tumours to the point of virtually eradicating them, with a remarkable extension of overall survival. Based on this preclinical study fadraciclib entered clinical trials for children with high-risk neuroblastoma as part of the international eSMART clinical trial, supported in the UK by CRUK, and led in the UK by RM/ICR. Existing therapies for aggressive forms of neuroblastoma are very intense and take a toll on young patients, often leaving them with long-term side effects. Therefore, there is an urgent need to develop

smarter treatments that are less toxic. The close connection between research and clinic means that patients are offered new experimental therapies, and therefore have increased chance for a longer life and survival.

Our joint working is further exemplified by the development of next generation sequencing panels for stratified medicine in paediatric cancers. Researchers in the Paediatric Oncology Experimental Medicine developed a next generation sequencing (NGS) panel that determines the incidence of genomic mutations in paediatric solid tumours and is now being used to inform treatment for UK paediatric patients. The test detects alterations in paediatric solid tumours, incorporating genes commonly mutated in these cancers – including ALK mutations originally found by the ICR. The NGS panel was prospectively tested in a pilot study and then rolled out through a Children's Cancer and Leukaemia Group (CCLG)-approved national trial with RM/ICR as the genomics hub and Great Ormond Street Hospital (GOSH) as a partner genomics hub.

Building on this work, we established the Stratified Medicine Paediatrics (SMPaeds) national molecular profiling study for children with relapsed and refractory cancer. SMPaeds uses this panel alongside other profiling modalities including lcWGS, RNA fusion panel (4) and equivalent DNA panels and lcWGS in blood-based plasma circulating tumour DNA assays. SMPaeds has enrolled >500 patients and established a reference pathway for multiomics sequencing of children with cancer. The pathway was co-ordinated via reference diagnostic labs (particularly the North Thames Genomic Laboratory Hub), which meant that transition to NHS implementation was in a remarkably rapid timescale. SMPaeds is prospectively supporting biomarker-driven trials in the UK such as eSMART and CRUK-DETERMINE, major first-concept combined adult-paediatric trial driven by multiomic sequencing.

Our joint research led to direct alteration of care pathways for children who relapse with cancer. The development of genomic technologies to a clinical diagnostic standard, and the parallel establishment of practical testing pathways has allowed rapid incorporation into NHS rapid diagnostics pathways. Bioinformatics tools were validated for the identification of actionable events from targeted gene sequencing and the RNA fusion panel leading to precision diagnostics. The impending implementation of liquid biopsy panels will similarly transform care with the possible transition away from tissue biopsy to plasma biomarker testing. This is so critical for children given the risk and cost of tissue biopsy for these fragile patients.

This research and impact has been made possible by the close working relationship between clinicians and scientists at ICR and RM, the co-location and groups operating as part of a joint institution, with a joint research strategy. Even putting the issues of co-location aside, it would take many years to recreate that relationship.

36. King's College London

Senior Vice President Health & Life Sciences

Professor Richard C Trembath FRCP, FMedSci

1.4 Hodgkin Building
Guy's Campus
London SE1 1UL
Tel +44 (0)20 7848 8045
Email Richard.trembath@kcl.ac.uk

12th December 2023

Principal Treatment Centre for children's cancer services consultation
NHS England
Via: england.childrenscancercentre@nhs.net

Dear NHS England

We write in response to your consultation on the new Principal Treatment Centre for children's cancer services. We are proud to be the main academic partner for Evelina London Children's Hospital, known globally for its outstanding leadership in children's health research, and fully support their proposal. Together, our partnership has made impact on the lives of sick children, from pioneering clinical trials into peanut allergies, to imaging studies which have transformed our understanding of heart and brain function. We have unrivalled expertise to address the holistic needs of children with cancer and their families, from research to understand how cancer develops in children and adults, through to mental health and policy research.

We are pleased to note that NHS England's panel of independent experts in paediatric oncology have independently assessed Evelina London as having the best potential for enhancing children's cancer research.

Extending our partnership to formally include the world renowned RMH clinical research team and building on established collaborations with the Institute for Cancer Research, would enable us to create an outstanding programme of research for paediatric oncology, having impact on the lives of children with cancer and their families globally.

Using Evelina London's dedicated children's research wards and in partnership with the specialist children's research teams, we could immediately begin new children's cancer clinical research studies and offer the latest immune therapies like CAR-T. We will strengthen our capacity to develop cutting edge therapies and treatments which will be critical for the future of children's cancer care, including seeking to appoint a Chair in paediatric oncology.

A great strength of the combination of the pairing of King's College London multi-faculty environment, with Evelina London as a comprehensive children's hospital, is the holistic approach to children's cancer research and care that we can offer.

We have extensive university, health partner and industry collaborations to offer paediatric oncology researchers, providing a comprehensive research environment to complement Evelina London Children's Hospital proposals. These include the CRUK City of London Major Centre (£25m), and CRUK RadNet City of London Radiation Research Unit (£14m), both multi-institutional cancer research programmes. The GSK-KCL Translational Oncology Research Hub accelerates development of anti-cancer drugs; and our strategic collaboration with UCB Biopharma in immunology, oncology, neuroscience, and bone health, includes the Phase 1 trial of UCB's first ever cancer therapy.

Through the KCL Institute of Cancer Policy, we influence major national and international policy programmes, including paediatric oncology. The Centre for Cancer, Society, and Public Health has a strong focus on both global cancer studies and local translational research using real world evidence such as epidemiological studies and clinical trials embedded in healthcare and using electronic health records.

The KCL School of Biomedical Engineering and Imaging Sciences, co-located with Evelina London, is a world-class centre for imaging and data analytics research. It will shortly house England's only total-body PET scanner, at St Thomas' Hospital, which exposes patients to considerably lower doses of radiation, meaning more children can participate in clinical trials to improve our understanding of disease, including cancer, and benefit from improved treatments as a result.

The Pears Maudsley Centre for Children and Young People within the KCL Institute of Psychiatry, Psychology & Neuroscience (IOPPN), a world leading centre of excellence for childhood mental health research, is ideally positioned to lead studies on the mental health aspects associated with paediatric cancer, including long-term impacts, while the Cicely Saunders Institute is world renowned for palliative care research.

Health services research would be a key component of the combined offer to strengthen holistic care for children. Evelina London and King's College London's Child Health Systems and Policy Research Group has extensive expertise in engaging children in research, including recruiting c.2000 local children to trials of early biopsychosocial care intervention, resulting in model of care changes for 120,000 children in South London. The NIHR Applied Research Collaboration for South London has Children and Young People as a core theme, and patient and public engagement and involvement is fundamental to our approach, including through advisory groups.

KCL offers an excellent clinical academic training environment which would be extended to paediatric oncology researchers joining Evelina London. This includes the King's Doctoral Training Centre, NIHR Integrated Academic Training programme, and King's Clinical Academic Training Office. Furthermore, we offer adjunct appointments to give highly research-active NHS staff full university support, including holding grants, finance access and PhD supervision.

We fully support the Evelina London proposals and look forward to extending and deepening our research and education partnerships to improve the lives of children with cancer and their families in the South-East and globally.

Yours faithfully

Professor Richard Trembath
Senior Vice President, Health and Life Sciences
Executive Director, King's Health Partners

Professor Bashir M. Al-Hashimi
Vice President, Research and Innovation

37. King's Health Partners

KING'S HEALTH PARTNERS

An Academic Health Sciences Centre for London

Pioneering better health for all

King's Health Partners Academic Health Sciences Centre

Counting House, Guy's Hospital

London SE1 9RT

17th December 2023

RE: Principal Treatment Centre for children's cancer services consultation

NHS England

Via: england.childrenscancercentre@nhs.net

Dear NHS England,

We write in response to your consultation on the new Principal Treatment Centre for children's cancer services. We are proud that Evelina London Children's Hospital through Guy's and St Thomas's NHS Foundation Trust is part of King's Health Partners (KHP) Academic Health Sciences Centre (AHSC). We write to build on the consultation response from King's College London (KCL), our university partner in the AHSC, and in support of Evelina London's proposal.

Our purpose together as KHP is to deliver real-world benefit for our patients, people and populations through integrating excellence in research, education and training, and health and care delivery. We are doing this by focusing on three interconnected priorities - personalised health, health digital and data sciences, and population health - integrating mental and physical health across everything we do. KHP was first accredited as one of the first five AHSCs in 2009, and again accredited in 2014 and 2020, and is one of now eight AHSCs in England. Through integrating clinical academic collaboration within clinical services, our mature AHSC supports our partners unrivalled expertise to address the holistic needs of children with cancer and their families (as detailed in the consultation response from KCL).

KHP Women and Children's Health is one of the priority clinical academic partnerships in our AHSC, providing practical support to our people to close the translational gaps between evidence and practice: by embedding research and evaluation in clinical services; by providing practical and technical support to develop and deliver research; by developing and delivering multi-professional training; and by connecting colleagues for high-impact research, career development and networking. KHP Women and Children's health clinical academic partnership is hosted by Evelina London, which would support the extension of our partnership to formally include the world renowned RMH clinical research team and facilitate building on established collaborations with the Institute for Cancer Research. The clinical academic partnership is led by Professor Ingrid Wolfe, whose clinical work at Evelina London and academic work at KCL is at the forefront of the KHP approach to population health, embodied in the CHILDS framework, which is serving as a model for our approach to addressing health inequalities across our population.

These interactions would be further supported through collaborations across our established clinical academic partnerships and groups, including in Neurosciences, Cancer, Child and Adolescent Mental Health and Palliative Care, leveraging the extensive university, health partner and industry collaborations detailed in the KCL response.

KING'S HEALTH PARTNERS

This clinical academic environment is enhanced by our recently launched Centre for Translational Medicine, which combines our outstanding clinical and scientific expertise to deliver excellent outcomes for patients, and develops the next generation of clinical-academic leaders skilled in delivering impactful translational biomedical research.

Through our long-standing focus on integrating Mind & Body, our patients and people benefit from world-leading mental health research within the NIHR Maudsley BRC and the KCL Institute of Psychiatry, Psychology and Neurosciences (IoPPN), which includes the Pears Maudsley Centre for Children and Young People, a world leading centre of excellence for childhood mental health research. This provides an exceptionally supportive environment for research that will advance our understanding of, and ability to provide care for, the mental health impacts of cancer diagnosis and its treatment.

KHP Education supports and enhances KCL's excellent clinical academic training environment which would be extended to paediatric oncology researchers joining Evelina London. In close partnership with the King's Doctoral Training Centre, NIHR Integrated Academic Training programme, and King's Clinical Academic Training Office, KHP Education supports tailored education to support clinical academic collaboration including through the KHP Learning Hub and KHP Digital Health Hub.

Our clinical academic collaborations are enhanced through system partnerships including with the Health Innovation Network (HIN) South London and NIHR Applied Research Collaboration (ARC) South London, as well as collaborations with our local integrated care systems such as the South East London Coalition for Better Health and Equity and Mind & Body Improvement Network across London.

We fully support the Evelina London proposals and look forward to extending and deepening our academic health partnership to improve the lives of children with cancer and their families locally, regionally, nationally and globally.

Yours faithfully,

Rt Hon Professor Lord Kakkar KBE PC
Chairman, King's Health Partners

Professor Richard Trembath
Executive Director, King's Health Partners

F. Charities and not-for-profit organisations

38. Action for XP

13th December 2023

To Whom it may concern,

Children's Cancer Services for South London and Southeast England

I am writing to you with from three perspectives in relation to this bid. The first is as a person with a complex condition myself; xeroderma pigmentosum (XP) which is a multi-systemic, ultra-rare condition. Incidentally, XP carries a 10,000 fold increased risk of developing skin cancer compared to unaffected individuals. The second is as chairperson for Action for XP, which is a UK-based charity that supports people and their families affected by XP. The third is a dermatology registrar in my last year of training prior to consultancy.

Amongst many of these rare conditions, XP included, there looms the threat and very real risk of developing a wide array of different malignancies. This is quite a formidable prospect for anyone to face at any age but certainly so for children and their respective families. Coordinating the children's cancer services for South London and Southeast England from the Evelina would allow the world-renowned expertise of this centre to deliver the pioneering care imperative to these children and their families.

Not only will the centre be best placed geographically, the rich academic track record of the unit and the calibre of healthcare staff it attracts will ensure it will continue to thrive. The unit is further supported by the robust backing provided by Guys' & St Thomas Hospital which has a wide array of tertiary level teams already established.

As a patient and doctor, I highly value dedicated condition-specific teams, and it gives me great relief to know that world leading services are available onsite across a multitude of specialties for further support and even for transition of care.

I fully support the proposition for the Evelina London as the proposed site of relocation and bringing together of paediatric cancer care services and clinical research to serve the southeast of England.

Yours faithfully

Richard Barlow

Email: richard@actionforxp.org
Web: www.actionforxp.org
Facebook & Twitter: **@ActionforXP**

39. Christopher's Smile

Response to the Public Consultation for the Proposals for the future location of very specialist cancer treatment services for children living in south London and much of south east England

This response is from Kevin Capel, parent of a child who was treated at the Royal Marsden and St. George's who subsequently died from childhood cancer and co-founder of Christopher's Smile a charity funding paediatric cancer research.

December 2023

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Executive Summary

This response to the public consultation on the Future of South Thames Paediatric Oncology Services gives my views on the bids by the Evelina London Children's Hospital and St. George's Hospital and my options for the future. My aim has been to be as objective as possible and to give background and context to the options I have documented.

My view is that neither Evelina London Children's Hospital or St. George's are suitable candidates to become a Principle Treatment Centre and that should NHS London move the paediatric oncology services from the Royal Marsden Hospital to either centre it will be a gross waste of public money and a degradation of service for the vast majority of patients.

The NHS finds itself in the biggest crisis in its history. Waiting lists are at an all-time high, there are severe staff shortages, recurring winter capacity issues, the impact of RAAC on its buildings, the prospect of future capacity issues with an ever aging and unhealthy population and ongoing industrial action. Yet NHS London are intent on forging ahead with this project.

I therefore propose that work proceeds immediately in 3 stages. Stage 1 which is mandatory is the risk stratification of paediatric oncology treatments and those treatments deemed as carrying a greater than 5% of PCC Level 3 admittance is carried out at St. George's Hospital as part of the joint Royal Marsden Hospital/St. George's Hospital Principle Treatment Centre.

Stage 2 which is optional is to start a trial of an 'eICU' solution for paediatrics aimed at providing more PCC Level 2 and 3 coverage across the country and enabling those hospitals such as the Royal Marsden who do not have PCC Level 2 or 3 facilities to have patients linked to intensive care specialists at a hub location.

Stage 3 is to build a new children's specialised services hospital at a South Thames location with far better access than that offered by either the Evelina or St. George's. I have 2 options, one is the current site of the Sutton Hospital on the Royal Marsden/Institute of Cancer Research Campus and the other location is Kenley south of Purley in Surrey.

Stage 3 would be the most expensive but would enable all paediatric specialised services to be housed under one roof. This would create capacity for the health needs of the local community at the fixed footprint inner city hospitals currently housing these services. As building work is very expensive and logistically complex in inner cities, building a hospital on the periphery of London would be a cost effective solution to meeting future capacity shortfalls.

It is time NHSE reviewed all South Thames Paediatric Specialised Services and produced a single strategic plan that took into account the capacity issues facing all hospitals for all age groups. This plan needs to be a bold step forward and must not in any way pander to individual trust protectionist policies. Children must come first. Decades of malaise need to be remedied. Simply moving the Paediatric Oncology Principle Treatment Centre from the Royal Marsden to either the Evelina or St. George's in a tactical 'quick fix' will not improve levels of care for children and will in the longer term be a costlier option.

Kevin Capel

December 2023

Background factors to this response

In 2021 the Service Specification for Children's Cancer Principal Treatment Centres[1] (PTCs) was published with the amendment mandating that PTCs must be co-sited with a Paediatric Critical Care (PCC) Level 3 facility. This amendment was added as a result of a review produced by Prof. Sir Mike Richards of Children's Cancer Services[2]. By mandating the co-siting of PTCs with a PCC Level 3 facility, this effectively mandated relocations of 2 PTCs in London; The Royal Marsden and UCLH. The reasons given in the review for the mandating of co-siting was that there was a near unanimous support for this from individuals and organisations based outside of London. There was also support for co-siting from National Organisations. However the review did not spell out the implications of mandatory co-siting nor was there any indication of the cost to the taxpayer of any change. So I can only surmise that the individuals and organisations contacted by Prof. Richards gave their views purely on a point of principle and not on an informed viewpoint taking into account the implications of any service change. Yet the Service Specification was amended citing near unanimous support. This change to the Service Specification effectively signed a death sentence to the Royal Marsden Children's Unit, something NHS London had been advocating since the 2015 London Paediatric Oncology Review chaired by Prof. Mike Stevens[3]. This review concentrated only on streamlining services and supported a single PTC for the whole of London, although a 2 PTC option was considered. The 2015 review included the findings of the 2011 National Clinical Advisory Team's report on the Royal Marsden/St. George's Hospital joint PTC stating that *"In the longer term we think the most advantageous long term solution is to re-provide the whole paediatric oncology Principal Treatment Centre clinical activity on the site of a children's specialised services hub in South Thames, alongside other essential services as set out in the 'Safe and Sustainable' recommendations"*. I can therefore only assume that NHS London's long term objective has all along been to close the Royal Marsden's Children's Unit and create a PTC in line with the 2011 NCAT recommendations.

Although the single PTC option was favoured by the 2015 Review, NHS London proceeded with the 2 PTC option, one for the North of London and the surrounding areas and one for South of the Thames. The amended Service Specification published in 2021, provided NHS London with the justification they needed to proceed with their objective to close the Royal Marsden's Children's Unit and relocate Children's Oncology Services to an alternative site which met the requirements of the Service Specification. It must be noted that up to the point that NHS London decided on the course of action to seek an alternative PTC location for South Thames, no study had taken place to assess the impact of any PTC relocation on patients and their families, the staff working at the Royal Marsden and the close working relationship between the Institute of Cancer Research and the Royal Marsden in conducting research activities, particularly in the area of drug development.

The 2015 Review of London Paediatric Oncology Services highlighted the fragmented nature of paediatric oncology services South of the Thames. In my document "Proposal for the Future of South Thames Children's Cancer Services"[4] I too have highlighted the fragmented nature of paediatric oncology services and blamed decades of malaise on the part of NHSE and no strategic objective to remedy the situation. In the North of the Thames all services apart from paediatric radio therapy are concentrated at GOSH. This is mainly from a historical perspective whereby London had a much smaller population and Great Ormond Street was the only paediatric hospital for London providing very specialist services. In the South of London, specialist paediatric services have evolved at a number of hospitals and have resulted in the current configuration. So in order to potentially co-site paediatric oncology services with other paediatric services, no one site offers a solution whereby all paediatric specialist services, both oncology and non-oncology, are housed under one roof.

The Two Bidders

If we turn our attention to the two bidders for the South Thames paediatric oncology services, neither the Evelina nor St. George's can provide a single site solution for all specialist services. It must also be noted that both bidders are London hospitals and the respective Trusts provide both District General Hospital services and specialised services for adults, TYA and children. Both bidder hospitals, St. Thomas'/the Evelina and St. George's have a fixed footprint and cannot expand outside of their boundaries. Although the Evelina planned to shoehorn an additional building adjacent to the current main Evelina building, this has not materialised. St. George's intention is to use underutilised administrative floor space for any paediatric oncology centre. Both hospitals suffered from a lack of capacity last winter[5] and this issue will only be exacerbated by an increasingly unhealthy and aging population. I cannot understand how both hospitals can contemplate the using of precious ward space for patients from outside their District General Hospital catchment areas when there is a clear need for more hospital beds for local people.

Costs

With regards costs, there has been no estimated figure released for sunk costs so I will assume £10M. If this figure is added to the figure from NHSE (£20M) and a further £10M from local ICBs the total would be approximately £40M. I would have to ask whether this is the best use of funds considering across NHSE there is a lack of capacity for winter patient numbers, an ever growing patient backlog that has not been addressed and the impact on NHSE hospitals of the RAAC (Reinforced Autoclaved Aerated Concrete) issue that will need considerable capital spend. I cannot understand why the PTC project is being allowed to forge ahead when there are so many serious issues that need urgent funding. I would ask whether prioritisation reviews take place and what factors are taken into account when prioritising spend? Everyone is aware that the NHS does not have an infinite budget. Tax payers expect funding to be used on items that bring the greatest patient benefit and that careful consideration takes place as to how imperative the spend is to either maintain current services or meet a current unmet need. The PTC move does not fix a shortfall in the current service from a patient perspective and certainly does not meet a current unmet need. I am sure some in NHS London would see the Royal Marden's inability to meet the current service specification as a short fall in service and the prospect of introducing CAR-T cell treatments meets an unmet need. However when operating theatres have leaking roofs due to RAAC, hospitals across the country cannot meet their A+E processing times and millions of patients are awaiting treatment, the co-location of a PCC Level 3 with a PTC simply to comply with a service specification is trivial and does not warrant funding at this time.

I must add at this time the often reiterated comments from NHS London regarding the implementation of CAR-T cell treatment. This has been repeatedly cited as the reason why PTCs must be co-located with a PCC Level 3 facility as this treatment would carry a higher risk of needing an intensive care admittance. There have been no estimates of future CAR-T cell patient numbers, neither has there been any data presented by NHS London showing PCC Level 3 occupancy rates. Consequently there has been no allowance whatsoever included in the costs for any increase in PCC Level 3 capacity at either of the bidder sites.

If paediatric oncology services move from the Royal Marsden in Sutton to either of the two bidders, patients in West Sussex and South West Surrey would have a shorter and simpler journey to Southampton Hospital PTC than to either of the two bidding hospitals. I have been in communication with the Chief Operating Officer of Southampton Hospital who has stated that any increase in patient numbers would need associated funding. There has been no funding included for any future increase in patient numbers at Southampton.

Views on Evelina London Children's Hospital as PTC

The Evelina Children's Hospital is an integral part of St. Thomas' Hospital in Lambeth. The Evelina hospital is the favoured bidder by NHS London.

I would like to comment on the Evelina hospital using the 4 domains used in the evaluation of which the stakeholder group were only allowed input to one domain

Clinical domain

I am sure the clinical standard of care will meet the necessary statutory requirements mandated by the relevant Royal Colleges and NHS Service Specifications.

Patient and Carer Experience Domain

This domain was the only one that the Stakeholder Group were allowed an input. This domain includes accessibility of the site and the expected experience of both patients and families. The Evelina has an associated Ronald McDonald House. This facility has been described as one of the largest in the country but no current occupancy rates have been included as part of the Evelina bid. If the Ronald McDonald House is currently running at nearly full where would the families of oncology children stay? Alternatively would parents who currently stay at the Ronald McDonald House be angry with the Evelina for attracting Paediatric Oncology if suddenly they found themselves unable to stay at Ronald McDonald House due to much higher demand? This item has not in any way been addressed and it is fundamental to oncology families.

Of the two bidders, the Evelina is the only one in the London Congestion Charge Zone. While this charge is refundable for patients themselves, visiting family members including parents would have to pay the charge. With regards access, travel to the Evelina would be horrendous for families in Kent, E. Sussex and Surrey. In the week Monday 11th December 2023 to Friday 15th December 2023 I queried the journey times using Google between 07:45 and 08:15 from 3 locations; Ramsgate – Kent, Lewes – East Sussex and Chiddingfold – Surrey. I chose Chiddingfold in Surrey as it is a rural location and being located South West of Guildford may find travel to Southampton more convenient. The results I obtained showed that at this time of the morning (assuming a 10:30 clinic appointment) the journey to the Evelina by car from Ramsgate was 28% longer in time than to the Royal Marsden in Sutton. The journey to the Evelina by car from Lewes was 94% longer in time than to the Royal Marsden in Sutton. The journey to the Evelina by car from Chiddingfold was 43% longer in time than to the Royal Marsden in Sutton. The journey to the Evelina by car from Chiddingfold was 20% longer in time than to Southampton Hospital. This data was an average of the figures obtained during the week. For locations closer to the Royal Marsden in South West London and North East Surrey the differences would have been more pronounced. Car transport was used for the example as a neutropenic child cannot use public transport. This data clearly shows that for the majority of patients in the South Thames catchment area, travel would be significantly longer, a much more difficult drive and when you finally reached the Evelina have nowhere to park as St. Thomas' Hospital Car Park would be full. The St. Thomas' Hospital website recommends the use of public transport as it states that the car park is often full. Oncology children cannot use the public transport option.

Enabling Domain

There is a dependence on staff transferring from the Royal Marsden to the hospital of the winning bidder. I see no incentive whatsoever for staff to transfer from the Royal Marsden in Surrey to the Evelina. Travel would be a huge issue. For any current staff member living in Surrey, the journey, especially at the end of a late shift would be horrendous so why would anyone move? Has there been an assumption that paediatric oncology nurses would put paediatrics before oncology and feel they

would have to make the move? As paediatric nurses they could work at a number of hospitals in Surrey in general paediatric wards. If they wanted to stay in oncology they could fill vacancies at the Royal Marsden in adult wards or work in adult oncology wards at other Surrey hospitals. With current NHS vacancy levels there must be a realisation that there is no incentive whatsoever for staff to transfer to the Evelina.

At the start of the public consultation the Evelina announced that instead of siting the prospective paediatric oncology ward in a part of St. Thomas' Hospital, an area had been found in the main Evelina building. No drawings of this area have been made available to the Stakeholder Group and its suitability with regards to space is unknown.

It must be noted that the Evelina bid will require £10M of funding from St. Thomas' Hospital Foundation. As the trustee of a charity I do not think it right that charity funding is used in order to attract services to the hospital. In fact the Evelina has stated that *"Evelina London is the only children's hospital in the Children's Hospital Alliance of 11 children's hospitals in England that does not have an oncology service."*. Yet it appears that to meet the aspiration of obtaining paediatric oncology there is a need for charity funding. If the service stayed where it is or was moved to St. George's the charity could use its funds on other projects and not merely submit to Trust aspirations.

I find the Evelina bid even more intriguing when in October 2021 a report in the Evening Standard[6] stated "But councillors were told the Evelina was already over-capacity with more than 100,000 patients a year" and "Marian Ridley, director of Evelina London, said the hospital's services would have become "fragmented" had permission not been granted" in relation to the planning permission for an extension to the Evelina. However it appears that even with no physical expansion, space can be provided for the introduction of paediatric oncology. I would have to ask if the message to Lambeth councillors at the time was somewhat disingenuous?

Research Domain

The Evelina has had no involvement with Paediatric Oncology Research yet scored higher than St. George's in the evaluation. How this occurred I have no idea. All references to oncology research in the Evelina bid have been to adult oncology research which is completely different to paediatric research. There has been no detail as to how the Evelina, whose academic partner is Kings College would work with the paediatric researchers of the Institute of Cancer Research. Neither has there been any detail as to how the current high number of drug trials in children would be maintained.

Views on St. Georges Hospital as PTC

St. George's Hospital in Tooting currently operates as the partner in the Joint PTC with the Royal Marsden in Sutton. It is a District General Hospital, a teaching hospital and the Tertiary Paediatric Trauma hospital for South Thames.

The hospital is situated in the heart of Tooting, an extremely busy urban area with few open spaces nearby.

I would like to comment on the St. George's hospital using the 4 domains used in the evaluation of which the stakeholder group were only allowed input to one domain

Clinical domain

I am sure the clinical standard of care will meet the necessary statutory requirements mandated by the relevant Royal Colleges and NHS Service Specifications.

Patient and Carer Experience Domain

This domain was the only one that the Stakeholder Group were allowed an input. This domain includes accessibility of the site and the expected experience of both patients and families. St. George's has an associated Ronald McDonald House. No current occupancy rates have been included as part of the St. George's bid. If the Ronald McDonald House is currently running at nearly full where would the families of oncology children stay?

Car parking is limited at St. George's. Access is better than the Evelina for families in Surrey and East Sussex but again journey times are longer than for the Royal Marsden in Sutton.

Enabling Domain

I have the same comments on staff transferring to St. George's as I had for the Evelina. Should the Evelina be successful in winning the bid St. George's will still need to provide area trauma centre services. The cost of keeping this service with no parallel paediatric cancer surgical work would mean a £2M-£3M deficit in the St. George's budget. This amount should be added to the Evelina costs.

Research Domain

Although there are closer ties to the Royal Marsden I am still unsure as to how the relationship with the Institute of Cancer Research will work.

My Proposal

I see the two bidders as unsatisfactory and I think it irresponsible of NHS London to move the paediatric oncology services to one of the bidders simply because the bid is judged as better than the other regardless of whether the bid meets patient need. Therefore I propose that neither the Evelina nor St. George's are appointed as PTC. My proposal consists of 3 stages which can be reduced to only Stages 1 + 2 or even just Stage 1 if it is deemed appropriate.

Stage 1 Activity

In Prof. Sir Mike Richards 2020 report he states:

"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."
and

"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 would therefore recommend that between the Royal Marsden and St. George's, risk stratification is introduced as quickly as possible and any treatment which is estimated to carry a 5% or above risk of the patient needing PCC Level 3 admittance is carried out at St. George's instead of the Royal Marsden in line with Prof. Sir Mike Richards comments on GOSH/UCLH.

Stage 2 Activity

Since the pandemic we have seen changes in mind set in the way health services are delivered. Part of this mind set is how the adoption of new technologies can bring significant benefits to both the health service and patients. During this process to review the future of South Thames Paediatric Oncology Services there has been a suggestion that some Paediatric Oncology Shared Care Units (POSCUs) be enhanced to provide a greater range of services. There are currently 3 levels of POSCU, Level 1 being the lowest level, Level 3 the highest. The suggestion was that if there was a greater number of Level 3 POSCUs the amount of travelling for the patient would decrease as visits to PTCs for Systemic Anti Cancer Treatment (SACT) would be decreased. In the 2015 report by Prof. Mike Stevens, there was a recommendation that Level 3 POSCUs must be co-sited with at least a PCC Level 2 facility (previously known as High Dependency). To meet this recommendation which goes beyond that of the current POSCU Service Specification would mean a significant increase in PCC facilities. In this time of acute staff shortages and available budget an alternative solution would need to be sought.

In recent years new technologies have enabled 'eICU' solutions. These work using a hub and spoke pattern with skilled and experienced intensivists at the hub and for each 'spoke' there is an 'ICU' bed connected to the hub utilising ICU monitoring equipment remotely relaying patient data back to the hub intensivists. The intensivists would then oversee care and make the decision to transfer the patient to a PCC Level 3 facility if the need arose. This solution would not only be a benefit to children receiving SACT but also to trauma patients and children with multiple complex genetic conditions who suffer from respiratory issues especially in winter.

I would therefore recommend that work starts on planning a trial of a 'Paediatric eICU' solution without delay. This would not only have the benefit of reducing patient travel times in the longer term but also help to supply additional PCC facilities across the country where the implementation of a traditional PCC would not be feasible. I would recommend that the first site of any such trial be the Royal Marsden Children's Unit. If successful, the Royal Marsden Children's Unit would have remote Paediatric Critical Care connectivity which would need evaluation as to the level of PCC care the solution would provide.

Stage 3 Options

The 2015 Prof. Mike Stevens review stated that paediatric oncology services South of the Thames are fragmented. This is a result of years of no strategic direction from NHSE and individual trust protectionism. From my perspective to meet the challenges of the future the time has come to radically reconfigure all paediatric specialised services South of the Thames. Not only does there need to be relocated paediatric services but the realisation that space must be found in inner city District General Hospitals to cater for an ever aging and unhealthy local population. As building work in inner city locations, especially in central London, is extremely expensive and logistically complex any work must be kept to a minimum. Therefore as many existing resources should be repurposed to provide services for the local community. Patients from wider areas needing specialised services should be treated in specialised hospitals outside of city centres and preferably near to trunk routes, both public and road transport.

As stated above, specialist paediatric services are split across several hospitals and trusts with no one trust having ownership of all specialised services. The recommendation in Prof. Sir Mike Richards' report of 2019 was that PTCs are co-located with other specialised paediatric services as well as PCC Level 3. Although the Evelina and St. George's can provide a subset of specialist services, neither can provide the combination of neurosurgery, cardiac services, liver services, kidney services, general surgery in addition to PCC Level 3. I can only surmise that it was for this reason that no bid was submitted for a new paediatric specialist services hospital South of the Thames. I have a strong belief that without NHSE strategic planning and full support from the County Councils and South London Boroughs the option of a new paediatric hospital will not be progressed. With regards location of any new hospital, the best possible location would surely be between the M25 and the edge of the South London Boroughs with access to public transport links.

From my own experience from losing my son, the moment you lose your child you need solace and somewhere that is a sanctuary for you to grieve. How could either the Evelina in the heart of London or St. George's in the middle of a busy London town centre ever provide an environment that can provide solace and sanctuary? In order to provide a calming environment for bereaved parents, any hospital would need to be located in a quieter location.

It is with the above thinking that I propose the following two options.

Option 1

A new paediatric specialised services hospital on the site of the old Sutton Hospital in Sutton.

This option would involve the building of a new children's hospital on the site of the old Sutton Hospital on the same campus as the Royal Marsden and Institute of Cancer Research.

The hospital would be home to the following services allowing space being made available for greater adult capacity in current locations and alleviating the need for very expensive and logistically complex building work at inner city hospitals.

Service	Current Provider
Paediatric Oncology	Royal Marsden and St. George's
Specialist Cardiac Services	Evelinal
Specialist Kidney Services	Evelina
Paediatric Neuro Surgery	St. George's and Kings
Specialist Liver Services	Kings
Congenital Heart Services	The Brompton
Tertiary Trauma Services for the South East	St. George's
Paediatric Critical Care Level 3	St. George's, Evelina, Kings, Brompton

Benefits

- Site owned by the NHS
- Would bring all Specialised Paediatric Services under one roof and enable economies of scale
- Road access would be easier than any inner London location for the vast majority of patients
- No impact on current Royal Marsden staff
- No impact on paediatric oncology research
- Make space available in 5 London hospitals enabling greater capacity for our aging in increasingly unhealthy population
- Building work would be easier and cheaper than attempting to expand inner city hospitals
- If managed by Royal Marsden Foundation Trust further operational synergies can be exploited to reduce costs
- The hospital and accommodation would be designed specifically as a specialist children's hospital
- Would remove risk of capacity issues at Southampton Hospital
- Parking capacity would meet the requirement of the hospital and not rely on current parking availability
- Energy saving measures would be inherent in the design

Risks/Disadvantages

- Movement of existing staff to the Sutton site
- Integrating the research activities of Kings into the new hospital
- Public transport links not as comprehensive as inner city hospitals
- Helicopter operations for trauma patients may be difficult with residential housing at close proximity
- Reconfiguration of paediatric services at the Evelina, Kings and St. George's would need to occur to ensure services met local need.

Option 2

A new paediatric specialised services hospital on the site of the old Kenley aerodrome south of Purley located between the A22 and A23.

I found this location purely by chance and I have used it as an example of an out of town location. This option would involve the building of a new children's hospital on the site of the World War 2 Battle of Britain aerodrome RAF Kenley. This site is in Surrey

The hospital would be home to the following services allowing space being made available for greater adult capacity in current locations and alleviating the need for very expensive and logistically complex building work at inner city hospitals.

Service	Current Provider
Paediatric Oncology	Royal Marsden and St. George's
Specialist Cardiac Services	Evelinal
Specialist Kidney Services	Evelina
Paediatric Neuro Surgery	St. George's and Kings
Specialist Liver Services	Kings
Congenital Heart Services	The Brompton
Tertiary Trauma Services for the South East	St. George's
Paediatric Critical Care Level 3	St. George's, Evelina, Kings, Brompton

Benefits

- Would be a new hospital with no ties to any current hospital and could be run by its own Trust
- Would bring all Specialised Paediatric Services under one roof and enable economies of scale
- Road access would be easier than any inner London location for the vast majority of patients as it would have access to the A22, A23 and M25.
- Make space available in 5 London hospitals enabling greater capacity for our aging in increasingly unhealthy population
- Building work would be easier and cheaper than attempting to expand inner city hospitals
- Good rail access from nearby stations to London Bridge and Clapham Junction/Victoria
- A current aerodrome, helicopter operations could operate easily
- The hospital and accommodation would be designed specifically as a specialist children's hospital
- Would remove risk of capacity issues at Southampton Hospital
- Would be in an open quieter environment with plenty of fresh air and space
- Parking capacity would meet the requirement of the hospital and not rely on current parking availability
- Energy saving measures would be inherent in the design

Risks/Disadvantages

- Site owned by the MOD and would need change of use
- Movement of existing staff from all hospitals to the new site
- Integrating the research activities of Kings College, the Institute of Cancer Research and St. George's Medical School into a single London University multi college campus.
- Reconfiguration of paediatric services at the Evelina, Kings and St. George's would need to occur to ensure services met local need.
- The current user, a gliding club, would need to be relocated

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40. Children's Cancer and Leukaemia Group

Century House
24 De Montfort Street
Leicester LE1 7GB
0333 050 7654
info@cclg.org.uk
www.cclg.org.uk

NHS England – London Region
By email

December 2023

Re: Public consultation on the relocation of children's cancer services in south London and south east England.

Children's Cancer and Leukaemia Group (CCLG) is the UK and Ireland's professional association for those working in children and young people's cancer, as well as a leading UK charity funding research and supporting patients and families.

CCLG supports the aims of this consultation to ensure that the proposed future children's cancer Principal Treatment Centre will meet the requirements of the service specification. We thank NHS England for their thorough consideration of a wide range of issues in preparing for and conducting this consultation, for example through the thorough equalities and health inequalities impact assessment undertaken. We are also pleased that the views of a wide range of people have been considered in preparing for this consultation, including researchers, health professionals, charities and others, but in particular patients and families, and the staff likely to be affected by the change in location of the Principal Treatment Centre.

We agree with the things that NHS England have stated are important to focus on during the transition period, including ensuring the current high level of research is continued, supporting the staff involved both to support them and to ensure that the future PTC has the appropriate expertise, and to ensure that Teenage and Young Adult Cancer Services, currently at The Royal Marsden and outside of the scope of this consultation, are supported to continue. We do believe that there are – as to be expected in any complex change to services – a number of key risks that need to be thoroughly mitigated to ensure a successful transfer of services.

At a time of crisis in the NHS cancer workforce, there is a real risk that we will further diminish the highly specialised workforce (both clinical and research including trials and data team members) who may not be able to transfer to a role in central London or Tooting for family or economic reasons. There is also a risk that the new PTC may not be able to attract the best talent in terms of future clinical academics or future leaders if the attractiveness of the strong links with a world-leading research institution are not maintained. It will be important to ensure that future workforce planning takes this into consideration, and focuses on the staff required for research delivery as well as clinical care.

On the one hand, the proposed relocation of radiotherapy services to UCLH might be expected as increasing numbers of children with cancer receive proton beam radiotherapy and would have had their radiotherapy treatment at UCLH even if the PTC was not moved from the Royal Marsden. However, consideration needs to be given to capacity at UCLH

Registered charity number 1182637

(with appropriate funding) not just for standard photon/proton radiotherapy patients. Future resilience needs to be built into the system in the event of a major incident or similar, especially given UCLH has taken on patients from other centres for photon radiotherapy, where the service has ceased, which was not originally planned for. We also note that there is not consensus within the paediatric oncology community about the future move towards PBT for the majority of patients, with some feeling this is overestimated.

Special consideration needs to be given for patients requiring TBI as part of conditioning for BMT treatment, who will be transferred between the PTC and UCLH when they are particularly vulnerable. Learning from the proton service in terms of joint working between clinical and paediatric oncologists on different sites needs to be taken forward into the new service due to the loss of joint on-site clinics. Finally, consideration needs to be given to molecular radiotherapy (such as mIBG treatment). The Royal Marsden is a national referral centre and one of just three in the UK at present, and there might be an increasingly important role for this treatment in future.

We are concerned that considerations regarding paediatric neurosurgery were considered out of scope for this consultation. While not strictly required by the children's cancer services service specification, having neurosurgery carried out at a different hospital is less than ideal, and this would be the only PTC where neurosurgery is not carried out on site. 'Children's Neuroscience Networks (for the Neurosurgical Child): A framework for services in England' (NHS Specialised Services, 2012), states in section 7.6 that 'Children's Neurosurgery Centres must be co-located with Principal Treatment Centres for childhood cancer. In line with the Service Interdependency Framework, co-location is essential to provide a full specialised service'.

Furthermore, in Professor Sir Mike Richards' report on Children's Cancer Services (January 2020) highlighted a response from another PTC that stated "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".

The current status of c20% of neurosurgery being performed at St Georges is likely below the level of patient throughput required to provide safe and sustainable neurosurgery. This falls well below throughput in other PTCs and is not conducive to developing expertise. Again, Prof Sir Richards note, on Bristol PTC, "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." The 2015 London Paediatric Oncology Review: Report of the Independent Expert Panel Chaired by Professor Mike Stevens, commissioned by NHS England, but never published modelled the current split site arrangement and the benefit of an integrated paediatric neurosurgery unit within a PTC. The benefits of an integrated paediatric neurosurgery unit within a PTC are axiomatic. It is important to highlight that this report firmly concluded that "Paediatric neurosurgery for children with brain tumours in London should only be undertaken by the neurosurgical service co-located with the children's PTC as part of an integrated London paediatric neuro-oncology service.

Finally on this point, if a Principal Treatment Centre does not have an integrated paediatric neurosurgical centre then this PTC would become an outlier compared to the rest of the United Kingdom. This gives rise to inequality of access and care. While potentially out of scope for this consultation we wanted to ensure these points were raised and should be kept under consideration for future developments. This should be kept under consideration for future developments. However, given the significant upheaval of moving children's

cancer services from the Royal Marsden, there is here an opportunity to provide a complete, seamless package of holistic, safe and effective care for the population served and to be a 'once in a lifetime' event.

Evelina London does not currently provide cancer surgery, and the notion that this significant deficiency can be quickly solved (for example, unlike the oncology team at the Marsden that would have the option to transfer to the new PTC, it is unlikely that surgeons would) shows a lack of insight into the necessary training and expertise to provide top level surgical oncology as parents would expect. We would like to see further information about how this aspect would be managed in any transition process.

We would also like to understand more about the weight given to the fact that St Georges has been a member of the existing children's cancer network for many years as the co-provider of the current PTC with The Royal Marsden and because it runs a children's cancer shared care unit. The Clinical Senate have raised their concerns over the risks of moving a highly complex service. Making this change to a centre that has no prior experience or knowledge of CYP cancer service provision seems counter-intuitive, and while it might be easier to preserve and retain organisational memory and key skills and competencies where these are already in place, or to ensure that the timescales of and resources for additional support in establishing the new service are sufficient to meet the complexity of the change proposed.

CCLG commends the recognition that successful change will require strong clinical leadership. However, it is imperative to consider that leadership roles will be needed over and above the full-time roles of current staff. A senior clinician whose main focus is to oversee successful transfer of clinical services is recommended.

The focus on preserving research is to be commended as this drives innovation and change and adoption of best practice.

Agreement to provide the necessary clinical time in terms of allocation within consultant job plans is to be commended as this will ensure that there is time to ensure that the current international leading research at RMH and ICR is supported as best as possible. This needs to be sustained into the future.

Commitment by the potential providers to invest charity funding that sustains and develops research is welcomed. Without this there is a significant risk that the research knowledge in a niche but crucial area will be lost. However, this should not be underestimated. The Royal Marsden Cancer Charity invests significantly in research across a wide variety of roles, including clinical roles, and the current setup is attractive to charitable donors and organisations because of the strong links with ICR. There is a risk to grant funding if there is a loss of confidence in the ability of the new PTC to deliver the volume and quality of paediatric cancer research, especially by an unproven provider in that field. There is also a significant risk that the transfer of clinical trials (open and in set-up at the time of transfer) will result in trials not being opened at all during the transition period, disadvantaging patients. The new centre will need to demonstrate, rapidly, that they can comply with the O'Shaughnessy recommendations (in terms of rapid trial set up and delivery) and demonstrate to commercial and academic partners the ability to do so. The Royal Marsden is a high recruiter to late phase clinical trials, and, importantly, is the UK's largest and most active early phase trials unit. There is a huge risk to be mitigated here, around the impact on patient access to innovation and novel therapies. In Prof Sir Richards' report, in making suggestions for the potential future PTC, he suggests 'Royal Marsden @' branding as one

option. This should be given serious consideration if it protects research investment, maintains strong links with the ICR, and helps to mitigate the risks set out above.

Particular attention needs to be paid to access to clinical research for 16 and 17 year olds with paediatric diseases, given the splitting of paediatric and teenage and young adult cancer services, which will no longer be co-located. If sponsors choose not to (or are unable to) open trials at two sites rather than the current single site, and no 'adult' trial is available for these patients, this will again impact on equitable access to treatment/participation in clinical research for these patients.

The role of charitable funding in providing holistic care is also commended.

We recognise that families have a lot of questions about travel to the future PTC. We acknowledge that this is an important issue for families, and appreciate the work that has gone into looking at travel times to the future PTC. We would note that travel – both in terms of distance and cost – is an issue nationally for families of children with cancer. The necessity of organising treatment in specialised tertiary centres (which is the correct approach for children with cancer) means that there are a limited number of PTCs, and in many areas this means long and/or expensive journeys to hospital. This is an area that should be looked at nationally, to ensure accessibility for all patients across the country, both in terms of strengthening the POSCU network and providing a travel costs fund for all families so that they are not left out of pocket by having to travel to hospital.

The scoring outcomes for the two proposals, highlighted in the consultation document, shows that the Evelina London proposal scored more highly overall, and more highly on three of the four domains looked at, than St George's. Given the amount of work and expertise, and robust process, that is behind this scoring, it is difficult to disagree with these outcomes, notwithstanding the points made above. While all domains are important, clinical services, on which the Evelina London scored higher, is clearly an important priority for the future service, ensuring that all children receive the best possible treatment and care, leading to the best possible outcomes. We would note that the majority of PTCs are in specialist children's hospitals which provide ready access to the majority of other relevant children's services that are required for children with cancer.

We note that in the patient and carer experience, and enabling (non-clinical factors) domains, there were a mix of scores, with each PTC having a number of sub-criteria where they scored the same. Finally, we note that Evelina London scored higher across all sub-criteria in the research domain. Research is a vital part of a successful children's cancer PTC, as many children are treated on clinical trials or participate in other research studies. We know that outcomes are better for children treated as part of a trial. This is also an important aspect of equity of access to treatment – as children's cancer clinical trials are run nationally (often as part of international studies) with trials open at the majority of PTCs across England, ensuring children are able to participate wherever they are located.

We are happy to discuss any of these issues further, and are pleased to have had the opportunity to support this process at various points in our important role as the relevant professional association for paediatric oncology. We look forward to continuing to support NHS England in this process and working with the chosen provider of the future Principal Treatment Service.

Yours faithfully

Professor Richard Grundy
Chair

Ashley Ball-Gamble
CEO

41. Guy's and St Thomas' Foundation

Guy's &
St Thomas'
Foundation

Investing in a healthier society

15th December 2023

Dear Sir/Madam,

Children's Cancer Centre for south London & south east England

I write as chair of the board of Trustees of Guy's and St Thomas' Foundation to express the Foundation's support for Evelina London as the proposed site for the future Principal Treatment Centre for south London and much of south east England.

Guy's and St Thomas' Foundation is one of the largest charities supporting healthcare in the UK. Our mission is to build the foundations of a society that helps everyone stay healthier, for longer. With an endowment of c.£1 billion and direct charitable expenditure of more than £37m in 2021/22, we are well-placed to support institutions and accomplish this mission in our region. Alongside our work as a Foundation driving greater health equity, we have established three charities to focus our NHS charitable support: Guy's and St Thomas' Charity, Guy's Cancer Charity and Evelina London Children's Charity.

We have a strong track record of fundraising to support both cancer and children's services. Evelina London Children's Charity has fundraised and donated almost £20m over the last 5 years to the Evelina London Children's Hospital, providing support for ground breaking medical equipment including a new MRI and intervention suite; the development of the children's Clinical Research Facility enabling early phase trials to take place in the heart of the hospital; a new children's cardiac and critical care ward; and numerous projects improving patient environment, patient experience and staff support. All staff at Evelina London are able to benefit from programmes supported by the wider Guys and St Thomas' Charity which include significant investments in staff wellbeing and psychology support.

We have committed, through Evelina London Children's Charity, to support the Principal Treatment Centre at Evelina London. This includes underwritten support, in the form of a substantial anchor donation confirmed by our board of Trustees (for a minimum of £10m) to support the build and development of the new cancer centre. We recognise the important role that the Royal Marsden Charity plays in fundraising to support the children's cancer service and we have also committed to continue to support the service over time with fundraising each year, including ambitions to grow current fundraising and philanthropic income. This strategy would be developed in partnership with the team from the Royal Marsden and Institute of Cancer Research, to ensure that our funding support is appropriately targeted.

We have made Evelina London one of our priorities for funding support because we recognise the world-class care and ground-breaking research that happens here, in the region's only dedicated, outstanding-rated children's hospital.

The Grain House
46 Loman Street
London, SE1 0EH

Tel: 020 7089 4550
Email: info@gsttfoundation.org.uk

gsttfoundation.org.uk
@GSTTFoundation

Guy's &
St Thomas'
Foundation

Investing in a healthier society

Evelina London brings to patient care an advanced co-located Paediatric Intensive Care service (PICU) essential to the delivery of modern paediatric cancer care, and its related research. I understand that, as well as caring for many thousands of other seriously unwell children every year, the teams at Evelina London already treat children with cancer – including for heart and kidney complications needing expert input and through the children's ambulance service. I also understand that this is a service where shared care is of particular importance, and this is an area in which Evelina London has huge experience, delivering over 1,000 clinics every year in local hospitals and a clinical education team that trains staff at every other hospital in the region.

Children with cancer, like other seriously unwell children, need the advances in care that pre-clinical and clinical research can bring. Through our support for the internationally excellent research at Evelina London, we know that it is the only place that has the requisite potential for enhancing children's cancer research, developing novel therapies and thereby creating the strongest future facing service. In partnership with King's College London and the Institute of Cancer Research, I have no doubt that the team at Evelina London would build on the outstanding research that the Royal Marsden team lead at present, advancing our understanding of children's cancer in areas such as immune therapies (which require the expertise and facilities that only Guy's and St Thomas' can offer) and imaging and personalised medicine (supported by unrivalled capabilities, such as the research MRI that we have supported and the new MRC-funded Total Body PET imaging centre that will provide a unique opportunity to study cancer in children).

For all these reasons and many more, I have no doubt that we would be hugely successful in fundraising to support the children's cancer service at Evelina London and that the support that we can provide to children's cancer would be unrivalled in this region.

In conclusion, my board and I strongly support this proposal which represents a once in a generation opportunity to bring together the Royal Marsden's leading children's cancer experts with existing world-class specialist paediatric teams at Evelina London, and we are ready to begin our fundraising to support children's cancer as soon as a decision is taken on the future location of this vital service.

Yours faithfully,

Susanne Given
Chair of the board of Trustees
Guy's and St Thomas' Foundation

The Grain House
46 Loman Street
London, SE1 0EH

Tel: 020 7089 4550
Email: info@gsttfoundation.org.uk

gsttfoundation.org.uk
@GSTTFoundation

42. Rare Revolution Magazine

RARE REVOLUTION MAGAZINE

12th December 2023

To whom it may concern,

Children's Cancer Services for South London and South East England

I am writing to you with two interests in this bid. One as editor-in-chief of RARE Revolution Magazine, a not-for-profit, open access magazine dedicated to amplifying the voices of the rare disease community, and two as a mother of a child with the complex, multi-systemic, ultra-rare disease, xeroderma pigmentosum.

I would like to show my support for the Evelina London as the proposed site of relocation and bringing together of paediatric cancer care services and clinical research to serve the south-east of England.

There are 35 million people affected by rare disease in the UK and a great many of those are children. Of those children affected by rare disease, cancer is a common comorbidity. Whether it be xeroderma pigmentosum, neurofibromatosis type 1 or any of the great many other rare diseases that cause uncertainty due to increased risk of cancer, the need for robust and timely diagnosis, care coordination and treatment is paramount. The UK Rare Diseases Framework and England's Rare Disease Action Plan endorsed by the Department of Health and Social Care captured this by identifying four key priorities; helping patients receive a faster diagnosis, increased awareness among healthcare professionals, better coordination of care and improved access to specialist care, treatment, and drugs.

Bringing together Evelina London's world-class clinical care delivery with its proven track record in research represents, for the benefit of the childhood cancer community, is an exciting opportunity to reimagine the future of clinical care for children and young people affected by cancer. With over 180 children's research studies ongoing, Evelina London has strong connections with academia and industry partners, making them well-placed to drive pioneering studies and clinical trials and deliver the latest in cancer therapies, such as CAR-T and future innovations, all from one single site.

Evelina also offers significant geographical benefits that will enhance both care coordination and overall patient experience. Its proximity to Guys' & St Thomas (GSST) Hospital, which is home to a number of specialist commissioned centres, MDTs and leading rare disease HCPs, means that care coordination between disciplines and treating professionals can be enhanced across the one site for both proactive monitoring and reactive treatment of resultant cancers.

Furthermore, and what cannot be underestimated, is the practical importance of geography for families. Proximity to a mainland rail station makes Evelina considerably more favourable from the perspective of patients' families. The hub station of Waterloo is a very short walking distance from Evelina, meaning families will benefit from direct transport connections to the served areas of the south-east.

Seeking treatment for a child with cancer is a terrifying time for families, and in many ways their hospital becomes a home from home during these times. As a dedicated children's hospital this is an area where Evelina London already excels. Families can stay close and connected, with free accommodation available at Ronald McDonald House. They can also benefit from free parking close by, subsidised travel costs, on-site counselling, award-winning play specialists and play areas, and even access to a hospital school which is rated 'outstanding' by Ofsted. In a time of great need, these are the things that make the greatest difference to the lived experience of children and their families and help them maintain some level of normality and control in a time when they may otherwise feel quite out of control.

The proposed centre at Evelina London, I believe, represents a very welcome development for our rare disease paediatric community, and will help deliver on England's Rare Disease Action Plan **within the context of rare disease and cancer**—putting diagnosis, care coordination, HCP awareness and treatments at the forefront of what will be a world-class facility.

Yours sincerely

Nicola Miller
Editor-in-chief, executive director
RARE Revolution Magazine
editor@rarerevolutionmagazine.com

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www.rarerevolutionmagazine.com

43. Ronald McDonald House Charities UK

Ronald McDonald House Charities United Kingdom

Keeping families close™

Ronald McDonald House Charities UK comments on the proposed future location of specialist cancer services for children

Background on RMHC

The best care for a seriously ill child isn't always close to home. That's why each year, Ronald McDonald House Charities UK supports over 6,500 families across its 14 Ronald McDonald Houses located at specialist NHS children's hospitals. Its mission is to ensure every specialist children's hospital in the UK has free, homely, and supportive accommodation for families.

Marian Ridley, Director of Evelina-London Children's Hospital, shared: *'The emotional and financial burden of a sick child in hospital has increased exponentially. For many, the ability to travel and fund the cost of being away from home, is simply not possible. Close accommodation for parents is paramount for the effective treatment of critical child illness. We need Ronald McDonald House Charities UK more than ever.'* Alongside supporting the NHS' commitment to improving health outcomes, the Charity's ambition is that every child in hospital has family close, and families are fully supported and actively involved in their child's care.

Ronald McDonald Houses take families away from the clinical, busy hospital setting and offers them a place to call their own during their most difficult days. The Houses provide families with fully equipped kitchens and dining rooms, communal lounges, and playrooms as well as access to laundry facilities and space to work from "home". Most importantly, families are allocated their own ensuite bedroom. Each bedroom has a telephone connected directly to their child's ward, easing much of the separation anxiety families experience when stepping away from their child's bedside.

"*Leaving our beautiful daughter at three days old…nowhere to go...miles from family, was the darkest introduction to becoming a parent. Frantically looking at hotels as our heart lay in a hospital's incubator. RMHC gave us a home, they knew what we needed before we knew we needed it."*

Without Ronald McDonald House Charities UK's services, 98% of families report they'd find it difficult to stay with their child (Family Survey, 2021). Houses are described as supportive environments which ease principal areas of stress e.g. disruption to family routines and financial strain. Typically, 62 miles from home, the Charity saves families £405 per week in food and travel costs alone (Bliss, 2022).

Ronald McDonald House Charities UK has been building and operating Houses close to specialist children's hospitals for 30 years. Approximately 20% of Trustees, staff and

volunteers have lived experience of some of the issues faced by the families it supports, thus understanding and empathising greatly with the challenges of child illness. The Charity has grown by listening to the families it serves; their experiences shape ongoing activity and the building of new Ronald McDonald Houses. Each House team is in daily contact with its affiliated Hospital's wards to ensure the Charity is adhering to NHS guidance on providing safe accommodation and crucial support to families and seriously sick hospitalised children. The partnership with hospitals has enabled the Charity to respond to challenges, such as COVID-19, effectively and keep families together while continuously striving to reduce health inequalities and improve child outcomes.

Ronald McDonald House Evelina London

Ronald McDonald House Evelina London is a purpose-built 59 bedroom Ronald McDonald House at Evelina London Children's Hospital, part of Guy's and St Thomas' NHS Foundation Trust.
It has been developed with a significant contribution from Guy's and St Thomas' NHS Foundation Trust, and Guy's and St Thomas' Charity provided the land. We already had a 20-bedroom House near London Bridge, our Guy's and St Thomas' House, but the number of families needing accommodation already far exceeded what we could offer. The new House, which opened in December 2016, can accommodate three times the number of families who were accommodated in a year at the Guy's and St Thomas' House. The House is located just a five minute walk from the Evelina London Children's Hospital, helping families to be as close as possible to their child.

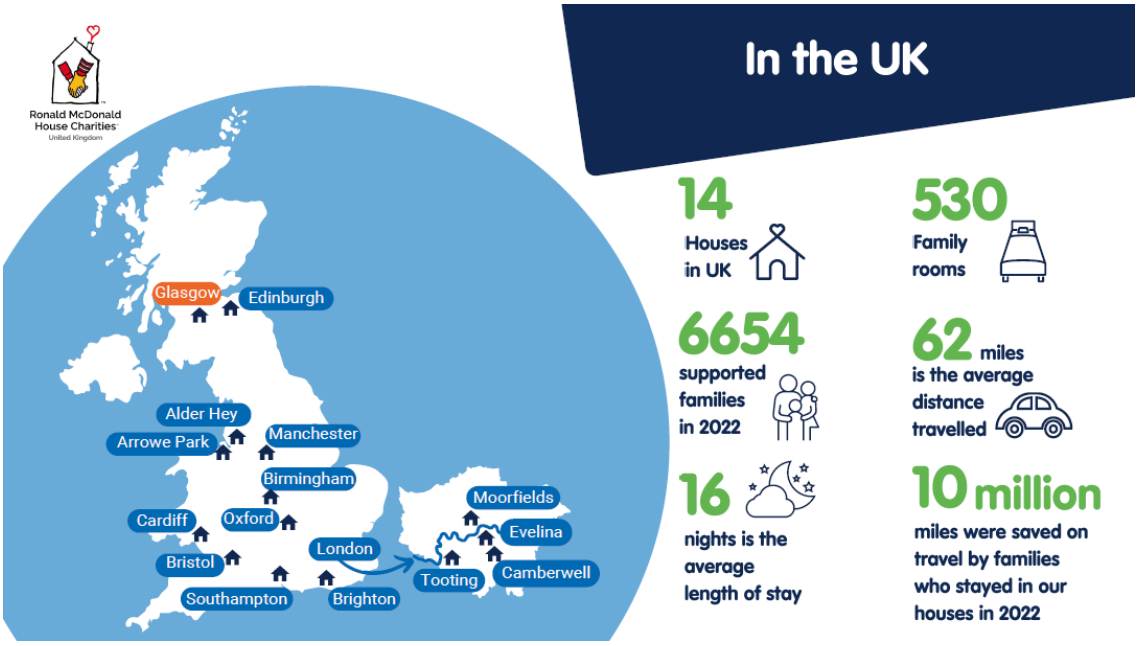
The longest family stay last year was 335 nights
808 families stayed here in 2022

Ronald McDonald House Tooting

Ronald McDonald House Tooting keeps families together by providing free 'home away from home' accommodation for families with children at St George's Hospital. The House has eight en suite bedrooms, a kitchen, so that families can prepare themselves good home-cooked food, laundry facilities and a lounge area, enabling them to continue to operate as a proper family unit.

The longest family stay last year was 149 nights
104 families stayed here in 2022

Impact of Ronald McDonald House Charities



As global partners in enabling family-centered care for more than 40 years, Ronald McDonald House Charities strives to be part of the solution in improving the lives of children and their families by providing programmes that strengthen families during difficult times. When children must travel long distances to access top medical care, accommodations for families can be expensive or not readily available. Ronald McDonald Houses helps families stay close to their ill or injured children, increasing the caregivers' ability to spend more time with their child, to interact with their clinical care team and to participate in critical medical care decisions.

Since the programme's inception, parents have shared with RMHC in their own words how the Ronald McDonald House programme has impacted their lives. To better evaluate the impact of the Ronald McDonald House programme, Global research was commission to collated formal evidence RMHC Chapters across different countries, including research carried out in the UK.

Key findings include:

In a survey of 250 families, researchers found that children and their parents, who stayed at a Ronald McDonald House, had a better perceived quality of life than expected for children with chronic diseases[1].

27% of parents experienced post-traumatic stress symptoms several months after their child's discharge from a hospital stay, but Ronald McDonald Houses help their guests strengthen coping abilities by keeping families together[2].

[1] Sanchez et al., Archivos Argentinos de Pediatria (2014)
[2] Franck et al. International Journal of Nursing Studies (2014)

Parents whose children have longer hospital stays benefit from higher quality sleep at a Ronald McDonald House compared to parents who slept at their child's hospital bedside[3].

The Ronald McDonald Houses' proximity to hospitals provides important benefits for children and their caregivers, such as improved psychological well-being and better perceptions of their child's recovery[4]

A study carried out by RMHC Sydney in Australia specifically focusing on the impact of Paediatric Oncology found that:

Accommodation and travel cause a heavy financial burden

Key positives of communal living, such as Ronald McDonald Houses, included meeting others, proximity to the hospital, privacy and access to children's play areas[5].

More recently RMHC UK carried out some research at the start of 2023 into the impact of the Cost of Living on families with sick children in hospital. It provided some start insights into the hardships that our families are currently facing, including:
78% of surveyed families said having a child in hospital has had a negative impact on their finances

Almost a quarter of surveyed families have skipped meals to make ends meet

More than 40% of surveyed families have asked family or friends to borrow money within the past 12 months.

Our Ronald McDonald House's provide more than just a bed for the night and plays a key role in enabling family-centred care.

Comments on the proposed plans

The need for accommodation has been highlighted in both Trust's proposals, and both Trusts have referenced the existing provision of a Ronald McDonald House on site. However, we are not aware of their expectations as to our Charity's ability to support this potential increase in demand for parental accommodation. We would want to be an active partner and support whichever hospital did become the principal treatment centre. Sufficient, high quality accommodation is fundamental to providing the right environment for the child and their family to successfully navigate their journey through cancer treatment.

Both Ronald McDonald Houses are already run at capacity (i.e. are consistently full), and it is clear that the Ronald McDonald House at St George's is already too small for the existing paediatric provision in the hospital with demand far outstripping the supply of rooms in this property (of only eight bedrooms).

[3] Franck et al., Behavioural Sleep Medicine (2013)
[4] Franck et al., Families, Systems & Health (2013)
[5] Daniel et al., Rural and Remote Health (2013)

Ronald McDonald House Charities UK would be interested to work in partnership with St Georges to grow our accommodation provision if they did become the principal treatment centre. However, whilst the Charity has the experience and proven track record to do this, it does not have funding to do this in the timescales available.

Within the proposal from St George's, they highlighted the creation of a number of 'adjoining family rooms'. Ronald McDonald House Charities would be open and keen to collaboration on creative (and cost effective) ideas about how to provide additional accommodation including inside the hospital.

Ronald McDonald House Charities is keen to have further conversations with both Trusts to discuss how we can support and think ahead to what implementation of the plans would look like if the Centre did move to their hospital. RMHC UK will engage directly with both Trusts and we are keen to be an activate partner in this project.

44. The Royal Marsden Cancer Charity

Chelsea
Fulham Road
London SW3 6JJ
Tel 020 7808 2233

Sutton
Downs Road
Surrey SM2 5PT
Tel 020 8661 3391

Email charity@royalmarsden.org
Website royalmarsden.org

The Royal Marsden Cancer Charity's response to the NHS England consultation into the future provision of children's cancer services

The Royal Marsden Cancer Charity raises money solely to support The Royal Marsden NHS Foundation Trust. The Charity's mission, through our grants program, is to support our nurses, doctors and research teams in providing the very best care and developing life-saving treatments, which are used across the UK and around the world.

Last year, The Royal Marsden Cancer Charity raised £34.4 million, reinforcing the hospital's confidence in the continuity of charitable support, that allows it to go faster and further in its delivery of research, treatment and care.

Innovating in areas of national and international priority allows the hospital, with its partner the Institute of Cancer Research, to continue to lead in the delivery of world leading cancer research and through that, better outcomes for cancer patients. The Royal Marsden's worldwide reputation for excellence, enhanced by the Charity's support, allows the hospital to attract internationally renowned talent, thereby enhancing the scope and scale of its research and development expertise.

Charitable support for the paediatric service at The Royal Marsden has been invaluable over the last decade, totalling £43 million. This has enabled the building of the Oak Cancer Centre for Children and Young People (OCCYP) in 2011, a wonderful age-appropriate dedicated facility in Sutton, co-located with the Oak Paediatric and Adolescent Oncology Drug Development Unit (OPAO DDU), a leading drug development facility which is the most comprehensive specialist research unit in the UK for children with cancer. Both of these practice-changing facilities are supported by The Royal Marsden Cancer Charity.

The impact of the OPAO DDU, co-located with the OCCYP, has been transformational. Supported by Oak Foundation with additional funding from many other supporters of the Charity, that totals over £12 million in the last decade, the OPAO DDU has made significant research advances. In the last year, a trial called NANT 2015-02 Lorlatinib, led by Dr Lynley Marshall, investigated using the drug Lorlatinib alone, and in combination with cyclophosphamide and topotecan, to treat children and young adults with relapsed and treatment-resistant neuroblastoma. This saw some patients achieving responses great enough to go on to receive surgery, chemotherapy and other kinds of treatment, which would have previously not been possible, providing genuine improvements in outcomes.

The success of the Charity in fundraising for the paediatric service is based on a long history of building philanthropic giving from donors with an interest in supporting paediatric cancer patients, an area of less interest to the pharmaceutical industry, given (mercifully) the few instances of paediatric cancer. Most notably the longstanding relationship with Oak Foundation, built over nearly two decades, enabled the building of the OCCYP and the establishment, and ongoing funding of, the Oak Paediatric and Adolescent Oncology Oak Drug Development Unit. This relationship between Oak Foundation and The Royal Marsden Cancer Charity is unique and not easily replicated. It is based on experience that has built trust, together with a deep understanding of the hospital's global impact,

based on its world-leading research, treatment and care and the Charity's first-class stewardship of the relationship.

Moreover, significant support from patients, parents and their families has raised over £3 million, allowing the Charity to continue to enhance its support for paediatric cancer research, treatment and care. We are concerned that this source of funding will not be available in the future, should the relationship between The Royal Marsden Cancer Charity and paediatric cancer patients no longer exist, while support from The Royal Marsden Cancer Charity to fund paediatric cancer research will remain vital.

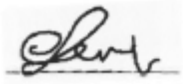
In conclusion, The Royal Marsden Cancer Charity is concerned that, with the proposed future move of the service from 2026, the level of charitable support being provided for research and to the paediatric service will decline, given uncertainty over the timing of the proposed move and the fact that many donors pledge their support over multiple years. Replacing this dedicated funding will not be easy, certainly in the short term. We note with concern that the 'case for change' did not evidence where this current significant additional funding, which is needed to continue to provide the service at the same level, or better, will come from. We believe it is critical that there is a deliverable plan to meet the stated guarantee, that the existing scope and excellence of paediatric cancer research will be preserved in all aspects, and not downgraded in any respect.

The Royal Marsden Cancer Charity therefore wishes to have formally noted its concerns about the potential decline in charitable funding in the future, caused by the move of children's cancer services, which it believes will have a detrimental and significant impact on children and their families who today rely on the world-leading expertise of The Royal Marsden and its research partner, the Institute of Cancer Research.

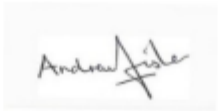
Yours sincerely,

Sir Terence Leahy
Senior Independent Trustee

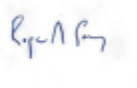
Baroness Bloomfield
Independent Trustee



Varun Chandra
Independent Trustee



Andrew Fisher OBE
Independent Trustee



Roger Gray
Independent Trustee

Anya Hindmarch CBE
Independent Trustee

45. St George's Hospital Charity

St George's Hospital Charity

Better care, healthier lives

NHS England- London
NHS England- South East

14 December 2023

To Whom It May Concern,

RESPONSE TO PTC CONSULTATION

On behalf of the staff and supporters of St George's Hospital Charity, we are writing to lend our support to St George's Hospital's bid to be the Principal Treatment Centre (PTC) for children's cancer services in South London, Kent, Surrey and Sussex.

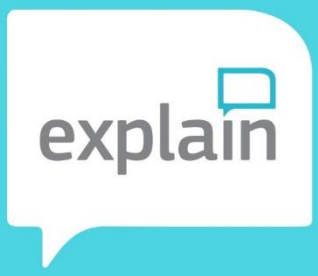
At St George's Hospital Charity, we work closely with St George's to improve the experience of patients, families, staff, and the wider community served by the hospital. We hear the personal stories from families and witness first-hand the many reasons that demonstrate why children with cancer and their families deserve St George's.
We wish to bring to your attention to just some of those key reasons why we believe children with cancer will be better supported at St George's.

St George's **has 25 years' experience** of delivering paediatric cancer care. This extensive experience is more than the Evelina and has fostered a wealth of expertise and cultivated professional relationships among clinical specialists, crucial for the effective treatment of children with cancer and not easily replicated. This includes the strong partnership with The Royal Marsden. St George's children's services have an outstanding rating from the CQC.

The **services that matter most for children with cancer are available on site at St George's**. Along with King's hospital, St George's provides neurosurgery whereas the Evelina London Children's Hospital does not. Given that 1 in 4 children with cancer have neuro-oncological cancer, and sometimes children with other cancers also need neurosurgery in an emergency, having this service readily accessible is paramount. Similarly, Evelina London Children's Hospital does not have paediatric oncology surgeons (who operate on children with other cancer tumours) and would need either to rely on surgeons from St George's going to work at the Evelina, or to build a new surgical team.

St George's can deliver **what parents of children with cancer say they want**. Which is, above all, expertise and experience. But parents have also said that when you have a child with cancer, potentially on immunosuppressants, you take them to hospital by car not on public transport. Parents have consequently said they would prefer the children's cancer centre to be outside of central London, with good parking provision. St George's will and does offer this, with dedicated parking spaces and a drop-off zone for the families of children with cancer, directly outside the entrance of the Trust's proposed new, state-of-the-art Children's Cancer Centre.

Consolidating the children's cancer centre at St George's will be **easier and less costly** for the NHS to deliver. With a significant portion of the service already in place at St George's, the transformation of existing non-clinical space into a state-of-the-art cancer centre can be achieved swiftly and with minimal disruption to staff. This approach is in stark contrast to the challenges and costs associated with relocating services and personnel to central London.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